

**Researchers' construction and management of ethical
issues in post-conflict mental health research: a
qualitative study**

Thesis submitted in accordance with the requirements of the
University of Liverpool for the degree of Doctor in Philosophy

by

Anna Louise Chiumento

Submitted: 27th October 2017

Resubmission after minor modifications: 11th April 2018

Researchers' construction and management of ethical issues in post-conflict mental health research: a qualitative study

Anna Chiumento

Abstract

Conducting research in emergencies – including following conflict or disaster - is essential to understanding the prevalence of mental health and psychosocial problems, and to strengthening the evidence base for interventions. Recognising that all research must be conducted ethically, questioning what underpins researchers' construction and management of ethical research procedures and practice are important. To address these questions this thesis presents a qualitative study exploring researchers' understanding and experiences of research ethics in their everyday practice of post-conflict mental health research.

Research involves a multi-site case study conducted in three post-conflict countries in South Asia. 35 qualitative interviews were conducted with researchers ranging from primary investigators (n=5) to field supervisors (n=7) and frontline research assistants (n=23). Adopting a phenomenological epistemology foregrounds researchers' everyday lived experience of research ethics, acting as an entry point to explore the continuum between procedural and in-practice ethics. Interview questions explored procedural ethics such as ethical review; as well as ethics-in-practice such as enacting informed consent. As a result of interpreters' involvement in qualitative interviews, and conducting a proportion of interviews online, this thesis presents methodological considerations arising from the research process.

Thematic data analysis highlights researchers' acceptance of a principalist research ethics framework. Analysis draws attention to the multiple social worlds co-producing and applying procedural ethical documents such as the research protocol and informed consent forms, applying the theoretical framework of boundary objects to explore how researchers negotiate this process. This analysis reveals researchers' autonomy when applying procedures to practice, foregrounding the situated nature of moral judgements in research where the demands of ethics, methodology, and context are balanced to reach conclusions about the right course of action.

Further analysis of researchers' practice of enacting informed consent highlights the underpinning role of trust which manifests itself at societal, organisational, and interpersonal levels. In researchers' narratives trust is seen as a critical resource, both instrumentally to

facilitate research conduct, and normatively as demonstrating researcher integrity and adherence to ethical research standards. Alongside trust is its natural antithesis: that of control, which is evident in descriptions of efforts to monitor and verify the trustworthiness of researchers' practice in the field.

Overarching findings are three meta-themes of trust, control, and voice which emerge methodologically in qualitative interviewing with interpreters and via online platforms; and in relation to research findings exploring the intersection between procedural and in-practice research ethics. Fundamentally this thesis contributes to the existing research ethics literature by drawing attention to the role of the researcher at the centre of procedural and in-practice ethics. Recommendations are drawn to support reclaiming the researchers' voice in asserting the scope and application of ethics in post-conflict mental health research.

Declaration

This thesis is the product of my own work. The material presented is not being submitted in whole or part for any other degree qualification.

I initiated, designed, and conducted all of the research presented. I was responsible for the study design including writing the study protocols (presented in Appendix 1), obtaining and amending ethical approvals in-country and from the University of Liverpool¹. I coordinated all practical arrangements for fieldwork, in line with Terms of Agreement with each in-country host institution (see Appendix 5). I conducted all qualitative interviews, with the support of interpreters where required. Interpreters were hired and trained for the purpose of this study.

Data was transcribed with assistance from interpreters and a two-person transcription team. I trained all interpreters and transcribers in transcription conventions, and checked all transcripts for accuracy prior to data analysis (see the Data Analysis chapter for further details). I conducted all data analysis, with input from supervisors and colleagues in a data analysis group.

I am first author on all peer-review journal publications presented as part of this thesis – both those already published and those pending submission for publication. A declaration of authorship contributions for each paper is provided in the introduction.

¹ These are not included as part of this thesis due to anonymity procedures for this study where the sites of research conduct are not identified.

Acknowledgements

I would like to thank my three supervisors Professor Atif Rahman, Dr Lucy Frith and Dr Laura Machin for their advice, insight, support, and encouragement offered throughout the conduct of this research. Notable insights and encouragement include Professor Atif Rahman's unrelenting focus upon the real-world application of learning from my thesis; Dr Lucy Frith's availability to chat through roadblocks and her patience with my challenges with punctuation; and Dr Laura Machin's invaluable feedback on the research process and findings from the perspective of a qualitative researcher and research ethics committee member, and her enthusiasm at every stage of thesis development.

I would like to thank the Economic and Social Research Council for providing me with a 3 year PhD Studentship, including a 3 month extension to support my internship with the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergencies; as well as additional overseas fieldwork funding. Without these opportunities this study would not have been carried out.

In addition to supervisors, I am grateful for all of the informal input, practical guidance, and supportive friendship from researchers at in-country organisations who contributed to this study. I would also like to particularly thank Dr Ciara Kierans for her guidance when developing the Economic and Social Research Council Studentship application, and for her ongoing supportive input throughout data collection and analysis.

I am appreciative of the opportunity to conduct an internship with colleagues at the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergencies. Notably I would like to thank Professor Wiese Tol, Dr Mark van Ommeren, Leslie Snider, and Dr Margriet Blaauw for their support and encouragement throughout the internship and beyond.

I would like to acknowledge all co-authors of publications included in this thesis for their patience and support through the process of writing, and often re-writing, each paper. I would also like to thank anonymous reviewers for their critical feedback on each paper (including rejection), which led to their enhancement and gradual improvements in my writing style.

I gratefully acknowledge the generosity of interpreters, transcribers, and importantly research participants without whom this thesis would not have been possible. I would like to thank all of the researchers who took time out of demanding schedules to share with me

their insights and experiences of research ethics in their everyday research practice. Equally, I would like to extend my thanks to all six of the interpreters and two transcribers hired to support data collection and transcription. I thoroughly enjoyed working with each of you, and am grateful for your contributions to the methodological learning in this thesis, as well as for your friendship during periods of data collection and beyond.

I am also highly appreciative of all the support I have received from family, friends, and colleagues throughout my PhD journey. I am indebted to several colleagues for their insightful comments and recommendations for approaching the task of conducting and writing up a thesis, focusing my attention when it was beginning to waver, or encouraging a break when it was overdue.

I would particularly like to acknowledge my sisters (Rachel, Laura, and Jenny) who have remained steadfast in their support throughout the highs and lows of preparing, collecting, analysing, and writing up the research presented in this thesis. Finally, I would like to recognise my incredible mum Sarah for her never-ceasing love, encouragement, and proof-reading skills! To all of my family I send my thanks for the non-stop group messages and sharing of photos and videos of my nieces, nephew, and family dogs; all of which kept me amused whilst providing some often much needed distraction from research.

Writing this thesis and conducting all of the research that has gone into it has been an exciting, trying, and emotional journey; but it is one I am incredibly grateful for. I can only hope this thesis does justice to all of the opportunities, support, and encouragement I have been provided to reach this point.

Table of contents

ABSTRACT.....	i
Declaration.....	iii
Acknowledgements.....	iv
THESIS INTRODUCTION.....	10
Research overview.....	10
Thesis presentation.....	4
References.....	7
INTRODUCING THE LITERATURE REVIEW.....	11
The context and purpose of the literature review.....	11
The literature review paper.....	13
Summary of literature review findings.....	13
References.....	14
ETHICAL STANDARDS FOR MENTAL HEALTH AND PSYCHOSOCIAL SUPPORT RESEARCH IN EMERGENCIES: REVIEW OF LITERATURE AND CURRENT DEBATES.....	16
Abstract.....	16
Background.....	17
Methods.....	18
Results.....	19
Discussion.....	51
Summary and recommendations.....	57
Conclusion.....	58
References.....	59
LINKING THE LITERATURE REVIEW WITH THE CASE STUDY.....	66
Case study: exploring some key unresolved debates raised in the literature review.....	66
How the case study builds upon the literature review.....	67
References.....	68
MANAGING ETHICAL CHALLENGES TO MENTAL HEALTH RESEARCH IN POST-CONFLICT SETTINGS.....	69
Abstract.....	69
Introduction.....	69
Case study.....	72
Maintaining ethical standards.....	73
Research ethics in emergencies: arguing for specified normative frameworks.....	86
Conclusion.....	91
References.....	93

DRAWING FROM THE LITERATURE REVIEW AND CASE STUDY TO SET UP THIS RESEARCH..	98
Situating the literature review and case study in the context of this research.....	98
Literature review as a process ongoing throughout research conduct.....	100
Strengths, limitations and reflections upon the approach taken.....	101
Conclusion.....	102
References	102
EPISTEMOLOGY, METHODOLOGY, AND ETHICAL CONSIDERATIONS	104
Introduction	104
Qualitative research.....	104
Qualitative research in empirical ethics	105
Epistemology.....	107
Research question.....	111
Research setting.....	112
Method	113
Interview procedure	122
Positionality	125
Ethical considerations.....	131
Funding statement.....	135
Conclusion.....	135
References	136
MEDIATED RESEARCH ENCOUNTERS: METHODOLOGICAL CONSIDERATIONS IN CROSS- LANGUAGE QUALITATIVE INTERVIEWS	142
Abstract.....	142
Introduction	142
The study: ethics in mental health research in post-conflict settings	143
Cross-language interpreter mediated interviewing.....	144
Discussion.....	156
Conclusion.....	160
References	161
ONLINE INTERVIEWING WITH INTERPRETERS IN HUMANITARIAN CONTEXTS	165
Abstract.....	165
Introduction	165
Case study: Researchers' construction and management of ethical issues in post-conflict mental health research.....	166
Online interviewing.....	168
Methodological considerations for managing online interviews	178

Conclusion.....	180
References	180
DATA ANALYSIS	183
Orienting to interview data.....	183
Transcription.....	185
Thematic data analysis.....	196
Respondent validation: sharing research findings with participants	207
Strengths and limitations of the approach to data analysis	208
Reflections	209
Conclusion.....	210
References	210
INTRODUCTION TO PROCEDURAL ETHICS RESULTS PAPER.....	214
References	215
WRITING TO TEMPLATE: RESEARCHERS’ PERSPECTIVES OF PROCEDURAL ETHICS IN MENTAL HEALTH RESEARCH IN POST-CONFLICT SETTINGS	218
Abstract.....	218
Introduction	219
Methods.....	223
Results.....	228
Discussion.....	245
Conclusion.....	251
References	252
LINKING THE PROCEDURAL ETHICAL RESULTS PAPER WITH THE IN-PRACTICE ETHICS RESULTS PAPER.....	260
References	261
TRUST IN ETHICAL RESEARCH PRACTICE: MANIFESTATIONS, METHODS, AND IMPLICATIONS	262
Abstract.....	262
Introduction	262
Methodology.....	269
Results.....	272
Discussion.....	284
Conclusion.....	294
References	294
DISCUSSION.....	303
Overview of research.....	303

Research reflections.....	313
Research recommendations and future research directions	318
Considering the potential for change	324
Concluding comments	329
References	329
APPENDIX 1: RESEARCH PROTOCOL	341
APPENDIX 2: INTERVIEW TOPIC GUIDE.....	357
APPENDIX 3: INTERPRETER GUIDELINES.....	360
APPENDIX 4: REFLECTIVE E-MAILS TO SUPERVISORS ON FIELDWORK PROGRESS FROM C1	361
APPENDIX 5: TERMS OF AGREEMENT WITH HOST ORGANISATIONS &	370
POSITION STATEMENT ON ETHICAL RESEARCH REPORTING.....	370
APPENDIX 6: DISSEMINATION HANDOUT.....	374

Table of tables:

Table 1 Thematic analysis of ethical principles applicable to MHPSS research in emergencies	23
Table 2 Bioethical, social science and mental health definitions of vulnerability	40
Table 3 Recommendations for specialist training related to MHPSS research in emergencies	43
Table 4 Unresolved debates	52
Table 5: Ethical challenges	72
Table 6: Documentation for content analysis.....	120
Table 7: Interview overview.....	144
Table 8: Key characteristics of interviews conducted online.....	167
Table 9: Logistical and methodological recommendation for managing online research interviews.....	178
Table 10: Extract from example transcript from Country 1.....	189
Table 11: Transcription conventions.....	192
Table 12: Example transcript cover page.....	194
Table 13: Sub-sample of transcripts for open coding.....	201
Table 14: Interview overview.....	225

Table of Figures:

Figure 1: Flow chart of literature searches	21
Figure 2: Aspects to the empirical ethical reflection model	89
Figure 3: Outline of interpreter training	148
Figure 4: Considerations for interpreter-facilitated cross-language interviews in cross- cultural contexts	157
Figure 5: Data analysis process	198
Figure 6: Data analysis process	227
Figure 7: Trust in ethical research practice: the example of informed consent.....	268

THESIS INTRODUCTION

This thesis presents a qualitative study of how researchers' define, understand, and apply research ethics in their everyday practice of mental health research in post-conflict settings in South Asia.

In this introduction, I provide a brief overview of the contents and key findings presented in this thesis. Following this, an explanation of how the thesis is presented is provided, outlining sections presented as peer-reviewed published papers² or papers prepared for publication, identifying the publication status and author contributions for each; and identifying sections presented as thesis chapters or link sections that introduce and tie the thesis together into a coherent narrative. Therefore, the aim of this introduction is to orient the reader to what follows.

Research overview

Research commenced with a multidisciplinary literature review to identify ethical principles applicable to mental health and psychosocial support research in emergency settings, encompassing conflict, man-made disasters, and natural events. The results of this literature review revealed tensions in the operationalisation of ethical research principles to practice (Chiumento *et al.*, 2017a). This tension was taken up as the focus of this study, exploring the intersection between procedural research ethics and ethics-in-practice (Guillemin and Gillam, 2004). This distinction views procedural research ethics to encompass all of the documentation and procedural processes associated with applying for and securing formal ethical approval for research from recognised ethical review boards. Conversely, ethics-in-practice refers to the day-to-day experiences of ethics and ethical issues that arise during the conduct of research, and that may or may not have been anticipated at the procedural ethics stage.

As the first known attempt to explore researchers' understanding and experiences of research ethics in post-conflict mental health research, a qualitative methodology was

² This thesis presents the approved final version of published papers, prior to journal copy-editing and author proofing of the version to be published. Due to minor corrections, some papers presented here differ from the published versions. All papers have furthermore been reformatted to Harvard referencing style (with references presented at the end of each chapter throughout), and all figures and tables have been renumbered to run consecutively throughout the thesis. These amendments have been made to ensure consistency in referencing style throughout the thesis. As a result there are minor formatting and content discrepancies between the versions presented here, and the published papers.

employed. This was underpinned by a phenomenological epistemology that emphasises the lived-through quality of researchers' experiences of research ethics (Schutz, 1944; 1945; 1967). Qualitative interviews were chosen for their ability to allow research participants to lead discussions and reveal facets about their everyday experiences of procedural and in-practice research ethics. 35 qualitative interviews were conducted between September 2014 and February 2015 with researchers ranging from primary investigators (n=5) to field supervisors (n=7) and frontline research assistants (n=23).

This study focusses upon the lived experiences of researchers, and does not include the experiences of ethical review board members, humanitarian practitioners, or research participants. This is because there is a broad existing empirical literature exploring the ethical understanding and experiences of ethical review board members (Allen, 2008; Dixon-Woods *et al*, 2007; Douglas-Jones, 2012; 2015, Guta *et al*, 2013; Hedgecoe, 2012; Heimer, 2013; Schopper *et al*, 2009; Stark, 2013), complemented by theoretical insights into the ethical review process (Hammersley, 2006; 2009; Israel and Hay, 2006). Similarly, research participant's experiences of research ethics have been empirically investigated, such as their experiences of informed consent (Fitzgerald *et al*, 2002; Hynes, 2003; Kass *et al*, 1996). Furthermore, recent studies have explored the ethical experiences of humanitarian practitioners (Boulanger, 2015), complementing an extensive critical literature in which humanitarian workers explore the ethics of humanitarian intervention (see e.g. Kennedy, 2004; Michael and Zwi, 2002). Consequently, whilst there is an existing literature encompassing reflective contributions discussing researchers' experiences of ethical issues arising in studies they have conducted in both emergency and non-emergency settings (see e.g. Allden *et al*, 2009; Boulton and Parker, 2007; Siriwardhana *et al*, 2013); and global empirical ethical studies exploring frontline researchers experiences of ethics (see e.g. Kingori, 2013; 2015); this research is the first known attempt to systematically explore researchers views and experiences of research ethics in post-conflict settings.

As a result of the research *process*, this study makes methodological contributions to the literature on conducting qualitative interviews with interpreters (Chiumento *et al.*, 2017b) and interviewing via online internet-based platforms (Chiumento *et al.*, submitted). These call attention to the voices articulating research findings, and draw upon my lived-experience of conducting the qualitative interviews that form the foundation of this thesis.

Through thematic data analysis, this research contributes to how researchers' understand and apply research ethics to their everyday practice. When considering procedural research

ethics, the framework of boundary objects (Star and Griesemer, 1989) is applied to illuminate the work procedural documents perform as shared constructions developed and applied by researchers, ethical review boards, and others such as research funders. This analysis reveals researchers' often strategic engagement with procedural ethics processes which are frequently viewed as a bureaucratic control mechanism to be negotiated to proceed to the work of conducting research (Chiumento *et al.*, in preparation-b). From here the role of researchers' application of research procedures to practice was highlighted, which the narratives of participants in this study identified as underpinned by relationships of trust. Further analysis was conducted on the application of the informed consent procedure to research practice to reveal the underpinning mechanisms and role of trust and control operating at the interpersonal, organisational, and societal levels (Chiumento *et al.*, in preparation-a).

From these research findings the discussion draws together three overarching meta-themes of trust, control and voice. Finally, research recommendations are drawn from methodological experiences as well as research findings. These include recommendations to strengthen current approaches to procedural and in-practice research ethics, for example through developments in ethical review procedures and training of frontline research assistants, as well as identifying potential future research directions.

Thesis presentation

This thesis is presented via a series of peer-preview published papers, thesis chapters, and linking sections. Below is a brief statement of each:

1. Introduction to the literature review

Brief introduction to the context and purpose of the literature review paper, and its role in identifying research gaps to be addressed in this thesis.

2. Literature review

Chiumento, A., Rahman, A., Frith, L., Snider, L., and Tol, W. (2017) 'Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates', *Globalization and Health*; 13(1): pp. 8-26³

Author contributions: All authors contributed to conceptualisation of the research. AC conducted the literature review and initial synthesis, with contributions from WT and LS. Further synthesis was supported by WT, LS, and AR. AC prepared the first draft of the manuscript, while LF, WT, LS and AR edited and reviewed subsequent drafts. The final draft was reviewed and approved by all authors.

3. Linking the literature review into the case study

This section identifies how the unresolved debates identified in the literature review paper are explored in the case study paper.

4. Case study

Chiumento, A., Khan, M.N., Rahman, A., and Frith, L. (2016) 'Managing ethical challenges to mental health research in post-conflict settings', *Developing World Bioethics*; 16(1): pp. 15-28¹

Author contributions: AC, MNK and AR contributed to the conceptualisation of the research. AC and MNK facilitated reflective discussions upon which this paper is based. AC analysed the reflections, with contributions on key themes and wider literature to support interpretation of findings from MNK, AR, and LF. All authors contributed to conceptualising the presentation of the case study in manuscript form. AC prepared the first draft of the manuscript. MNK, AR, and LF reviewed and provided edits to subsequent manuscript drafts. All authors reviewed and approved the final manuscript for publication.

³ The version of the paper presented in this thesis includes additional references and content to the published version.

5. Drawing from the literature review and case study to set up this research

This section situates the literature review and case study paper in the context of this thesis, how the identified research problem arises in response to the gaps highlighted in the literature review paper and explored in the case study paper.

6. Chapter: Epistemology, methodology, and ethical considerations

Adopting a chapter format, this section provides an in-depth discussion of the chosen research epistemology, methods, and research procedures. It also considers some key ethical considerations and highlights the role of the research funder. To conclude, this chapter identifies how methodological issues raised in this chapter continue to be built upon in the methodological papers and data analysis chapter that follow.

7. Methodology paper: Qualitative interviewing with interpreters

Chiumento, A., Rahman, A., Machin, L., and Frith, L (2017) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, online pre-print, available at: <http://journals.sagepub.com/doi/abs/10.1177/1468794117730121>

Author contributions: AC designed and conducted the research from which this paper is drawn. All authors provided ongoing supervision feedback on AC's research experiences, leading to conceptualisation of this paper. AC prepared the first draft of the manuscript, with subsequent drafts developed through contributions from LF, LM and AR. All authors reviewed and approved the final manuscript for publication.

8. Methodology paper: Conducting qualitative interviews online

Chiumento, A., Machin, L., Rahman, A., and Frith, L. (2018) 'Online interviewing with interpreters in humanitarian contexts, *International Journal of Qualitative Studies in Health & Well-being*, 13(1): pp. 144487-144496.

Author contributions: AC designed and conducted the research from which this paper is drawn. All authors contributed to the paper concept. AC prepared the first draft of the manuscript, which was reviewed and edited by AR, LM, and LF. All authors reviewed and approved the final manuscript for submission for publication.

9. Chapter: data analysis

In chapter format this section details the approach to thematic data analysis, with explicit links made back to the chapter on the research epistemology, methodology, and ethical considerations. This includes discussion of data transcription and stages of thematic analysis, seeking to render transparent the decisions made at each stage. The

chapter concludes by critically considering the strengths and limitations to the approach taken.

10. Introduction to procedural ethics results paper

This section provides a brief introduction to the first results paper which focuses upon researchers experiences of procedural research ethics. It situates the paper in light of what it adds to existing literature and the potential implications of these findings, which are further explored in the procedural research ethics paper, and the discussion section.

11. Procedural ethics results paper

Chiumento, A., Rahman, A., Machin, L., Frith, L (in preparation) 'Writing to template: researchers' perspectives of procedural ethics for mental health research in post-conflict settings', *Unsubmitted*

Author contributions: AC designed and conducted the study on which this paper is based. AC led data analysis, with input from LF, LM, and AR, and interpreters involved in conducting qualitative interviews. All authors provided advice on the presentation of research findings, and on the application of theoretical frameworks to interpret data. AC prepared the first draft of the manuscript which was reviewed and edited by LM, LF and AR. All authors reviewed and approved the final manuscript for submission for publication.

12. Linking the procedural ethics results paper with the in-practice ethics results paper

Section linking the paper exploring researchers' experiences of procedural research ethics, with the paper that follows which considers ethics-in-practice, specifically foregrounding the role of trust.

13. In-practice ethics results paper

Chiumento, A., Machin, L., Rahman, A., and Frith, L (in preparation) 'Trust in ethical research practice: manifestations, methods, and implications', *Unsubmitted*

Author contributions: This paper is based upon research that was designed and conducted by AC. Data analysis was led by AC, with input from LF, LM, and AR. Theoretical framing of research findings was strengthened through interpretations from LM, LF and AR. AC wrote the first draft of the manuscript. All authors' reviews and edited subsequent manuscript drafts, and approved the final manuscript for publication.

14. Chapter: Discussion

The thesis concludes with a discussion chapter that draws together the papers in this thesis through consideration of three meta-themes of trust, control, and voice. It then identifies some overarching recommendations for mental health research in emergency settings, including methodological advances and suggestions for adapting or enhancing approaches to procedural and in-practice research ethics. Following this, reflections upon the potential for influencing ethical procedures and practice in humanitarian mental health research are offered, before posing some concluding thoughts.

15. Appendices

For additional information, the following appendices are provided:

- Appendix 1: Research protocol submitted for ethical approval to all ethical review boards providing ethical oversight of this study
- Appendix 2: Interview topic guide
- Appendix 3: Interpreter guidelines
- Appendix 4: Example extract from e-mail correspondence with supervisors reflecting upon the progress of interviews in C1
- Appendix 5: Terms of reference with partner organisations and position statement on ethical research reporting
- Appendix 6: Summary handout of research findings provided to research participants

References

- Allden, K., Jones, L., Weissbecker, I., Wessells, M., Bolton, P., Betancourt, T. S., Hijazi, Z., Galappatti, A., Yamout, R., Patel, P. and Sumathipala, A. (2009) 'Mental health and psychosocial support in crisis and conflict: report of the Mental Health Working Group', *Prehospital and Disaster Medicine*, 24(Suppl 2), pp. s217-s227.
- Boulton, M. and Parker, M. (2007) 'Informed consent in a changing environment', *Social Science & Medicine*, 65(11), pp. 2187-2198.
- Chiumento, A., Machin, L., Rahman, A. and Frith, L. (in preparation-a) 'Trust in ethical research practice: manifestations, methods, and implications', *Unsubmitted*.
- Chiumento, A., Machin, L., Rahman, A. and Frith, L. (2018) 'Online interviewing with interpreters in humanitarian contexts', *International Journal of Qualitative Studies in Health and Well-being*; 13(1), pp. 144487-144496

Chiumento, A., Rahman, A., Frith, L., Snider, L. and Tol, W. A. (2017a) 'Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates', *Globalization And Health*, 13(1), pp. 8-26.

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017b) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online pre-print, available at: <http://journals.sagepub.com/doi/abs/10.1177/1468794117730121>.

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (in preparation-b) 'Writing to template: researchers' perspectives of procedural ethics in mental health research in post-conflict settings', *unsubmitted*.

Dixon-Woods, M., Angell, E., Ashcroft, R. E. and Bryman, A. (2007) 'Written work: The social functions of Research Ethics Committee letters', *Social Science & Medicine*, 65(4), pp. 792-802.

Douglas-Jones, R. (2012) 'A single broken thread', *Durham Anthropology Journal*, 18(2), pp. 13-27.

Douglas-Jones, R. (2015) 'A 'good' ethical review: Audit and professionalism in research ethics', *Social Anthropology / Anthropologie Sociale*, 23(1), pp. 53-67.

Fitzgerald, D. W., Marotte, C., Verdier, R. I., Johnson, W. D. and Pape, J. W. (2002) 'Comprehension during informed consent in a less-developed country', *Lancet*, 360(9342), pp. 1301-1302.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.

Guta, A., Nixon, S. A. and Wilson, M. G. (2013) 'Resisting the seduction of "ethics creep": using Foucault to surface complexity and contradiction in research ethics review', *Social Science & Medicine*, 98, pp. 301-310.

Hammersley, M. (2006) 'Are ethics committees ethical?', *Qualitative Researcher*, 2, pp. 4-8.

Hammersley, M. (2009) 'Against the ethicists: On the evils of ethical regulation', *International Journal of Social Research Methodology*, 12(3), pp. 211-225.

Hedgecoe, A. M. (2012) 'Trust and regulatory organisations: The role of local knowledge and facework in research ethics review', *Social Studies of Science*, 42(5), pp. 662-683.

Heimer, C. A. (2013) 'Wicked' ethics: Compliance work and the practice of ethics in HIV research', *Social Science & Medicine*, 98, pp. 371-378.

Hynes, T. (2003) *The issue of 'trust' or 'mistrust' in research with refugees: choices, caveats and considerations for researchers*. Geneva: UNHCR. [Online]. Available at: <http://www.unhcr.org/3fcb5cee1.html>. (Accessed: 16.01.2014).

Israel, M. and Hay, I. (2006) *Research ethics for social scientists: between ethical conduct and regulatory compliance*. SAGE Publications [electronic book]. Available at: <http://srmo.sagepub.com/view/research-ethics-for-social-scientists/SAGE.xml>.

Kass, N. E., Sugarman, J., Faden, R. and Schoch-Spana, M. (1996) 'Trust: The Fragile Foundation of Contemporary Biomedical Research', *The Hastings Center Report*, 26(5), pp. 25-29.

Kennedy, D. (2004) *The dark sides of virtue: reassessing international humanitarianism*. Princeton: Princeton University Press.

Kingori, P. (2013) 'Experiencing everyday ethics in context: Frontline data collectors perspectives and practices of bioethics', *Social Science & Medicine*, 98, pp. 361-370.

Kingori, P. (2015) 'The 'empty choice': A sociological examination of choosing medical research participation in resource-limited Sub-Saharan Africa', *Current Sociology*, 63(5), pp. 763-778.

Michael, M. and Zwi, A. B. (2002) 'Oceans of need in the desert: ethical issues identified while researching humanitarian agency response in Afghanistan', *Dev World Bioeth*, 2(2), pp. 109-30

Schopper, D., Upshur, R., Matthys, F., Singh, J. A., Bandewar, S. S., Ahmad, A. and van Dongen, E. (2009) 'Research Ethics Review in Humanitarian Contexts: The Experience of the Independent Ethics Review Board of Médecins Sans Frontières', *PLoS Medicine*, 6(7), pp. 1-6.

Schutz, A. (1944) 'The Stranger: An Essay in Social Psychology', *American Journal of Sociology*, 49(6), pp. 499-507.

Schutz, A. (1945) 'On multiple realities', *Philosophy and Phenomenological Research*, 5, pp. 533-576.

Schutz, A. (1967) *The phenomenology of the social world*. Evanston: Northwestern University Press.

Siriwardhana, C., Adikari, A., Jayaweera, K. and Sumathipala, A. (2013) 'Ethical challenges in mental health research among internally displaced people: Ethical theory and research implementation', *BMC Medical Ethics*, 14(1), pp. 13-20.

Star, S. L. and Griesemer, J. R. (1989) 'Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39', *Social Studies of Science*, 19(3), pp. 387-420.

Stark, L. (2013) 'Reading Trust between the Lines: 'Housekeeping Work' and Inequality in Human-Subjects Review', *Cambridge Quarterly of Healthcare Ethics*, 22(4), pp. 391-399.

INTRODUCING THE LITERATURE REVIEW

This section introduces the paper *Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates* (hereafter: “literature review paper”) (Chiumento *et al.*, 2017) in the context of this study. It commences with a description of the context and purpose of conducting a literature review. Following this key findings from the literature review are highlighted, identifying how this study seeks to address these knowledge gaps.

The context and purpose of the literature review

The literature review was conducted during an internship placement with the Inter-Agency Standing Committee Reference Group (IASC-RG) on Mental Health and Psychosocial Support in Emergencies. The purpose of this internship was to support the IASC-RG to develop recommendations for the ethical conduct of mental health and psychosocial support research in emergency settings (hereafter: the recommendations)⁴. The need for a guidance document had been recognised in a 2 day meeting on mental health and psychosocial support research and monitoring and evaluation in emergencies. Following this, at the annual IASC-RG meeting, developing ethical recommendations was identified as a priority activity for 2014-15, with funding committed by the International Organisation for Migration. Following attendance at this IASC-RG annual meeting I was invited to lead development of these recommendations by undertaking an internship with the IASC-RG.

Prior to conducting the literature review brief searches were carried out to get a sense about what literature already existed on the topic, and to prevent a duplication of knowledge. Only one other rapid literature review was retrieved, conducted on the similar topic of developing an ethical framework for health research proposals designed for conduct in humanitarian contexts (Curry *et al.*, 2014). Other statements of recommendations for ethical review had been made, for example from *Medicine Sans Frontieres* (Schopper *et al.*, 2009); and efforts to address the specificities of mental health research made by Allden *et al.* (2009). However, this initial literature search identified that the literature tended to consider research ethics in relation to all health research, including mental health, and therefore did not address the potential ethical specificities of mental health research in emergency settings which IASC-RG members felt may require particular ethical consideration. It was also observed that the literature discussing research ethics spanned both a procedural literature that considered

⁴ Available at:

https://interagencystandingcommittee.org/system/files/1._iasc_recommendations_for_ethical_mh_pss_research_in_emergency_settings_0.pdf

definitions of ethical principles and accompanying formal mechanisms such as review by an ethical review board; as well as reflective accounts of experiences of applying ethical principles to mental health research conducted in emergencies. Given the disparate sources and discussion within the literature about the applicability of ethical principles to mental health research in emergency contexts, it was felt that there was a sufficient need to conduct our own review of the literature to bring together and assess the literature to support development of the recommendations.

An IASC-RG working group was established to oversee development of the recommendations which included academic researchers⁵; mental health and psychosocial support practitioners from international Non-Governmental Organisations⁶ and the International Federation of the Red Cross and Red Crescent Societies; and representatives of United Nations Agencies⁷. This group acted as a steering committee for the direction of work during the internship placement. A work plan was developed which included the conduct of a literature review as a first step to developing the guidelines. Subsequent steps included collecting case studies⁸ from organisations to illustrate examples of practice that stimulated ethical considerations, and writing the recommendations.

Conducting a literature review sought to inform the recommendations by identifying the ethical principles considered applicable to mental health and psychosocial support research in emergencies, and exploring their application to research practice. There was also a concern to identify commonly-used lay terminology to refer to ethical principles, moving away from technical language. The findings from the literature review have been applied in two ways:

1. To inform the IASC-RG *Recommendations for the ethical conduct of mental health and psychosocial support research in emergency settings*. This included informing how ethical principles were organised and presented, as well as identifying appropriate lay terminology.

⁵ Academic researchers were from the John Hopkins Bloomberg School of Public Health

⁶ International Non-Governmental Organisations represented included the Centre for the Victims of Torture, International Medical Corps and Regional Psychosocial Support Initiative (REPSSI).

⁷ United Nations Agencies included the United Nations Children's Fund, the Office of the United Nations High Commissioner for Refugees, the World Health Organisation, and the International Organisation for Migration.

⁸ The case studies in the Recommendations differ from the case study paper presented in this thesis. Please see the Recommendations for details.

2. As the paper *Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates*, published in *Globalisation and Health* in January 2017 (Chiumento *et al.*, 2017).

The literature review paper

The literature review paper moved beyond what was required of the literature review for the recommendations to engage critically by identifying sites of tensions and disagreements within and across the literature. These were presented as debates about the *application* of ethical principles to mental health and psychosocial support research in emergencies, as the literature revealed broad consensus about ethical principles themselves.

Therefore, the literature review paper focusses upon unpacking what existing literature has to say about the interaction between procedural and in-practice ethics, as ethical procedures are applied to practice (Guillemin and Gillam, 2004). As such the literature review achieves the following:

1. Contributes new knowledge by integrating cross-disciplinary literature which broadly addresses the topic of mental health and psychosocial research in emergency settings;
2. Critically engages with the differing disciplinary stances and experiential accounts of the applicability of ethical principles to mental health and psychosocial research in emergency settings;
3. Engages in a dialogue with the tensions and debates within the literature; and
4. Makes recommendations about potential ways to manage the tensions, including identifying gaps in existing knowledge to be addressed through further research.

Summary of literature review findings

Findings from the literature review confirm that there is broad agreement concerning procedural ethics – both the ethical principles and the formal procedures such as review of research by an ethical review board. However, findings also challenge the dominance of a biomedical lens through which ethical principles are operationalised, revealing a disciplinary tension permeating the literature. Considering empirical and reflective accounts of research practice within the scope of the review brought to the fore a gap in understanding *how* to apply ethical principles to practice, with the voice of the front-line field researcher often missing from accounts of research experiences.

Some of the literature recommended learning lessons about research conduct (Michael and Zwi, 2002), or conducting ethical reflection (Zwi *et al.*, 2006; World Health Organisation,

2007; Wessells, 2008; Siriwardhana *et al.*, 2013), leading to calls for further efforts to document research experiences from an ethical perspective to “inform how ethical principles are interpreted and applied in a challenging research field” (Chiumento *et al.*, 2017, p.25). It is this knowledge gap that this study seeks to address, prioritising the views of researchers to explore how research principles and procedures are applied in practice.

References

Allden, K., Jones, L., Weissbecker, I., Wessells, M., Bolton, P., Betancourt, T. S., Hijazi, Z., Galappatti, A., Yamout, R., Patel, P. and Sumathipala, A. (2009) 'Mental health and psychosocial support in crisis and conflict: report of the Mental Health Working Group', *Prehospital and Disaster Medicine*, 24(Suppl 2), pp. s217-s227.

Chiumento, A., Rahman, A., Frith, L., Snider, L. and Tol, W. A. (2017) 'Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates', *Globalization And Health*, 13(1), pp. 8-26.

Curry, D., Waldman, R. and Caplan, A. (2014) *An Ethical Framework for the development and review of health research proposals involving humanitarian contexts*. [Online]. Available at: http://www.elrha.org/wp-content/uploads/2015/01/FINAL-R2HC-Ethical-Framework_Final-Report_24-January-2014_0.pdf (Accessed: 03.02.2014).

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.

Michael, M. and Zwi, A. B. (2002) 'Oceans of need in the desert: ethical issues identified while researching humanitarian agency response in Afghanistan', *Developing World Bioethics*, 2(2), pp. 109-30

Schopper, D., Upshur, R., Matthys, F., Singh, J. A., Bandewar, S. S., Ahmad, A. and van Dongen, E. (2009) 'Research Ethics Review in Humanitarian Contexts: The Experience of the Independent Ethics Review Board of Médecins Sans Frontières', *PLoS Medicine*, 6(7), pp. 1-6.

Siriwardhana, C., Adikari, A., Jayaweera, K. and Sumathipala, A. (2013) 'Ethical challenges in mental health research among internally displaced people: Ethical theory and research implementation', *BMC Medical Ethics*, 14(1), pp. 13-20.

Wessells, M. G. (2008) 'Do no harm: Challenges in organizing psychosocial support to displaced people in emergency settings', *Refuge*, 25(1), pp. 6-14.

World Health Organisation (2007) *WHO Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies*. Geneva: WHO. [Online]. Available at: http://www.who.int/gender/documents/OMS_Ethics&Safety10Aug07.pdf (Accessed: 03.02.2014).

Zwi, A. B., Grove, N. J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D. and Tarantola, D. (2006) 'Placing ethics in the centre: negotiating new spaces for ethical research in conflict situations', *Global Public Health*, 1(3), pp. 264-277.

ETHICAL STANDARDS FOR MENTAL HEALTH AND PSYCHOSOCIAL SUPPORT RESEARCH IN EMERGENCIES: REVIEW OF LITERATURE AND CURRENT DEBATES

Abstract

Background: Research in emergencies is needed to understand the prevalence of mental health and psychosocial problems and strengthen the evidence base for interventions. All research - including operational needs assessments, programme monitoring and evaluation, and formal academic research - must be conducted ethically. While there is broad consensus on fundamental principles codified in research ethics guidelines, these do not address the ethical specificities of conducting mental health and psychosocial support (MHPSS) research with adults in emergencies. To address this gap, this paper presents a review of multidisciplinary literature to identify specific ethical principles applicable to MHPSS research in emergencies.

Discussion: Sixty sources meeting the literature review inclusion criteria were analysed following a thematic synthesis approach. This approach involves first developing descriptive themes grounded in the sources reviewed, which are then reviewed to generate overarching analytical themes, in this case developed according to underpinning ethical principles. There was consensus on the relevance of universal ethical research principles to MHPSS research in emergencies, including norms of participant informed consent and protection; ensuring benefit arises from research participation; researcher neutrality, accountability, and safety; and the duty to ensure research is well designed and accounts for contextual factors in emergency settings.

We go onto discuss unresolved issues by highlighting six current debates relating to the application of ethics in emergency settings: (1) what constitutes fair benefits?; (2) how should informed consent be operationalised?; (3) is there a role for decision making capacity assessments?; (4) how do risk management approaches impact upon the construction of ethical research?; (5) how can ethical reflection best be achieved?, and (6) are ethical review boards sufficiently representative and equipped to judge the ethical and scientific merit of emergency MHPSS research? Underlying these debates is a systemic tension between procedural ethics and ethics in practice.

Summary and recommendations: In summary, underpinning the literature is a desire to ensure the protection of participants exposed to emergencies and in need of evidence-based MHPSS. However, there is a lack of agreement on how to contextualise guidelines and procedures to effectively maximise the perspectives of researchers, participants and ethical

review boards. This is a tension that the field must address to strengthen ethical MHPSS research in emergencies.

Background

In emergencies - including disasters triggered by natural events and armed conflicts, and associated refugee or internally displaced persons settings - the prevalence of mental health and psychosocial problems is high. Research in emergencies may be aimed at understanding the causes of mental health and psychosocial problems, or the acceptability and effectiveness of mental health and psychosocial support (MHPSS) interventions; and is needed to strengthen the evidence base for policy and practice (Zwi *et al.*, 2006; Tol *et al.*, 2011; Hobfoll, 2014). Research includes operational needs assessments, programme monitoring and evaluation, as well as formal academic studies; and may be conducted by a variety of actors including United Nations agencies, governmental and non-governmental organisations, academics, and field practitioners.

All research must be conducted ethically. Research guidelines codify the norms underpinning ethical research practice from a range of disciplinary perspectives including biomedical (Kieling *et al.*, 2011; World Medical Association, 2013 [1964]; Council for International Organisations of Medical Sciences (CIOMS), 2002) and social sciences (American Anthropological Association, 2009; Association of Social Anthropologists of the UK and the Commonwealth (ASA), 2011; Economic and Social Research Council, 2015). Existing guidelines do not directly address the ethical specificities of conducting MHPSS research in emergencies (Ager *et al.*, 2014; Chiumento *et al.*, 2016).

To address this gap, a multidisciplinary literature review was conducted to identify specific principles applicable to ethical MHPSS research with adults in emergencies. The Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergencies (IASC-RG) supported this effort through input and critical review, and by publishing a set of recommendations for ethical MHPSS research in emergencies based upon this review (Inter-Agency Standing Committee (IASC) Reference Group for Mental Health and Psychosocial support in Emergency Settings, 2014).

In the discussion we identify the strengths and limitations of the review. We then highlight the distinct features of conducting ethical MHPSS research in emergencies, and identify an underlying debate between those who recommend strengthening procedures, and those calling for more flexibility in applying ethical principles to MHPSS research practice.

Methods

This literature review aims to integrate and interpret empirical evidence on which ethical principles are applicable to MHPSS research with adults in emergencies.

Search strategy

The following medicine, social science and medical ethics databases were searched: SCOPUS; Web of Science; ProQuest Humanities and Social Sciences and ProQuest Health Sciences; Cochrane Library; MedLine; PROSPERO; PsycINFO; and the WHO Global Health Library and Regional Database. Key search terms included ethic*, research*, evaluat*, humanitarian, conflict, disaster, mental health, and psychosocial, with appropriate MeSH terms derived for each search engine - most commonly: ethic* AND (research* OR evaluat*) AND (humanitarian OR conflict OR disaster) AND (mental health OR psychosocial).

Additional searches were conducted on practitioner databases including mhps.net; refworld.org; and alnap.org. These provide the humanitarian community with platforms for sharing resources related to emergency MHPSS research, good practice, and policy. Search terms were “ethical” or “ethical research”.

Further literature was identified through cross-referencing citations of included sources and recommendations from the IASC-RG working group supporting this review. Searches were conducted between January and March 2014 by the lead author.

Inclusion criteria

Literature was considered for inclusion if it discussed ethical considerations relevant to MHPSS research in emergencies, or with refugee or asylum seeking populations. To ensure the practical applicability of findings, “research” was defined broadly covering formal research across academic disciplines, discussion papers, ethical analysis, and operational research such as assessment, monitoring and evaluation of MHPSS programmes. Published and unpublished empirical research and policy guidance were eligible, including reflective researcher and practitioner perspectives. Due to the broad scope of this review, sources were assumed to be of good quality since the majority were drawn from peer-review journals, books, or guidelines likely to have undergone some level of quality assessment.

Other inclusion criteria were publication in English; for academic databases publication in a scholarly peer reviewed journal or book (depending upon the search engine); and full text availability. No geographical or date limiters were set. Literature on research with children was excluded, recognising the additional legal and ethical considerations, principally related

to autonomy and capacity. However, the findings from this review similarly apply to research with children, but would require additional ethical assessment.

Analysis

All sources meeting the inclusion criteria were independently reviewed by the lead author. From this, key data was extracted from each paper on (a) the general ethical principles identified to promote ethical research; (b) the operationalisation of each principle; and (c) commentary on the appropriateness of each principle to humanitarian emergency settings. This extracted data was summarised and shared for review with the IASC-RG working group⁹ comprised of academic researchers, MHPSS practitioners from International Non-Governmental Organisations, the International Federation of Red Cross and Red Crescent Societies, and representatives of United Nations agencies.

Literature was analysed following a thematic synthesis approach (Thomas and Harden, 2008). Descriptive themes evolved iteratively alongside the literature review, by identifying and grouping ethical principles according to their role in promoting ethical practice. From this, descriptive themes were mapped to explore possible connections between principles and to identify analytical themes for a practice-focused framework. This process was continued until saturation was achieved. This process was initially conducted by the lead author and refined through monthly discussion with IASC-RG working group members. Once a framework was finalised, the literature was revisited and re-analysed by the lead author to ensure findings remained grounded in the data.

Through this process, key tensions across the literature surrounding the application of ethical principles to emergency MHPSS research practice became apparent. These emerged either as discussion points across papers, or through differing recommendations for managing or resolving key ethical issues. Therefore, in the final section of the paper, we outline six key debates to highlight why and where these controversies arise; offering researcher's suggested topics to reflect upon their own ethical practice.

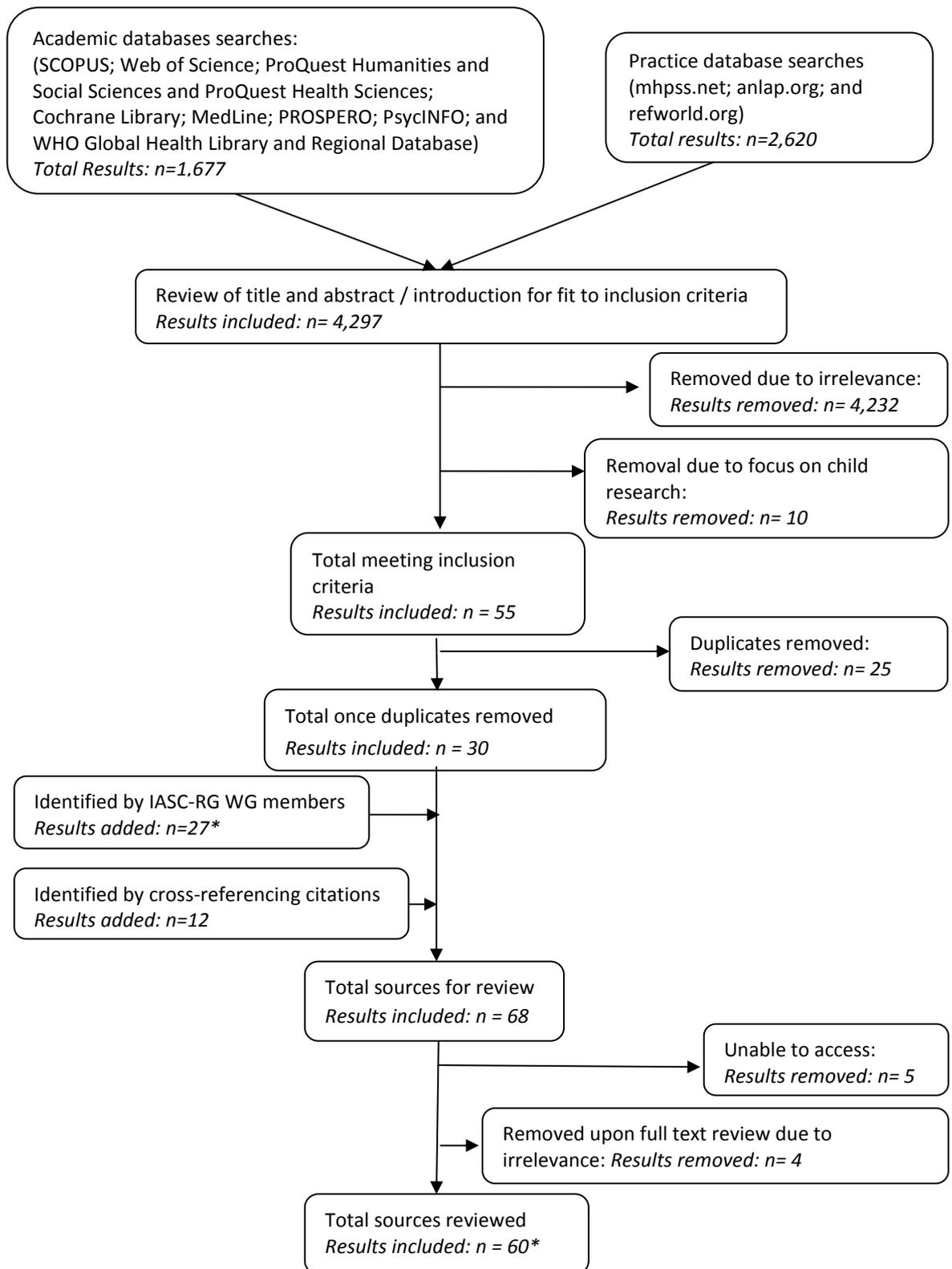
Results

Academic and practice database searches retrieved 4,297 results (1,677 and 2,620 results from each database respectively). Of these, review of the title and abstract or introduction led to removal of 4,232 papers as not relevant, 10 for focusing upon research with children,

⁹ New IASC-RG membership is restricted to those organisations working in a minimum of 2 countries. For the development of the ethical guidelines that arose out of this review we were able to include the perspectives of national NGO's.

and 25 duplicates. Further sources were added by IASC-RG Working Group members (n=27) and through cross-referencing (n=12). When conducting full text review five results were removed due to inaccessibility, and four for irrelevance. Therefore, combined searches on academic and practice databases identified a total of 60 results for inclusion in the review (see figure 1). Of these, the majority were published in peer-review journals (n=53), as peer-reviewed guidelines (n=2), working papers (n=3), conference papers (n=1) or commissioned reviews (n=1).

Figure 1: Flow chart of literature searches



**Please note that the version of the paper presented in this thesis includes an additional reference identified by VIVA examiners that is not in the version of this paper published in Globalization and Health.*

Table 1 presents the results according to five inter-related and overarching ethical principles: (1) Scientific research design; (2) Participation; (3) Safety; (4) Neutrality and (5) Purpose and Benefit. Each one represents the end-result or intended outcome of ethical practice and contains sub-themes of ethical considerations to be addressed. For example, informed consent is viewed as important to achieving the ethical principle of participation.

Table 1 Thematic analysis of ethical principles applicable to MHPSS research in emergencies

Ethical principle	Themes	Sub-themes	Source reference papers
Scientific research design	Selection of research question	Necessity	(Hynes, 2003; Jacobsen and Landau, 2003; Kilpatrick, 2004; Tomlinson <i>et al.</i> , 2006; WHO, 2007; Tol and Jordans, 2008; Wessells, 2008; Allden <i>et al.</i> , 2009; Madianos and Evi, 2010; Call <i>et al.</i> , 2012; Curry <i>et al.</i> , 2014; Sumathipala <i>et al.</i> , 2010)
		Researcher inherent biases	(Bäärnhielm and Ekblad, 2002; Benight and McFarlane, 2007; Tankink, 2007; Allden <i>et al.</i> , 2009)
	Risk / benefit evaluation	Emergency = heightened risk	(Richards, 1989; Goodhand, 2000; Leaning, 2001; WHO, 2003; Emanuel <i>et al.</i> , 2004; Kilpatrick, 2004; Levine, 2004; WHO, 2007; Kos, 2008; Wessells, 2008; Allden <i>et al.</i> , 2009; Iltis <i>et al.</i> , 2013; Sumathipala <i>et al.</i> , 2010)
		Benefits relative to burdens	(Neugebauer, 1999; Goodhand, 2000; Benatar, 2002; Hynes, 2003; WHO, 2003; Hastings Centre, 2004; Levine, 2004; Zwi <i>et al.</i> , 2006; WHO, 2007; Tol and Jordans, 2008; Wessells, 2008; Allden <i>et al.</i> , 2009; Jesus and Michael, 2009; Madianos and Evi, 2010; O'Mathuna, 2010; Juntunen, 2011; Sumathipala <i>et al.</i> , 2010)
	Appropriate methodology	Lack of methodological rigor	(Benatar, 2002; Black, 2003; Brown <i>et al.</i> , 2004; Emanuel <i>et al.</i> , 2004; Lavery <i>et al.</i> , 2013; Sumathipala <i>et al.</i> , 2010)
		Methodological transparency	(Jacobsen and Landau, 2003; WHO, 2003; Rosenstein, 2004; Tomlinson <i>et al.</i> , 2006; Benight and McFarlane, 2007; Mackenzie <i>et al.</i> , 2007; de Graaff <i>et al.</i> , 2008; Kortmann, 2008; Allden <i>et al.</i> , 2009; O'Mathuna, 2010; Curry <i>et al.</i> , 2014)
		Methods implemented well	(Leaning, 2001; Hynes, 2003; Jacobsen and Landau, 2003; WHO, 2003; Mollica <i>et al.</i> , 2004; Benight and McFarlane, 2007; Poudyal <i>et al.</i> , 2008; Tol and Jordans, 2008; Wessells, 2008; Allden <i>et al.</i> , 2009; Wessells, 2009; Madianos and Evi, 2010; Juntunen, 2011; Siriwardhana <i>et al.</i> , 2013)
	Critical reflection	Continuous reflexivity	(Bäärnhielm and Ekblad, 2002; Hunt, 2008; Tol and Jordans, 2008; Wessells, 2009; Madianos and Evi, 2010; Juntunen, 2011)
		Collective learning	(Emanuel <i>et al.</i> , 2004; Benatar <i>et al.</i> , 2005; Zwi <i>et al.</i> , 2006; WHO, 2007; Kortmann, 2008; Wessells, 2008; Siriwardhana <i>et al.</i> , 2013)

Participation	Meaningful opportunity for contributing to research design and conduct	Shared understanding	(Richards, 1989; Goodhand, 2000; Hynes, 2003; Jacobsen and Landau, 2003; Mollica <i>et al.</i> , 2004; Zwi <i>et al.</i> , 2006; Benight and McFarlane, 2007; Mackenzie <i>et al.</i> , 2007; Kortmann, 2008; Kos, 2008; Wessells, 2008; Allden <i>et al.</i> , 2009; Jesus and Michael, 2009; Wessells, 2009; Citraningtyas <i>et al.</i> , 2010; Sumathipala <i>et al.</i> , 2010)	
		Partnership model	(Richards, 1989; Neugebauer, 1999; Benatar, 2002; Black, 2003; Hynes, 2003; Emanuel <i>et al.</i> , 2004; Zwi <i>et al.</i> , 2006; Allden <i>et al.</i> , 2009; Schopper <i>et al.</i> , 2009; Citraningtyas <i>et al.</i> , 2010; Curry <i>et al.</i> , 2014; Sumathipala <i>et al.</i> , 2010)	
		Advising on management of ethical issues	(Richards, 1989; Benatar, 2002; Emanuel <i>et al.</i> , 2004; Zwi <i>et al.</i> , 2006; Hunt, 2008; Lavery <i>et al.</i> , 2013)	
	Fair selection of participants	Selection according to research objectives	(Hastings Centre, 2004; Sumathipala <i>et al.</i> , 2010)	
		Risks of targeted selection	(Allden <i>et al.</i> , 2009)	
		Informed by local knowledge	(Emanuel <i>et al.</i> , 2004; Zwi <i>et al.</i> , 2006; Allden <i>et al.</i> , 2009; Schopper <i>et al.</i> , 2009)	
	Informed consent:	Informed consent as an accepted ethical norm	(Black, 2003; Rosenstein, 2004; Harper, 2007; Tol and Jordans, 2008; Allden <i>et al.</i> , 2009; O'Mathuna, 2010; Yamout and Jabbour, 2010; Iltis <i>et al.</i> , 2013; Curry <i>et al.</i> , 2014; Sumathipala <i>et al.</i> , 2010)	
		As a contested concept	(Benatar, 2002; Hoeyer <i>et al.</i> , 2005; Harper, 2007)	
		As (flexible) process	(Neugebauer, 1999; Emanuel <i>et al.</i> , 2004; Hoeyer <i>et al.</i> , 2005; Mackenzie <i>et al.</i> , 2007; WHO, 2007; Allden <i>et al.</i> , 2009; Schopper <i>et al.</i> , 2009; Wessells, 2009)	
		Procedural considerations	(WHO, 2003; Call <i>et al.</i> , 2012; Curry <i>et al.</i> , 2014)	
		i. Information provided	Consent as "informed"	(Goodhand, 2000; Benatar, 2002; Allden <i>et al.</i> , 2009)
			Information provided	(Goodhand, 2000; Harper, 2007; Contractor, 2008)
		ii. Comprehension of information	Strength of information exchange process	(Bäärnhielm and Ekblad, 2002; Hynes, 2003; Emanuel <i>et al.</i> , 2004; Harper, 2007; WHO, 2007; Allden <i>et al.</i> , 2009; Schopper <i>et al.</i> , 2009; Call <i>et al.</i> , 2012)
Barriers to comprehension	(Leaning, 2001; Benatar, 2002; Fitzgerald <i>et al.</i> , 2002; Wessells, 2009; O'Mathuna, 2010; Iltis <i>et al.</i> , 2013)			

	iii. Voluntariness	Strategies to verify comprehension	(Benatar, 2002; Fitzgerald <i>et al.</i> , 2002; Hynes, 2003; WHO, 2007)
		Factors influencing	(Goodhand, 2000; WHO, 2003; Brown <i>et al.</i> , 2004; Rosenstein, 2004; Wessells, 2008; Allden <i>et al.</i> , 2009; Jesus and Michael, 2009; O'Mathuna, 2010)
		Potential coercion due to emergency context	(Neugebauer, 1999; Goodhand, 2000; Benatar, 2002; Zwi <i>et al.</i> , 2006; Mackenzie <i>et al.</i> , 2007; Wessells, 2008; Allden <i>et al.</i> , 2009; Jesus and Michael, 2009; O'Mathuna, 2010; Sumathipala <i>et al.</i> , 2010)
	Autonomy and capacity	Normative connections	(Bäärnhielm and Ekblad, 2002; Levine, 2004; Mackenzie <i>et al.</i> , 2007; Allden <i>et al.</i> , 2009; Jesus and Michael, 2009; Yamout and Jabbour, 2010)
		Decision-making capacity debate	(Rosenstein, 2004; Mackenzie <i>et al.</i> , 2007; Jesus and Michael, 2009; Wessells, 2009; O'Mathuna, 2010)
		Limiting potential exploitation	(Emanuel <i>et al.</i> , 2004; Zwi <i>et al.</i> , 2006; Wessells, 2008; Siriwardhana <i>et al.</i> , 2013; Sumathipala <i>et al.</i> , 2010)
		Procedural considerations	(Rosenstein, 2004; Bhan, 2010)
	Confidentiality and anonymity	Increased importance of in emergencies	(Jacobsen and Landau, 2003; WHO, 2003; WHO, 2007; Wessells, 2008)
		Limits in emergencies	(Leaning, 2001; Emanuel <i>et al.</i> , 2004; Harper, 2007; Allden <i>et al.</i> , 2009; Madianos and Evi, 2010; O'Mathuna, 2010; Aube, 2011)
		Harms if breached	(Neugebauer, 1999; Jacobsen and Landau, 2003; WHO, 2003; Wessells, 2008; Wissow <i>et al.</i> , 2012)
		Duty to safeguard	(Goodhand, 2000; WHO, 2007; O'Mathuna, 2010; Call <i>et al.</i> , 2012)
		Management of data	(Hynes, 2003; Mackenzie <i>et al.</i> , 2007; WHO, 2007; Allden <i>et al.</i> , 2009; Call <i>et al.</i> , 2012)
	Safety	Participant vulnerability i. Protection needs	Protection framework
Vulnerability: contested concept			(Hynes, 2003; Levine, 2004; Mackenzie <i>et al.</i> , 2007; Jesus and Michael, 2009; Sumathipala <i>et al.</i> , 2010)
Individual situational approach			(WHO, 2003; Levine, 2004)

		Serious mental disorders	(WHO, 2003; Allden <i>et al.</i> , 2009; Wissow <i>et al.</i> , 2012; Siriwardhana <i>et al.</i> , 2013)
		Potential for exploitation	(Hastings Centre, 2004; Rosenstein, 2004; Allden <i>et al.</i> , 2009; Sumathipala <i>et al.</i> , 2010)
	Accountability i. Fair selection and specialist training of research and auxiliary staff	Adequate preparation	(Richards, 1989; Neugebauer, 1999; Black, 2003; Hynes, 2003; Mollica <i>et al.</i> , 2004; Tomlinson <i>et al.</i> , 2006; Contractor, 2008; Tol and Jordans, 2008; Wessells, 2008; Citraningtyas <i>et al.</i> , 2010; Madianos and Evi, 2010; Juntunen, 2011; Wissow <i>et al.</i> , 2012; Siriwardhana <i>et al.</i> , 2013; Curry <i>et al.</i> , 2014; Sumathipala <i>et al.</i> , 2010)
		Answerable to stakeholders	(Black, 2003; Siriwardhana <i>et al.</i> , 2013)
		Transparent staff selection	(Goodhand, 2000; Michael and Zwi, 2002; Hynes, 2003; Hunt, 2008; Wessells, 2008; Allden <i>et al.</i> , 2009; Aube, 2011; Juntunen, 2011; Redfield, 2012; Siriwardhana <i>et al.</i> , 2013)
		Specialist training	(Hynes, 2003; WHO, 2003; Mollica <i>et al.</i> , 2004; Rosenstein, 2004; Zwi <i>et al.</i> , 2006; Harper, 2007; Mackenzie <i>et al.</i> , 2007; WHO, 2007; Contractor, 2008; Hunt, 2008; Allden <i>et al.</i> , 2009; Wessells, 2009; Juntunen, 2011; Call <i>et al.</i> , 2012; Wissow <i>et al.</i> , 2012; Iltis <i>et al.</i> , 2013; Siriwardhana <i>et al.</i> , 2013; Curry <i>et al.</i> , 2014)
		Tensions in collaborative partnerships	(Brown <i>et al.</i> , 2004)
		Researcher self-care	Protecting against negative reactions to emergency context and/or research topic
		Self- and team-care strategies	(Tankink, 2007; Wessells, 2008; Juntunen, 2011; Curry <i>et al.</i> , 2014)
	Environmental, political and health safety	Working “in-extremis”	(Jacobsen and Landau, 2003; WHO, 2003; Contractor, 2008; Bhan, 2010; Juntunen, 2011)
		Procedures to respond	(Benatar, 2002; Jacobsen and Landau, 2003; WHO, 2003; WHO, 2007; Contractor, 2008; Allden <i>et al.</i> , 2009; Bhan, 2010; Juntunen, 2011; Iltis <i>et al.</i> , 2013; Curry <i>et al.</i> , 2014)

Neutrality	Access and exit strategies i. Gatekeepers and power	Coordinating with existing systems	(Mollica <i>et al.</i> , 2004; Contractor, 2008; Citraningtyas <i>et al.</i> , 2010; Curry <i>et al.</i> , 2014; Sumathipala <i>et al.</i> , 2010)
		Power & knowledge asymmetries	(Hynes, 2003; Jacobsen and Landau, 2003; WHO, 2003; Brown <i>et al.</i> , 2004; Sumathipala and Siribaddana, 2005; Allden <i>et al.</i> , 2009; Aube, 2011)
		Gatekeepers: benefits and critique of	(Goodhand, 2000; Bäärnhielm and Ekblad, 2002; Michael and Zwi, 2002; Jacobsen and Landau, 2003; WHO, 2003; Del Ben <i>et al.</i> , 2006; Mackenzie <i>et al.</i> , 2007; Allden <i>et al.</i> , 2009; Citraningtyas <i>et al.</i> , 2010; Aube, 2011)
		Transparency towards power	(Goodhand, 2000; Black, 2003; Hynes, 2003; Brown <i>et al.</i> , 2004; Tomlinson <i>et al.</i> , 2006; Hunt, 2008; Allden <i>et al.</i> , 2009; Wessells, 2009)
	Coordination with other researchers and organisations	Mutual respect /trust	(Emanuel <i>et al.</i> , 2004; Redfield, 2012)
		International collaborations and power	(Black, 2003; Tomlinson <i>et al.</i> , 2006; Hunt, 2008; Kos, 2008a; Allden <i>et al.</i> , 2009; Aube, 2011; Sumathipala <i>et al.</i> , 2010)
		Networked with emergency response	(Tol and Jordans, 2008; Wessells, 2008; Wessells, 2009; Citraningtyas <i>et al.</i> , 2010; Madianos and Evi, 2010; Juntunen, 2011; Sumathipala <i>et al.</i> , 2010)
		Risk of poor coordination	(Allden <i>et al.</i> , 2009; Wessells, 2009; Citraningtyas <i>et al.</i> , 2010)
	Declaration of researcher interests	Transparency about	(Benatar, 2002; Brown <i>et al.</i> , 2004; Tomlinson <i>et al.</i> , 2006; Zwi <i>et al.</i> , 2006; Kos, 2008a; Wessells, 2009; O'Mathuna, 2010; Aube, 2011; Curry <i>et al.</i> , 2014)
	Funding	Power of	(Richards, 1989; Brown <i>et al.</i> , 2004; Zwi <i>et al.</i> , 2006; Allden <i>et al.</i> , 2009; Wessells, 2009)
		Impact of emergency upon budget / funding	(Hastings Centre, 2004; Curry <i>et al.</i> , 2014)
		Advocacy to funders	(Michael and Zwi, 2002; Brown <i>et al.</i> , 2004; Zwi <i>et al.</i> , 2006; Allden <i>et al.</i> , 2009)
	Purpose and benefit	Sustainable benefit	Levels of benefits
Haphazard process of accruing			(Benatar, 2002; Emanuel <i>et al.</i> , 2004; Hastings Centre, 2004; Citraningtyas <i>et al.</i> , 2010; Curry <i>et al.</i> , 2014)
Long-term collaborations & sustainable benefit			(Brown <i>et al.</i> , 2004; Tomlinson <i>et al.</i> , 2006; Mackenzie <i>et al.</i> , 2007; Wessells, 2008; Aube, 2011; Sumathipala <i>et al.</i> , 2010)

	Dissemination	Right to results	(Black, 2003; Hynes, 2003; WHO, 2003; Zwi <i>et al.</i> , 2006; Mackenzie <i>et al.</i> , 2007; Tol and Jordans, 2008; Alden <i>et al.</i> , 2009; Citraningtyas <i>et al.</i> , 2010; Siriwardhana <i>et al.</i> , 2013; Curry <i>et al.</i> , 2014; Sumathipala <i>et al.</i> , 2010)
		Potential risks in	(Richards, 1989; Jacobsen and Landau, 2003; Brown <i>et al.</i> , 2004; Harper, 2007; Kos, 2008; Alden <i>et al.</i> , 2009)
		Forms of	(Sumathipala and Siribaddana, 2005; Tomlinson <i>et al.</i> , 2006; Zwi <i>et al.</i> , 2006; WHO, 2007; Bhan, 2010; Curry <i>et al.</i> , 2014)
		Of data collection tools and methods	(Lohr <i>et al.</i> , 2006; de Graaff <i>et al.</i> , 2008)
	Ethical review	As accepted norm	(Kilpatrick, 2004; Jesus and Michael, 2009; Bhan, 2010; O'Mathuna, 2010; Sumathipala <i>et al.</i> , 2010)
		Responsibilities of reviewers	(Benatar, 2002; Brown <i>et al.</i> , 2004; Emanuel <i>et al.</i> , 2004; Levine, 2004; Curry <i>et al.</i> , 2014)
		Lack of specificity to emergencies	(Brown <i>et al.</i> , 2004; Zwi <i>et al.</i> , 2006; Wessells, 2008; Alden <i>et al.</i> , 2009; Iltis <i>et al.</i> , 2013)

Ensuring research is conducted ethically necessitates “a thoughtful process of balancing ethical considerations” (Emanuel *et al.*, 2004, p.936), requiring that researcher’s “bring the question of ethics – too often neglected to a one off aspect of the research process – to something that suffuses all we do” (Harper, 2007, p.2241). Ethical themes are presented with an overview paragraph, followed by a brief discussion of sub-themes specific to conducting MHPSS research with populations in emergencies. Whilst themes are presented separately, authors frequently discussed them interdependently, with considerations under one theme typically influencing others.

1. Scientific research design

It was generally agreed that ensuring a scientific research design is a core principle of ethical research. Given that much emergency research is conducted in low and middle income countries (LMIC), authors call attention to contextual realities including: culture (World Health Organisation, 2007; Sumathipala *et al.*, 2010); patterns and dynamics of conflict (Goodhand, 2000); inequity of healthcare (Benatar *et al.*, 2005); and political and socioeconomic vulnerabilities of individuals and communities (Benatar *et al.*, 2005; Benight and McFarlane, 2007; Sumathipala *et al.*, 2010). Since emergency research frequently operates alongside relief initiatives, it was stressed that research design should:

- not impede relief (Jesus and Michael, 2009; O'Mathuna, 2010; Sumathipala *et al.*, 2010);
- build upon existing systems and resources (Citraningtyas *et al.*, 2010);
- recognise field practice difficulties, minimising risk (Zwi *et al.*, 2006);
- be conducted at an appropriate time (Citraningtyas *et al.*, 2010; Sumathipala *et al.*, 2010); and
- pay attention to communal and non-pathological processes including resilience, and not only MHPSS vulnerabilities (Brown *et al.*, 2004; Mollica *et al.*, 2004; Allden *et al.*, 2009).

1a: Selection of research questions

The findings indicate that research questions require a scientific rationale for *why* the research should be conducted in an emergency, addressing priority unanswered questions (Kilpatrick, 2004; World Health Organisation, 2007; Allden *et al.*, 2009; Madianos and Evi, 2010; Curry *et al.*, 2014; Sumathipala *et al.*, 2010) and not duplicating research (Call *et al.*, 2012). Theoretical and practical relevance should be ensured (Jacobsen and Landau, 2003; Tol and Jordans, 2008), avoiding over-researching a population (Tomlinson *et al.*, 2006;

World Health Organisation, 2007; Sumathipala *et al.*, 2010) including those considered “at risk” (Wessells, 2008), and have a purpose beyond contributing to knowledge alone (Hynes, 2003).

As in all research, authors caution that research (including selecting research topics, (Allden *et al.*, 2009), design, and analysis procedures (Bäärnhielm and Ekblad, 2002; Benight and McFarlane, 2007; Tankink, 2007) must correspond to what emergency-affected communities require or are seeking (Sumathipala *et al.*, 2010), and not only be informed by the professional expertise and interests of the researcher. For example, researchers with specialist training – whether in epidemiology, qualitative interviewing, or psychological treatments - should avoid pursuing research questions that align with their strengths and interests where these are not relevant to affected communities’ priorities and needs.

1b: Risk and benefit evaluation

Authors stressed the ethical imperative to maximise benefit and minimise harm through a favourable risk / benefit ratio and appropriate strategies to mitigate the inherent risks present in all research (Benatar, 2002; World Health Organisation, 2003; Hastings Centre, 2004; Jesus and Michael, 2009). This does not require research to be risk free (Kilpatrick, 2004), but recognises that emergencies automatically expose participants to higher risks (Emanuel *et al.*, 2004; Iltis *et al.*, 2013; Sumathipala *et al.*, 2010).

Whilst what constitutes “fair” benefits was contested, there was broad agreement that benefits be defined in direct relation to burdens: as risks increase, so should the benefits (Hastings Centre, 2004). Certain risk / benefit considerations were identified as requiring special attention in emergencies:

- awareness of socio-political context (Goodhand, 2000; Zwi *et al.*, 2006) including safety considerations such as when gathering groups (Allden *et al.*, 2009);
- strength of confidentiality and anonymity procedures, avoiding (inadvertent) disclosure, recognising the harm this may cause to individuals and communities (Leaning, 2001; World Health Organisation, 2003; Allden *et al.*, 2009);
- understanding the impact dissemination may have upon communities receiving aid and services (Richards, 1989; Kos, 2008);
- adequate responses to research participants’ discomfort or adverse reactions, including functional referral pathways for MHPSS care (Neugebauer, 1999; Hynes, 2003; World Health Organisation, 2003; World Health Organisation, 2007; Tol and Jordans, 2008; Wessells, 2008; Madianos and Evi, 2010; O’Mathuna, 2010;

Juntunen, 2011) determined by the level of risk that the research (Rosenstein, 2004) or the participant's situation presents (Levine, 2004);

- communication of risks and benefits in informed consent, identifying risks that matter to participants in/following a particular emergency (Iltis *et al.*, 2013).
- ensuring researcher self-care (World Health Organisation, 2007; Wessells, 2008).

1c: Appropriate methodology

A number of sources stated that to undermine the research methodology is to undermine its ethical status (Benatar, 2002; Black, 2003; Brown *et al.*, 2004; Emanuel *et al.*, 2004; Lavery *et al.*, 2013), arguing that ethically no data is better than bad data (Allden *et al.*, 2009). An appropriate methodology involves transparency about methods, results, and limitations - including potential sources of bias such as sentimentality (Jacobsen and Landau, 2003; Tomlinson *et al.*, 2006; de Graaff *et al.*, 2008; Kortmann, 2008; O'Mathuna, 2010). This underscores the idea that to over generalise or promote knowledge founded upon unreliable methods may cause harm (Jacobsen and Landau, 2003).

It was advised that protocols clearly outline the research design (Jacobsen and Landau, 2003; Benight and McFarlane, 2007; Allden *et al.*, 2009). Considerations specific to emergencies include making explicit how contextual norms are addressed (World Health Organisation, 2003; Sumathipala *et al.*, 2010), inform study design, and will be evaluated during the research life-cycle (Curry *et al.*, 2014). Also emphasised was an assessment of how informed consent processes respond to changing circumstances (Mackenzie *et al.*, 2007; Curry *et al.*, 2014), and to participants with potentially impaired decision making capacity (Rosenstein, 2004).

Methodologically sound research requires methods to be practiced well (Wessells, 2009; Sumathipala *et al.*, 2010). Avoiding labelling, stigmatising or pathologising participants is viewed to be particularly important for populations who may be disempowered following an emergency (World Health Organisation, 2003; Wessells, 2008; Allden *et al.*, 2009; Juntunen, 2011). To achieve this, researchers need to be aware of contested or culturally rooted concepts such as "childhood" (Allden *et al.*, 2009), and to avoid reified and simplistic understandings of, for example, "community" (Wessells, 2008).

Methodological considerations specific to cross-cultural emergency research include:

(i) Cultural adaptation of standardised mental health instruments:

Ethnographic methods to inform instrument adaptation are recommended to ensure local applicability (Mollica *et al.*, 2004; Tol and Jordans, 2008; Allden *et al.*, 2009).

Given resource constraints in emergencies, authors promote developing instruments using local clinical standards (Poudyal *et al.*, 2008; Tol and Jordans, 2008) and evaluation tools that serve both clinical and research purposes (Tol and Jordans, 2008).

(ii) *Conducting interviews:*

Methodological considerations when interviewing in emergencies include: length and format (World Health Organisation, 2003; Siriwardhana *et al.*, 2013), sampling approach (Leaning, 2001; Hynes, 2003; Jacobsen and Landau, 2003), asking the right questions (Wessells, 2008; 2009) using appropriate language and phrasing (World Health Organisation, 2003; Benight and McFarlane, 2007; Allden *et al.*, 2009), and being aware of terminology that may reflect a policy stance or researcher sympathies (Hynes, 2003). Interview questions can inadvertently resemble other official procedures (e.g., history taking for refugee status claims) (Hynes, 2003), that may lead to participants “performing” (Wessells, 2008). Longer field time for data collection may reveal inconsistencies in participant narratives (Jacobsen and Landau, 2003), avoiding the pitfalls of time-bound “fly-in, fly-out” research (Madianos and Evi, 2010). For interviews on sensitive topics, authors recommend having a diversionary questionnaire that asks non-sensitive questions (e.g., basic demographic information) to draw upon should interview conditions become unsafe or privacy interrupted (World Health Organisation, 2003).

(iii) *Interpreters:*

Hynes (2003) notes the importance of researcher–interpreter trust. Others emphasise attention to bias in translation as a result of ethnic, cultural or status differences between interpreters and participants (Jacobsen and Landau, 2003; World Health Organisation, 2003), as well as the additional burden upon participants when interviews are conducted with interpreters (World Health Organisation, 2003).

1d: Critical ethical reflection

Critical ethical reflection supports reflexivity towards researcher power (Juntunen, 2011) and is suggested as a way to promote ethics as a natural discourse in emergency research (Hunt, 2008). Given the particular ethical challenges that may arise in emergency research, authors recommend conducting ethical reflection (Zwi *et al.*, 2006) to increase transparency and learning (Emanuel *et al.*, 2004; Benatar *et al.*, 2005; World Health Organisation, 2007; Siriwardhana *et al.*, 2013). In potentially changing contexts there is consensus that ethical issues be evaluated throughout research: in the inception and design phase (Tol and Jordans,

2008; Madianos and Evi, 2010); during data collection and analysis, extending to dissemination and post-dissemination (Bäärnhielm and Ekblad, 2002; Wessells, 2009). To do this, the researcher's role is reframed from that of "expert" to "co-learner" (Wessells, 2008), and for MHPSS practitioners to shift from "being assessed" to "self-assessment" (Kortmann, 2008).

2. Participation

The findings highlight that participation in research is universally viewed as a basic right (Michael and Zwi, 2002; Mackenzie *et al.*, 2007; Tol and Jordans, 2008; Wessells, 2008; Allden *et al.*, 2009), interacting with other rights such as respect for autonomy and self-determination (Michael and Zwi, 2002; Mackenzie *et al.*, 2007; Citraningtyas *et al.*, 2010). In emergencies, participation was viewed as remedying systemic disempowerment of displaced communities (Hynes, 2003), rebalancing the researcher / researched relationship (Benatar, 2002) by addressing the question of who is being researched and why (Richards, 1989). Participatory approaches to conducting research can deliver potential benefits to populations exposed to emergencies, such as:

- a pathway to being heard or regaining dignity (Wessells, 2008; Allden *et al.*, 2009);
- recapturing a sense of control (Wessells, 2008);
- ensuring research responds to local needs, priorities, knowledge (Jacobsen and Landau, 2003; Zwi *et al.*, 2006; Wessells, 2009; Sumathipala *et al.*, 2010), and values (Mackenzie *et al.*, 2007), and respects local knowledge (Citraningtyas *et al.*, 2010);
- engaging with service providers (Kortmann, 2008);
- enhancing public understanding of research (Jesus and Michael, 2009);
- providing opportunities for community dialogue and engagement on how to manage ethical issues (Hunt, 2008; Lavery *et al.*, 2013), promoting trust and effective research partnerships (Hunt, 2008).

2a: Meaningful opportunities for contributing to research design and conduct

It was generally agreed that grounding research in local explanatory models of an emergency (Benight and McFarlane, 2007) helps to build a common understanding between the researchers and the community from the outset (Richards, 1989; Hynes, 2003), and to ensure research meets community needs (Citraningtyas *et al.*, 2010; Sumathipala *et al.*, 2010). Participation was defined as collaborative partnerships with shared responsibility in all research stages (Emanuel *et al.*, 2004; Sumathipala *et al.*, 2010), requiring mutual commitment to a partnership model founded upon trust (Zwi *et al.*, 2006). Participation

builds upon an individual's capacity to join or lead studies with affected communities (Neugebauer, 1999; Benatar, 2002; Black, 2003; Citraningtyas *et al.*, 2010) and strengthens local institutions - deemed particularly important in LMIC where institutions may be weak or eroded following an emergency (Sumathipala *et al.*, 2010).

It was suggested that protocols propose scenarios for community engagement throughout the research life-cycle in each unique emergency context (Richards, 1989; Benatar, 2002; Allden *et al.*, 2009; Schopper *et al.*, 2009; Curry *et al.*, 2014). This includes engaging community participation to identify research questions (Richards, 1989); methods; tools; approaches to data analysis and interpretation; dissemination routes and formats (Zwi *et al.*, 2006); protocol development (Benatar, 2002); and approaches to enhance management of ethical issues (Emanuel *et al.*, 2004).

In emergencies the benefits of community participation include informing researchers about community-based practices that may protect psychological and psychosocial health (Mollica *et al.*, 2004), and those that may cause harm (Wessells, 2009). Participation can also help to address potential community suspicions relating to why data is being collected (Kos, 2008), and to counteract a "culture of silence" (Jacobsen and Landau, 2003, p.10) adopted by participants as a strategy to minimise exposure to risk (Goodhand, 2000).

2b: Fair selection of participants

Findings highlight that participants should be selected according to the research objectives (Hastings Centre, 2004). Participation can aid in reaching socially marginalised groups (Emanuel *et al.*, 2004) and those likely to self-exclude (Allden *et al.*, 2009). Cautions were raised that researchers should be aware that participant selection creates perceptions of who is being heard, and may cause intra-community conflict due to perceived discrimination or social injustice (Allden *et al.*, 2009).

Community involvement in participant selection is seen as a way to provide researchers with an opportunity to learn of ongoing research, and prevent participants from being involved in multiple studies that may lead to burnout (Zwi *et al.*, 2006; Allden *et al.*, 2009; Schopper *et al.*, 2009). It also offers opportunities for learning about contextual factors such as family or community coercion to participate, or the potential for incentives to be viewed as coercive (Emanuel *et al.*, 2004; Sumathipala *et al.*, 2010).

Error! Bookmark not defined.

2c: Informed consent

There was general consensus that informed consent is central to ethical research (Black, 2003; Harper, 2007; Tol and Jordans, 2008; Allden *et al.*, 2009; O'Mathuna, 2010; Sumathipala *et al.*, 2010). Consent is described as being intimately linked to norms of voluntariness, autonomy, and capacity (Rosenstein, 2004; Allden *et al.*, 2009; Ittis *et al.*, 2013; Sumathipala *et al.*, 2010); a process where research objectives and expectations are established (Yamout and Jabbour, 2010), and benefits presented and affirmed by participants (Curry *et al.*, 2014).

Conversely, some authors contest the concept of informed consent, questioning whom it aims to protect (Benatar, 2002; Hoeyer *et al.*, 2005; Harper, 2007). To address this, there is broad support for emphasising the consent *process* beyond providing forms to be read and signed (Hoeyer *et al.*, 2005; World Health Organisation, 2007), viewing consent as a partnership between researchers and participants (Neugebauer, 1999) that responds to cultural and social practices (Emanuel *et al.*, 2004).

Flexibility in obtaining informed consent was recognised as being necessary across different emergency and cultural contexts. Alternatives to written consent are suggested, such as: oral consent (Allden *et al.*, 2009; Schopper *et al.*, 2009; Wessells, 2009); an interviewer signing a form confirming participant consent; or participants signing a separate form that does not identify the study topic – deemed appropriate for sensitive research (World Health Organisation, 2007). Other suggestions for a flexible approach include consent taken at multiple levels (Emanuel *et al.*, 2004) and sources (Mackenzie *et al.*, 2007; Allden *et al.*, 2009) including community, elders or leaders, families, and individuals as appropriate to the setting. Taking this further, Mackenzie *et al.* (2007) propose approval of a consent framework which ensures norms such as autonomy and capacity are upheld, but that also provide the researcher with flexibility as to how these are implemented and ensured in practice.

Procedural considerations include processes for documenting or recording consent and managing identifiable personal data (World Health Organisation, 2003; Call *et al.*, 2012; Curry *et al.*, 2014), with additional considerations required where research involves the collection and storage of biological materials (Sumathipala *et al.*, 2010). Some authors recommend obtaining consent from research staff (e.g., data collectors, auxiliary staff such as drivers), recognising they undertake these roles in a context of additional risks associated with working in emergencies (Bäärnhelm and Ekblad, 2002; Benight and McFarlane, 2007; Curry

et al., 2014). This is particularly important when engaging student researchers who may feel compelled to take part as part of their studies (O'Mathuna, 2010).

i. Information provided

Consent as “informed” is defined universally as: “an understanding of study purpose, who are the targeted beneficiaries, and the implications of involvement...information is communicated in a form appropriate to the culture, age, and educational level of that individual” (Allden *et al.*, 2009, p.s224). Authors place emphasis upon uncoerced decision-making (Benatar, 2002) through clear and consistent explanations of research at all stages (Goodhand, 2000).

For MHPSS research conducted in emergencies, the information provided to participants is similar to that provided for research in non-emergency settings. Additional recommendations specific to emergencies are to provide information on the purpose of research for communities unfamiliar with this concept (Benatar, 2002), and on the limits of the researcher’s role to ensure realistic expectations (Goodhand, 2000; Contractor, 2008). A further concern specific to MHPSS research in all settings is avoiding therapeutic misconception (Harper, 2007; Sumathipala *et al.*, 2010) by clearly differentiating between therapeutic services and research (Schopper *et al.*, 2009), particularly important in emergency settings where resources can be scarce. Harper (2007) builds upon this, suggesting that therapeutic misconception is attributable to a transmission model of information transfer that emphasises only the sending and receiving of information, rather than its explanation.

ii. Comprehension of information

Simply providing information is not seen as sufficient for *informed* consent. Rather, information *exchange* beyond the informed consent form is viewed as pivotal to avoiding exploitation (Bäärnhielm and Ekblad, 2002; World Health Organisation, 2007; Schopper *et al.*, 2009), helping to ensure that information is fully understood and minimising false perceptions (Allden *et al.*, 2009). Cultural, linguistic (Wessells, 2009), economic, social status, and other barriers (Leaning, 2001; Fitzgerald *et al.*, 2002; Iltis *et al.*, 2013) between the researcher and participants are emphasised, highlighting the importance of effective communication (O'Mathuna, 2010) and the time, skill and resources this requires (Benatar, 2002). Authors recommended using clear local language and terminology (Hynes, 2003; Call *et al.*, 2012) presented in an appropriate format (Emanuel *et al.*, 2004). Partnerships with people who have the cultural and linguistic background to maximise comprehension and

minimise misunderstanding is suggested as one route to overcoming communication barriers (O'Mathuna, 2010; Sumathipala *et al.*, 2010). Other factors that may affect information comprehension include the communication skills and perceived authority of the person taking consent (Fitzgerald *et al.*, 2002), and the use of technology in communication (Iltis *et al.*, 2013).

Fitzgerald *et al.* (2002) cite a lack of practical guidance on ensuring full understanding of study information, and recommend an oral examination with participants to verify understanding. Less formally, the World Health Organisation (2007) recommends researchers ask participants to repeat back in their own words their understanding of the research, including the key principles of the right to refuse to participate and confidentiality. This approach offers an opportunity to assess participants' comprehension and to re-explain or rephrase information as required for each participant (Benatar, 2002; Hynes, 2003; World Health Organisation, 2007).

iii. Voluntariness (including compensation)

Authors recognise factors in emergencies that influence the voluntariness of consent to include: unequal power relationships (Allden *et al.*, 2009), fear of outsiders (World Health Organisation, 2003), incentives or compensation to populations living in a dependent status (Goodhand, 2000; Allden *et al.*, 2009; Jesus and Michael, 2009; O'Mathuna, 2010; Sumathipala *et al.*, 2010), and cultural or religious values (Brown *et al.*, 2004; Rosenstein, 2004) - including where refusal is seen as contrary to hospitality norms (Wessells, 2008; Allden *et al.*, 2009) or collectivist cultures (Brown *et al.*, 2004). Unequal power relationships may raise expectations of research benefits (Goodhand, 2000; Sumathipala *et al.*, 2010) including access to services (Mackenzie *et al.*, 2007; Allden *et al.*, 2009), money, or aid (Wessells, 2008). This is felt to be influenced by the dependence of populations experiencing emergencies (Jesus and Michael, 2009; Sumathipala *et al.*, 2010).

It is questioned whether participants are truly free to say no to research when it is connected to MHPSS services (Neugebauer, 1999; Jesus and Michael, 2009). O'Mathuna (2010) suggests emergencies increase the chance that incentives are coercive (Sumathipala *et al.*, 2010), where compensation beyond reimbursement of time and/or expenses can be ethically questionable. Zwi *et al.* (2006) argue that to ensure voluntariness research benefits must not act as excessive inducement, and should be distributed in a way that maintains confidentiality and doesn't worsen conflict within communities. Contrastingly, Benatar (2002) argues that incentives cannot constitute coercion, recognising that the structural

conditions in many LMICs mean that research participation may provide access to unavailable healthcare that populations have a right to, provided that the benefits of participation continue to outweigh the risks.

iv. Autonomy and capacity

As a norm, consent is identified to assume participant autonomy (Mackenzie *et al.*, 2007). Authors state that upholding autonomy requires considering the capacity of the participant to provide consent (Allden *et al.*, 2009) (based upon the principle of respect for persons by accounting for individual situational needs and vulnerabilities (Levine, 2004)); and prioritising protection needs over research (Bäärnhielm and Ekblad, 2002; Jesus and Michael, 2009).

Recent debate has focused upon the extent that exposure to emergencies affects decision-making capacity (DMC) (Rosenstein, 2004; Mackenzie *et al.*, 2007; Jesus and Michael, 2009; Wessells, 2009; O'Mathuna, 2010). Underlying this debate is a common view that the researcher has a responsibility to ensure respect for autonomy through uncoerced research participation (Yamout and Jabbour, 2010; Sumathipala *et al.*, 2010). Not addressing autonomy and capacity is deemed unethical research practice, and as potentially leading to the exploitation of participants (Sumathipala *et al.*, 2010). Emanuel *et al.* (2004) identify poverty, cultural and linguistic barriers, and limited understanding of research as increasing the chances of exploitation; particularly where regulatory structures to protect participants are underdeveloped. A participatory approach is recommended to identify those with potentially limited autonomy and capacity (Wessells, 2008). This includes recognising varying conceptualisations of autonomy to minimise coercion (Siriwardhana *et al.*, 2013). In support of a participatory approach, Zwi *et al.* (2006) maintain that failure to acknowledge the capacity of emergency-affected communities to take an active role in research is to undermine the potential for innovative studies.

Rosenstein (2004) calls for protocols and training on how to identify and respond to those at risk or with impaired DMC. For research involving participants with severe mental health difficulties, Bhan (2010) supports obtaining consent from both the participant and family.

v. Confidentiality and anonymity

Authors identify confidentiality, privacy and anonymity as fundamental research principles (World Health Organisation, 2007). It is accepted by many authors that potential harms resulting from breaches of these principles are heightened in emergencies, for example access to resources or causing stigma and community rejection (Jacobsen and Landau, 2003; World Health Organisation, 2003; Wessells, 2008).

Authors acknowledge that emergency contexts present challenges to ensuring privacy, and therefore to maintaining confidentiality (Madianos and Evi, 2010; Aube, 2011), including efforts not to inadvertently identify a population sub-group (Leaning, 2001). One example is the disclosure of mental health diagnoses that may leave participants open to stigma and community rejection (Wissow *et al.*, 2012), raising protection concerns that can be difficult to address in emergency settings (Neugebauer, 1999). Media involvement in dissemination may further increase the chance of accidental disclosure (Allden *et al.*, 2009; Call *et al.*, 2012).

Despite the challenges, the researcher's duty to safeguard privacy and confidentiality both during and after research is highlighted (Goodhand, 2000; O'Mathuna, 2010; Call *et al.*, 2012): "anyone asking someone to disclose information bears a responsibility to safeguard that information" (World Health Organisation, 2007, p.18). Recommendations are made for explaining confidentiality procedures to participants from initial contact until the research is disseminated, and to ask participants if these are adequate (World Health Organisation, 2003). It is recommended that explanations include stating that absolute confidentiality cannot be guaranteed (Emanuel *et al.*, 2004) by outlining foreseeable limits particular to any given emergency (O'Mathuna, 2010).

Procedurally, authors highlight that research protocols should identify how confidentiality and data security will be managed (Call *et al.*, 2012), including arrangements relating to interpreters (Hynes, 2003). This includes reporting "off the record" statements (Mackenzie *et al.*, 2007) and how privacy norms will be met, for example in situations where females require a male chaperone to be present during data collection (Allden *et al.*, 2009). It is emphasised that all members of the research team, including auxiliary staff, understand, agree to, and sign confidentiality agreements (World Health Organisation, 2007).

When considering dissemination, Allden *et al.* (2009) identify the challenges to ensuring participants understand the implications of allowing data to be shared or publicised. Furthermore, Harper (2007) asks if researchers should be required to return to participants for permission for each use of data not covered in the original consent, such as for teaching purposes.

3. Safety

There is agreement amongst authors that protecting participant and researcher safety is essential in emergencies (Jacobsen and Landau, 2003; Allden *et al.*, 2009; Jesus and Michael, 2009), forming one element of accountability to participants and research staff (Contractor, 2008; Tol and Jordans, 2008; Wessells, 2008; Madianos and Evi, 2010; Juntunen, 2011).

Ensuring safety is viewed as requiring accountability in staff selection and training (Mollica *et al.*, 2004; Zwi *et al.*, 2006; Mackenzie *et al.*, 2007; World Health Organisation, 2007; Contractor, 2008; Hunt, 2008; Allden *et al.*, 2009; Wessells, 2009; Juntunen, 2011; Call *et al.*, 2012; Redfield, 2012; Iltis *et al.*, 2013), and promoting staff self-care (World Health Organisation, 2003; Mollica *et al.*, 2004; Zwi *et al.*, 2006; Tankink, 2007; World Health Organisation, 2007; Wessells, 2008; Allden *et al.*, 2009; Curry *et al.*, 2014).

3a. Participant vulnerability and protection needs

Authors suggest that a protection framework ensures participant safety needs take priority over research (World Health Organisation, 2003; Allden *et al.*, 2009; Jesus and Michael, 2009; Sumathipala *et al.*, 2010). Maintaining confidentiality is seen as essential to avoid increasing participant vulnerability. For example, participants may be at increased risk if they are perceived to gain disproportionately from involvement in the research, such as being preferentially heard, included above other groups, or treated more favourably (Jacobsen and Landau, 2003; Allden *et al.*, 2009).

Researchers from varying disciplinary backgrounds differ in their definitions of vulnerability, as summarised in table 2.

Table 2 Bioethical, social science and mental health definitions of vulnerability

<i>Bioethics</i>	<ul style="list-style-type: none"> • Vulnerable populations are more susceptible to abuse and require additional protections (Jesus and Michael, 2009) • The “vulnerable” are those likely to be misled, mistreated or taken advantage of, which imposes duty on researchers and ethical review boards (ERB’s) to ensure protections are in place (Levine, 2004).
<i>Social Sciences</i>	<ul style="list-style-type: none"> • Vulnerability is conceptualised as group status: powerlessness and potential for exploitation, those who lack the power and / or resources to speak out and make voluntary choices (Levine, 2004). • Requires attention to individual and social vulnerabilities (Levine, 2004; Sumathipala <i>et al.</i>, 2010). • Factors that influence vulnerability include exposure to disaster, individual capacity to cope, and the potential for serious crisis to occur as a result of exposure (Levine, 2004). • Awareness of how displacement status (e.g., refugee or IDP), may affect individual vulnerability (Hynes, 2003).
<i>Mental Health</i>	<ul style="list-style-type: none"> • Vulnerability defined in opposition to resilience: from a biomedical perspective, populations are seen as inherently vulnerable to adverse mental health reactions following disaster; whereas from a social sciences perspective the focus is upon the interactions between individual and community levels which may give rise to vulnerabilities (Levine, 2004).

	<ul style="list-style-type: none"> • Assumptions of participant capacity and autonomy are unjustified in emergencies, requiring extra protections to avoid exploitation (Mackenzie <i>et al</i>, 2007).
--	--

All definitions of vulnerability are subject to critique, such as that the term is too elastic (Levine, 2004) and that it can stereotype and stigmatise (Jesus and Michael, 2009). Conversely, whilst accepting that a focus on vulnerability can lead to paternalism, O’Mathuna (2010) argues that this also stimulates awareness of human fragility and the need to ensure protection from harm. Furthermore, Sumathipala *et al.* (2010) highlight that vulnerability can arise equally in high and low resource settings.

Authors call for an individualised response to vulnerability (World Health Organisation, 2003), recognising that it may arise as a result of specific settings, circumstances, or individual capacities (Levine, 2004; Sumathipala *et al.*, 2010). Therefore, attention is drawn to the way researchers define and operationalise vulnerability, and the potential consequences that conferring “vulnerable” status may have upon an individual’s or group’s autonomy and agency in a specific emergency.

Participants involved in MHPSS research may present with specific protection needs including severe mental disorders (Wissow *et al.*, 2012), suicidal ideation (Siriwardhana *et al.*, 2013), and sexual exploitation and abuse (World Health Organisation, 2003; Allden *et al.*, 2009). Wissow *et al.* (2012) identify specific protection needs for people with serious mental health problems in emergencies, including: minimising lapses in medication, recognising the impact of social and economic disruption such as curfews, and ensuring equity of treatment access that may require identifying and engaging those who are marginalised. In often rapidly changing emergency contexts, it is essential that participant wellbeing is monitored (O’Mathuna, 2010) to ensure protection needs are identified and managed (Benatar, 2002).

Vulnerability and protection are intimately linked to informed consent, assessments of capacity, and the potential for research to lead to exploitation (Rosenstein, 2004; Allden *et al.*, 2009). However, the Hastings Centre (2004) argue that whilst vulnerability and protection needs may make exploitation more likely, these are neither necessary nor sufficient for its occurrence in any context.

3b. Accountability

Accountability is conceptualised as being answerable to funders and the community in which research is conducted (Black, 2003), requiring that researchers manage competing priorities

(Siriwardhana *et al.*, 2013). In all settings, accountability entails having in place the resources required to support research. For MHPSS research in emergencies, authors identify key considerations such as: access to specialist mental health services (Contractor, 2008; Tol and Jordans, 2008; Wessells, 2008; Madianos and Evi, 2010; Juntunen, 2011); meeting protection needs (Neugebauer, 1999; Mollica *et al.*, 2004); and minimising physical and emotional harm attributable to research (Hynes, 2003). It is recommended that a referral booklet of services (Contractor, 2008; Wessells, 2008; Juntunen, 2011) and procedures for responding to suicidal ideation (Siriwardhana *et al.*, 2013) are in place prior to starting the research. For severe mental health problems, authors highlight the duty to conduct legal review of deprivation of liberty (e.g., for persons at risk of harm to themselves or to others) (Wissow *et al.*, 2012).

Accountability further requires that researchers enter emergencies mentally, physically and materially prepared (Citraningtyas *et al.*, 2010), and that they are competent and ready to practice (Juntunen, 2011; Sumathipala *et al.*, 2010). This requires capacity building (Curry *et al.*, 2014) and supporting local research infrastructure (Richards, 1989; Black, 2003; Tomlinson *et al.*, 2006; Wessells, 2008; Citraningtyas *et al.*, 2010; Sumathipala *et al.*, 2010).

Emphasis is placed on research teams and auxiliary staff being fairly selected through transparent procedures (Hunt, 2008; Redfield, 2012). When working in conflict settings, authors argue that it is unethical to involve inexperienced researchers (Goodhand, 2000). However, Jacobsen and Landau (2003) caution that field experience is not a guarantee against poor practice, and that researchers' expectations must be aligned to "on the ground" realities (Juntunen, 2011). Researchers' understanding of local culture is emphasised as being of particular importance in emergencies (Michael and Zwi, 2002; Wessells, 2008; Aube, 2011). Additionally, the impact of interpreter and researcher backgrounds is highlighted (Hynes, 2003; Allden *et al.*, 2009), including religion, culture, and ability to access to the study site and population (Siriwardhana *et al.*, 2013). When researchers are hired from within the study community, it is important to consider potential impacts upon confidentiality and anonymity (Siriwardhana *et al.*, 2013), and how local attachments may make it difficult to negotiate traditional hierarchies (Redfield, 2012). In international collaborations, the need to understand asymmetries is recognised, including the extent that ethical discourse and practice are institutionally and professionally embedded (Brown *et al.*, 2004; Sumathipala *et al.*, 2010).

In emergencies authors recommend all research staff (including drivers and translators) be provided training in their role and in ethical codes of conduct (Mollica *et al.*, 2004; Zwi *et al.*, 2006; Mackenzie *et al.*, 2007; World Health Organisation, 2007; Contractor, 2008; Hunt, 2008; Allden *et al.*, 2009; Wessells, 2009; Juntunen, 2011; Call *et al.*, 2012; Iltis *et al.*, 2013). Hunt (2008) argues training should aim to build a culture of ethical analysis and discussion as a natural discourse in emergencies. Table 3 outlines other recommended specialist training related to MHPSS research in emergencies.

Table 3 Recommendations for specialist training related to MHPSS research in emergencies

- | |
|--|
| <ul style="list-style-type: none"> • Cross-cultural competencies (Allden <i>et al.</i>, 2009; Call <i>et al.</i>, 2012), including for researchers partnering with existing organisation staff in research (Kos, 2008); • Basic helping skills such as Psychological First Aid (World Health Organisation / War Trauma foundation & World Vision International, 2011) (Mollica <i>et al.</i>, 2004; Call <i>et al.</i>, 2012); • Identifying those at risk or considered vulnerable (Rosenstein, 2004); • Knowledge of referral pathways and responding to participant distress, vulnerability, and protection needs (World Health Organisation, 2003; Rosenstein, 2004; World Health Organisation, 2007; Contractor, 2008; Juntunen, 2011); including ongoing monitoring procedures (Curry <i>et al.</i>, 2014); • How to recognise, establish and maintain professional boundaries (World Health Organisation, 2007) and manage issues not directly related to study conduct (Contractor, 2008); • Mental health skills including recognising severe mental illness (Wissow <i>et al.</i>, 2012); • Risk management (Iltis <i>et al.</i>, 2013); • Safety covering emergency preparedness, field coordination practices, background to the emergency (Wessells, 2009), social and psychological risks associated with working in emergencies (Contractor, 2008), and self-care (World Health Organisation, 2007); • Understanding and implementing confidentiality and anonymity procedures (World Health Organisation, 2003; Zwi <i>et al.</i>, 2006; World Health Organisation, 2007); • Data management procedures and dissemination arrangements (World Health Organisation, 2007); • Background to the research topic (World Health Organisation, 2007); • Specialist training in any tools, instruments and documents, including interviewers engaging and developing rapport with respondents (World Health Organisation, 2007); • Specialist training that recognises the role of interpreters as active producers of research findings (Mackenzie <i>et al.</i>, 2007), covering confidentiality (Hynes, 2003; Zwi <i>et al.</i>, 2006) and power relationships (Hynes, 2003). |
|--|

In addition to training prior to research, authors recommend field mentoring (Hunt, 2008; Wessells, 2009) and post-study debriefing (Siriwardhana *et al.*, 2013) to ensure ongoing accountability and ethical reflection upon the particularities of working in emergencies.

Some authors recommend using case studies as a pedagogical tool to develop ethical standards (Harper, 2007; World Health Organisation, 2007).

3c. Researcher self-care

As in many settings, authors recognised the potential for researchers and participants to suffer physical and emotional harm from research involvement (World Health Organisation, 2003; 2007; Curry *et al.*, 2014). Accountability entails a duty to monitor and support researcher self-care, protecting against the possible negative effects of conducting research in difficult contexts and on potentially sensitive topics (World Health Organisation, 2003; Mollica *et al.*, 2004; Zwi *et al.*, 2006; Tankink, 2007; World Health Organisation, 2007; Wessells, 2008; Allden *et al.*, 2009; Curry *et al.*, 2014).

Vicarious trauma (Zwi *et al.*, 2006) and counter transference (Tankink, 2007) - including reactions such as stress, grief, anger, and over-involvement in participants lives - are risks for researchers, particularly in resource constrained environments such as emergencies. Allden *et al.* (2009) argue that strategies to manage these reactions are especially required in qualitative research where participants may reveal intimate aspects of their lives and where professional boundaries can be more porous.

To ensure researcher self-care Tankink (2007) calls for supervision throughout the research process, including during data analysis and dissemination. Others (Wessells, 2008; Juntunen, 2011) recommend that researchers work in pairs, and that organisational strategies to avoid burnout such as time off and ongoing self-assessment of competency to practice are implemented. Extending this, Curry *et al.* (2014) recommend that research staff give informed consent that includes explicit reference to increased health, security and other risks staff in emergencies are exposed to.

3d. Environmental, political and health safety

Working in emergencies is characterised as working “in extremis” (Juntunen, 2011) due to the potential threats to personal wellbeing and safety. Ensuring the environmental, political and health safety of researchers and auxiliary staff is highlighted by many authors (Jacobsen and Landau, 2003; World Health Organisation, 2003; 2007; Contractor, 2008; Allden *et al.*, 2009; Bhan, 2010; Juntunen, 2011; Iltis *et al.*, 2013; Curry *et al.*, 2014), and demonstrates respect for persons (Benatar, 2002). This encompasses having in place measures including exit strategies and procedures for safety monitoring, and accounting for any associated costs (World Health Organisation, 2003; Curry *et al.*, 2014).

Due to the changing nature of emergencies it is recognised that safety procedures must be able to respond to changing security threats (Allden *et al.*, 2009). Researchers may be at risk of violent attacks if they are viewed as a route to resources (Jacobsen and Landau, 2003); when meeting the protection needs of participants (World Health Organisation, 2003; Bhan, 2010); or in situations requiring they breach confidentiality - for example when reporting illegal activity (Contractor, 2008).

4. Neutrality

Findings reflect that in all settings neutrality requires that researchers remain aware of social and economic inequalities; inequity of healthcare access; and social characteristics such as age, gender, religion, and ethnicity (Wessells, 2008; Sumathipala *et al.*, 2010). This is achieved by maintaining principles of equity and impartiality (Aube, 2011) through non-discriminatory delivery of resources and services (Bhan, 2010). In conflict contexts research occurs within an intensely political environment (Goodhand, 2000), requiring special attention to maintaining neutrality (Black, 2003; Wessells, 2008; Bhan, 2010). These background considerations frame the implementation of ethical research (Benatar *et al.*, 2005), requiring active awareness of power imbalances that are augmented in emergencies and bring an increased potential to cause harm (Citraningtyas *et al.*, 2010).

4a. Access, exit strategies, gatekeepers, and power

Curry *et al.* (2014) draw attention to security and exit strategies for planned research, including the circumstances under which research would be suspended or terminated such as in an acute crisis (Contractor, 2008) - including research that commenced prior to the emergency (Sumathipala *et al.*, 2010).

Ethical access requires coordination with existing systems (Mollica *et al.*, 2004; Sumathipala *et al.*, 2010) or “reverse triage” that hands the local community control over who enters an emergency and for what purpose (Citraningtyas *et al.*, 2010). However, emergencies present asymmetries in knowledge and power between researchers and participants that require mitigation (Sumathipala and Siribaddana, 2005; Aube, 2011). These may include structural economic, political and power inequalities, as well as situational inequalities such as resource access or psychosocial status (Hynes, 2003; World Health Organisation, 2003; Brown *et al.*, 2004). Authors highlight that these may influence people’s motivation to participate in research, and can affect research validity (Jacobsen and Landau, 2003; Allden *et al.*, 2009).

In emergencies it is acknowledged that access to settings and participants are frequently negotiated via a “gatekeeper”. The benefits of this approach include help to navigate socio-

cultural (Citraningtyas *et al.*, 2010) and bureaucratic systems, including knowing where to gain research approvals (Del Ben *et al.*, 2006). Conversely, risks include potentially augmenting hierarchies through controlled access to research benefits (Michael and Zwi, 2002; Jacobsen and Landau, 2003; World Health Organisation, 2003; Mackenzie *et al.*, 2007; Allden *et al.*, 2009), or creating actual or perceived research bias in conflict contexts if negotiating access to participants via warring factions (Goodhand, 2000).

It is important to remain critical of who “speaks for” (Richards, 1989; Brown *et al.*, 2004) or represents a community, and to avoid privileging the voice of those with power or to silence those without (Black, 2003; Zwi *et al.*, 2006). For example, gatekeepers may undermine the expression of some voices (Hynes, 2003), including those related to the sharing of traditional cultural practices (Wessells, 2009) or support systems (Allden *et al.*, 2009): “Research necessarily involves making political choices about which voices to hear and whose knowledge counts” (Zwi *et al.*, 2006). Aube (2011) recognises the tension in resisting local gatekeepers due to the potential for expulsion from the setting, putting research and services in jeopardy. Finally, Bäärnhielm and Ekblad (2002) reposition the concept of gatekeepers by asking whether researchers themselves are viewed as gatekeepers to services or support.

4b. Coordination with organisations and researchers

Collaborative partnerships are defined as sharing responsibility in all research stages in a relationship founded upon mutual respect (Emanuel *et al.*, 2004; Sumathipala *et al.*, 2010). Redfield (2012) suggests that trust between local and expatriate researchers can be built through a shared commitment to humanitarian ideals achieved through research. Del Ben *et al.* (2006) recognise that collaboration between researchers and services offers opportunities for research and clinical care objectives to be met simultaneously.

Allden *et al.* (2009) draw attention to power differences between international and local researchers, and between researchers, service providers and communities, operating beyond categories of local / expatriate (Tomlinson *et al.*, 2006) and that can impact upon the research encounter. Such disparities can lead to the imposition of outside approaches and silencing of local practices (Allden *et al.*, 2009), and demands critical awareness of “white knowledge dominance” (Tomlinson *et al.*, 2006).

Authors emphasise coordinating research with emergency response (Madianos and Evi, 2010; Sumathipala *et al.*, 2010), ensuring it is networked into safety procedures, the socio-political emergency context (Wessells, 2009), and specific MHPSS mechanisms and services

(Wessells, 2008; Juntunen, 2011). This is recommended based on the view that coordination efforts help to identify existing resources to support successful research (Tol and Jordans, 2008; Citraningtyas *et al.*, 2010; Madianos and Evi, 2010). External, consultant-led studies may cause challenges to coordination by putting expatriate researchers in a position of power over service providers (Kos, 2008), and present potential difficulties in responding to substandard care by local service providers involved in the research (Hunt, 2008). To address these authors recommend coordinating with enduring institutions (Black, 2003) and establishing shared professional standards prior to starting the research (Aube, 2011).

It is recognised that poor coordination can lead to research duplication (Wessells, 2009) and undue burdens for participants (Citraningtyas *et al.*, 2010). Failure to share findings and co-learn can limit efforts to provide comprehensive MHPSS support. To address this, Allden *et al.* (2009) propose an open-source system to track data collection and facilitate coordination, a proposal echoed elsewhere (Sumathipala *et al.*, 2010).

4c. Declaration of researcher interests

In all settings, the ethical responsibility to declare researcher interests – including financial, career, and organisational or personal gains - is emphasised (Curry *et al.*, 2014), ideally avoiding all conflicts of interest (Benatar, 2002). Conflicts of interest specific to research in emergencies may occur when delivery organisations commission research, and researchers compromise the integrity of the study by looking for findings that the organisation want to hear (Kos, 2008; O'Mathuna, 2010), or when research is led by an external consultant and tensions occur between respecting cultural norms and imposing cultural values (Aube, 2011).

It is recognised that researchers, participants, ethical review bodies and organisations partnering in research all bring their own interests (Zwi *et al.*, 2006; Wessells, 2009). These can affect setting research agendas, particularly in the presence of a “powerful outsider” (Brown *et al.*, 2004), and lead to differing views of research success (Tomlinson *et al.*, 2006).

4d. Funding

It is acknowledged that the extent to which aid is tied to funder priorities (Allden *et al.*, 2009) or normative goals (Brown *et al.*, 2004) may constrain how research funds are spent (Richards, 1989), and whether research is viewed as the wielding of power by funders or a political tool of governments (Wessells, 2009). Funders may have ethical frameworks or review processes which must be adhered to, frequently with an individualistic bias that may conflict with local cultural norms (Hoeyer *et al.*, 2005). Conversely, Zwi *et al.* (2006) argue that funders are in a position to stimulate new ethical standards and ways of working.

Specific funding considerations relevant to emergency research include the implications of entry and exit strategies (e.g., research suspension or termination) (Curry *et al.*, 2014), and the question of who funds research benefits such as ongoing access to services or treatments (Hastings Centre, 2004). In addition, funders are often ill-equipped to judge the ethical and scientific rigor of research (Brown *et al.*, 2004; Allden *et al.*, 2009). Some authors call for funding to learn lessons about how research is conducted; putting into practice corrective efforts to ensure accountability (Michael and Zwi, 2002); recognising the benefits of potentially time-consuming research such as participatory methods; and the importance of accessible dissemination for collective learning (Zwi *et al.*, 2006; Allden *et al.*, 2009; Sumathipala *et al.*, 2010).

5. Purpose and benefit

A range of considerations relating to research purpose and benefit in emergencies are identified, such as: ensuring direct benefits to participating communities (Del Ben *et al.*, 2006; Allden *et al.*, 2009), building long-term collaborations that deliver sustainable benefit (Mackenzie *et al.*, 2007; Wessells, 2008), and disseminating findings to the participating community (Black, 2003; Mackenzie *et al.*, 2007; Tol and Jordans, 2008; Allden *et al.*, 2009; Sumathipala *et al.*, 2010). These raise contested imperatives of sustainability (Michael and Zwi, 2002; Brown *et al.*, 2004) and “reasonable benefits” that have stimulated academic debate (Benatar, 2002; Emanuel *et al.*, 2004; Hastings Centre, 2004).

5a. Sustainable benefit

There is consensus that research participants should benefit from their involvement (Benatar, 2002; World Health Organisation, 2003; Emanuel *et al.*, 2004; Hastings Centre, 2004; Del Ben *et al.*, 2006; Zwi *et al.*, 2006; Kos, 2008; Allden *et al.*, 2009; Curry *et al.*, 2014; Sumathipala *et al.*, 2010). Benefits range from the micro-level of occupying time, providing a sense of being heard (Allden *et al.*, 2009), and access to the fruits of research (Hastings Centre, 2004); to more generalisable benefits in the future social value of research (Richards, 1989; Emanuel *et al.*, 2004) such as improving service delivery (de Graaff *et al.*, 2008).

There are debates about the level and timing of benefits (Hastings Centre, 2004;) including mechanisms to benefit from results unknown at the study outset (Benatar, 2002; Emanuel *et al.*, 2004). Due to doubts about ensuring the future social value of emergency research, it is argued that direct benefits must also be assured (Citraningtyas *et al.*, 2010). Curry *et al.* (2014) propose that research protocols identify for whom and when benefit will arise, and, where relevant, how deferred benefit is ethically justifiable.

Authors call for avoiding “fly in-fly out” research (Mackenzie *et al.*, 2007; Wessells, 2008) in addressing research purpose and benefit: for example, is it a one-off endeavour or part of sustained involvement with a community (Brown *et al.*, 2004; Tomlinson *et al.*, 2006; Aube, 2011)? Brown *et al.* (2004) argue that research should promote solutions embedded into existing systems and not a parallel aid system, emphasising sustainability and avoiding skewing local economies and job markets.

5b. Dissemination

It is agreed that the participating community should be provided with research findings in an accessible format (World Health Organisation, 2003; Tol and Jordans, 2008; Allden *et al.*, 2009; Siriwardhana *et al.*, 2013; Sumathipala *et al.*, 2010), recognising these are a public asset (Black, 2003) and that communities have a right to this information (Mackenzie *et al.*, 2007). It is recommended that research be disseminated to local communities and policy makers (Tomlinson *et al.*, 2006; Sumathipala *et al.*, 2010); and internationally to policy and academic audiences (Tomlinson *et al.*, 2006; Bhan, 2010), and funders (Bhan, 2010).

Key issues relating to ethical research dissemination include data ownership, and the format and means of dissemination (Harper, 2007; Allden *et al.*, 2009). Authors identify specific considerations heightened in emergencies, including potential inadvertent disclosure (Allden *et al.*, 2009) and political manipulation (Richards, 1989) or misuse (Jacobsen and Landau, 2003) of results.

Therefore, literature emphasises that the researchers’ role is to collect and disseminate information in a timely (Citraningtyas *et al.*, 2010), scientific, and ethically sound manner (Zwi *et al.*, 2006; Sumathipala *et al.*, 2010), using publically accessible forums (Curry *et al.*, 2014). Failure to deliver this in any setting is seen as a breach of trust and the privileged relationship between researchers and participants (Hynes, 2003; Mackenzie *et al.*, 2007).

Difficulties predicting participant reactions to seeing oneself and one’s ideas described and objectified as symbolic and material resources are recognised (Brown *et al.*, 2004). These are seen to be heightened in LMIC settings, requiring efforts to ensure participants understand the implications of dissemination (Allden *et al.*, 2009). Hoeyer *et al.* (2005) argue that data should be shared with participants prior to dissemination, however challenges to this in emergencies are recognised, in particular population transience (Allden *et al.*, 2009). In emergencies it is important to remain aware of potential social, political or economic impacts that research interpretation and dissemination may have such as not reifying stereotypes, contributing to learned helplessness, or impacting upon the political will to aid those in need

(Kos, 2008). Brown *et al.* (2004) caution that research which aims to “give voice” can silence or downgrade other experiences, thereby causing harm.

Dissemination is recommended to include sharing data collection tools, methods (de Graaff *et al.*, 2008), and results, including those that identify potentially harmful practices (Lohr *et al.*, 2006). Dissemination should reach relevant audiences, recognising the importance of inter-agency learning (Zwi *et al.*, 2006) and ensuring research is not unnecessarily duplicated (World Health Organisation, 2007). Sumathipala and Siribaddana (2005) argue that journals should require evidence of local ethical approval and copies of informed consent to verify that overt exploitation has not occurred.

5c. Ethical review

Authors agree that review by an institutional review board, ethical review board (ERB) or ethical review committee has become an accepted norm for research involving human participants (Jesus and Michael, 2009; Bhan, 2010; Sumathipala *et al.*, 2010). When research is well designed - including taking reasonable steps to protect participants – it is argued that it is *unethical* to prevent its conduct as findings should answer important questions to inform emergency response (Kilpatrick, 2004; O'Mathuna, 2010; Sumathipala *et al.*, 2010). ERB responsibilities include:

- protection of participants, particularly potentially vulnerable participants (Emanuel *et al.*, 2004; Levine, 2004);
- ensuring exploitation – inadvertent or intended – is avoided (Curry *et al.*, 2014);
- verifying researcher training needs are identified and met (Brown *et al.*, 2004; Curry *et al.*, 2014);
- providing public accountability (Benatar, 2002) which includes educating and assisting researchers and communities in understanding research ethics, and ongoing research oversight - including data safety and monitoring (Curry *et al.*, 2014);
- ensuring researcher transparency and accountability (Emanuel *et al.*, 2004).

Authors critique ERBs for an inability to judge research conducted in emergencies (Brown *et al.*, 2004; Zwi *et al.*, 2006; Wessells, 2008; Alden *et al.*, 2009). They argue that generic ERB processes offer little guidance or oversight (Wessells, 2008) due to their lack of specificity to emergencies (Brown *et al.*, 2004), which can lead to paternalism (Zwi *et al.*, 2006). Equally, Sumathipala *et al.* (2010) recognise that emergencies may impact upon the existing ethical

research oversight infrastructure, including the capacity of ethical review boards to ensure effective governance of research.

Some authors contend that ERBs consider their task in more legal than ethical terms (Zwi *et al.*, 2006) which can result in researchers having to persuade ERBs of the ethical imperative for research and the strength of strategies to mitigate risk when working with groups perceived “high risk” (Iltis *et al.*, 2013). Awareness of the agendas of those conducting review, particularly in conflict or partisan contexts, is identified (Brown *et al.*, 2004). Emanuel *et al.* (2004) emphasise that researchers should seek to understand disagreement between different ERB judgements because this often relates to the relative weight of ethical principles by different bodies, whilst cautioning that the ethical standards of sponsor countries frequently prevail, potentially compromising participatory approaches towards protocol development.

Discussion

Consensus and unresolved debates

This section focuses on the distinctive features of applying ethical principles to MPHSS research conducted in emergencies, identifying areas where there is consensus and where there is disagreement. These were identified through the process of data analysis in which key tensions in the literature emerged either as points of discussion across papers, or through differing recommendations for managing or resolving key ethical tensions. The purpose of this section is not to offer an exhaustive discussion of these tensions, but to highlight where and why these controversies arise. This analysis of critical pressure points may be helpful to researchers reflecting on whether their research practice meets ethical standards identified as important for MPHSS research in emergencies.

At their foundation, ethical principles applicable to mental health research in emergencies correlate with universal standards (Kieling *et al.*; World Medical Association, 2013 [1964]; Council for International Organisation of Medical Sciences (CIOMS), 2002; American Anthropological Association, 2009; Economic and Social Research Council, 2015). There is consensus over the relevance of universal ethical research standards to MPHSS research in emergencies, for example the accepted norms of ensuring participant informed consent; the importance of researcher neutrality, accountability and safety; and the imperative to ensure research is well designed and takes into account the contextual factors in specific emergency settings.

Beyond this consensus, it is in the application of ethical principles to MHPSS research in emergencies unresolved debates have been identified. The following discussion focuses on six debates with distinctive features in emergency MHPSS research, outlined in Table 4. Each is briefly discussed in turn, before drawing conclusions that point to an underlying tension between procedural and in-practice ethics (Guillemin and Gillam, 2004).

Table 4 Unresolved debates

<p>Issue:</p> <ul style="list-style-type: none">➤ What constitutes fair benefits?➤ How should informed consent be operationalised?➤ Is there a role for decision making capacity (DMC) assessments?➤ How do approaches to risk management impact upon the construction of ethical research?➤ How can ethical reflection best be achieved?➤ Are ethical review boards (ERB's) equipped to judge the ethical and scientific merit of emergency MHPSS research?
--

What constitutes fair research benefits?

Fair benefits for research participation has been extensively debated (Hastings Centre, 2004) and remains contentious for research conducted in LMICs generally, and emergency settings specifically (Emanuel *et al.*, 2004). There is consensus that there is an ethical imperative to maximise research benefits (Benatar, 2002; World Health Organisation, 2003; Jesus and Michael, 2009; Sumathipala *et al.*, 2010), and that benefits should be identified in direct relation to burdens (Hastings Centre, 2004). However, how this could be implemented remains unclear beyond conducting a community assessment to verify that benefits / burdens are considered fair in a given context. Unresolved debates include questioning why the benefit of access to services is prioritised (Benatar, 2002; Hastings Centre, 2004) suggesting this confuses research with clinical care (Emanuel *et al.*, 2004). It is argued that other benefits could be of equal moral value, for example lasting policy and service impact (Tomlinson *et al.*, 2006) such as capacity building (Wessells, 2008; Aube, 2011) which increases the social value of research (Emanuel *et al.*, 2004) beyond the “temporary” nature of emergencies (Weissman *et al.*, 2004).

The Hastings Centre (2004) trace the fair benefits principle to the “reasonable availability” principle in the Council for International Organisation of Medical Sciences International Guidelines for Biomedical Research involving Human Subjects (2002), charging that it fails to distinguish considerations including: what amounts to fair benefits - continued access to

services, capacity or infrastructure building? To whom should benefits extend - participants, communities, an entire country? And who is responsible for funding benefits? Based upon these considerations, they conclude that the reasonable availability principle guarantees benefits but not necessarily *fair* benefits, and as such fails to protect against exploitation (Hastings Centre, 2004). To remedy this a number of authors argue that researchers have a moral duty to clearly define research benefits, allowing participants to make an assessment of their fairness relative to burdens specific to the context and research topic (Benatar, 2002; Emanuel *et al.*, 2004; Hastings Centre, 2004; Sumathipala *et al.*, 2010), avoiding paternalism and ensuring respect for those in whose interest the research is conducted (Leaning, 2001). This approach accounts for each emergency having its own background structural and situational context including: the strength of existing MHPSS services; population exposure to experiences that may impact upon mental health; limited resources; and community identification of benefits of value to them.

How should informed consent be operationalised?

There is consensus that it is the right of participants to be fully informed about research, and to voluntarily affirm their participation through providing informed consent. However, some authors contest the moral foundations of the informed consent concept (Hoeyer *et al.*, 2005), questioning whether consent protects participants or researchers (Harper, 2007), implying researchers serve self-interest in meeting quasi-legal rather than moral standards (Benatar, 2002). To achieve informed consent there are calls for moving away from procedural, juridical and ritualised consent, avoiding “a crude version of the biomedical model of consent: the dialogue should not be seen as merely ... making the informant understand and accept a pre-defined research package” (Hoeyer *et al.*, 2005, p.1746).

This is elaborated with a focus on the changing nature of emergencies, redefining the consent process to respond to evolving research (Bäärnhielm and Ekblad, 2002), changing contexts (Wessells, 2009; Curry *et al.*, 2014), or new information (Emanuel *et al.*, 2004). Additional considerations for consent likely to arise in LMIC emergency settings with largely collectivist cultures have been highlighted (Leaning, 2001; Brown *et al.*, 2004; Allden *et al.*, 2009; Jesus and Michael, 2009). These critique the individualistic bias inherent to informed consent, including a failure to acknowledge collective decision-making practices prevalent in some cultures (Zwi *et al.*, 2006). Attention has also been raised to the potential inflexibility of funders and ERBs when it comes to what informed consent must “look like” (Hoeyer *et al.*, 2005). Therefore, this review has identified tensions in how the ethical principle of informed consent is operationalised and implemented, with calls for prioritising cultural context and

attainment of moral duties over quasi-legal standards through a more flexible and nuanced approach in practice (Emanuel *et al.*, 2004; World Health Organisation, 2007; Alden *et al.*, 2009; Schopper *et al.*, 2009; Wessells, 2009), for example by approving a consent framework (Mackenzie *et al.*, 2007).

Is there a role for decision making capacity (DMC) assessments?

Debates about the role of DMC assessments similarly reflect a tension between in-practice moral duties and procedural processes. There is agreement that respecting participant autonomy remains paramount in emergencies, understood as the ability to determine the direction of one's life, make considered choices and act in accordance with one's self-belief (Mackenzie *et al.*, 2007). To uphold this and avoid harm it is argued requires assessments of DMC (Rosenstein, 2004; O'Mathuna, 2010). However, there are differing views on the effect emergencies have upon DMC. These include assumptions of autonomy not holding (Mackenzie *et al.*, 2007; Wessells, 2009); full autonomy being assumed unless reasonable reasons exist to think otherwise, drawing an analogy between the impact of exposure to emergency and having a severe mental health problem upon DMC (Rosenstein, 2004); or taking a middle road where DMC is seen as more severely affected in the acute emergency phase, thus requiring higher protections when research is conducted in this period (Jesus and Michael, 2009). Zwi *et al.* (2006) also note that participants may be motivated by fear, desperation or unrealistic expectations of assistance which may compromise DMC.

A wider moral concern relating to DMC assessments following emergencies is the potential to reinforce perceptions that mental health problems arises from exposure to emergency (Rosenstein, 2004). There are calls for proportionate procedures in which DMC safeguards are relative to the risk of harm a study presents (Rosenstein, 2004; O'Mathuna, 2010). This debate remains unresolved as the proportionality of measures is based upon underlying assumptions of risk of harm, informed by an a priori understanding of the impact of emergencies upon capacity. Therefore, whilst there is underlying consensus about the moral duty of researchers to ensure trained research and clinical staff are able to identify and respond to participant protection and vulnerability needs – including impaired DMC - there remains debate about the assumed impact exposure to emergencies has on capacity.

How do approaches to risk management impact upon the construction of ethical research?

As presented, the risks inherent to emergencies are understood to warrant higher protection of participants. However, there is considerable differences in the way that “inherent risks” are constructed and understood, and therefore what the appropriate response to such risks

may be - illustrated by debates around DMC and the vulnerability of those exposed to emergencies (Hynes, 2003; Levine, 2004; Mackenzie *et al.*, 2007; Jesus and Michael, 2009).

When considering the definition of risk in the Protection of Human Subjects, the US Department of Health and Human Services Code of Federal Regulations, states: “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life” (Department of Health and Human Services, 2009). Iltis *et al.* (2013) highlight that in emergencies the “harms and discomforts” encountered in “daily life” automatically expose participants to higher risk. In light of consensus that populations perceived high risk deserve scientifically rigorous study (Kilpatrick, 2004; O'Mathuna, 2010; Iltis *et al.*, 2013), there is a call to action for researchers, funders and ERBs to develop and share innovative ways to manage risks inherent to MHPSS research in emergencies. This call addresses concerns that attempts to ensure ethical research can lead to protectionism, paternalism and a priori exclusion (Jesus and Michael, 2009; Iltis *et al.*, 2013), rather than a positive moral obligation to ensure those experiencing emergencies are afforded the right to evidence-based and ethical research and services.

How can ethical reflection best be achieved?

One proposal for enhancing ethical research conduct is active reflection upon implementing ethical principles with a view to refining ethical research practice in specific contexts, and building transferrable knowledge for application across settings. Ways identified to achieve ethical reflection include study monitoring (Benatar, 2002), conducting a post-study ethical audit following a structured checklist and involving all members of the research team (Siriwardhana *et al.*, 2013), developing case studies based upon research experiences (World Health Organisation, 2007), and engaging in self-reflection (Wessells, 2008). Ethical reflection is argued for on the basis that it will support identification of best-practice (Zwi *et al.*, 2006) and, over time, development of practices for the application of ethical principles to emergency MHPSS research that account for contextual particularities conducting research in such settings give rise to.

Conducting ethical reflection complements the above discussions, promoting interrogation of research practice through an ethical lens with a view to enhancing the ethical foundation of emergency MHPSS research (Chiumento *et al.*, 2016). Such an approach recognises that ethical research necessitates a thoughtful process of balancing ethical considerations by researchers that should be rendered explicit (Kinard, 1996). Adopting a focus upon the specific needs of emergency-affected communities foregrounds a concern for global justice

(O'Mathuna, 2010) and promotion of a civic conversation around ethical research in emergencies (Zwi *et al.*, 2006).

Are ERB's sufficiently representative and equipped to judge the ethical and scientific merit of emergency MHPSS research?

International ethical guidance and review processes are charged with lacking focus upon the specific challenges that arise in emergencies (Leaning, 2001). Termed a “double-bind”, ERBs are able recognise risk and potential exploitation, but unable to offer practical guidance to address these (Zwi *et al.*, 2006, p.266). Procedurally it is recognised that in LMICs ERBs may be lacking or dysfunctional (Thornicroft *et al.*, 2012) with varying levels of expertise and professionalism to uphold ethical principles (Perrey *et al.*, 2009). It is also acknowledged that disasters themselves may impact upon the existing research ethics infrastructure, leading to impacts upon the capacity of ERBs to ensure research governance (Sumathipala *et al.*, 2010). Due to the multiple levels of review, researchers frequently strike a compromise that draws upon sponsor country ERBs familiarity with research with vulnerable participants and where possible emergency settings, alongside engaging in-country bodies to certify that cultural norms and participants interests are adequately reflected (Curry *et al.*, 2014). Recognising these multiple layers of review, Curry *et al.* (2014) encourage researchers to identify the ethical review processes and bodies that will be involved in protocol approval, including known strengths, weaknesses, and ability to provide initial and ongoing ethical oversight.

Suggestions for overcoming these difficulties include: review by peers (de Graaff *et al.*, 2008); a bioethics service (Rosenstein, 2004); an ethical, social and cultural research ethics service (Lavery *et al.*, 2013); or community-based advisory boards (Emanuel *et al.*, 2004; Allden *et al.*, 2009); and fast track processes (Allden *et al.*, 2009) involving protocol pre-approval with adaptation to a specific emergency before final approval and study commencement (O'Mathuna, 2010). For complex and evolving research such as ethnography, iterative ERB processes have been suggested (Zwi *et al.*, 2006). These proposals aim to fill gaps in existing ethical procedures by addressing the asymmetries of in-country and international guidance, and to encourage co-learning between ERBs, researchers and communities.

An additional consideration is the extent that ethical review mechanisms established by bodies such as funders are equipped with technical and ethical expertise, and sufficiently divorced from normative priorities of donors, to provide independent review (Brown *et al.*, 2004; Allden *et al.*, 2009). Conversely, others argue that funders can stimulate new ethical standards and ways of working (Zwi *et al.*, 2006). One proposal for clarifying the extent that

fundings promote or limit ethical research is to reflect upon potential discrepancies in different levels of review, providing opportunities for understanding how differences relate to the ways ethical principles are balanced, providing valuable contextual knowledge (Emanuel *et al.*, 2004). As this discussion summarises, current ERB procedures are not viewed as sufficiently responsive to the needs of emergency MHPSS research. However, there remains a lack of consensus about the ways to address and overcome shortcomings.

Strengths and limitations

Due to the multidisciplinary and expansive approach of this review the procedures do not adhere strictly to those of a formal systematic review. There is little consensus on how the quality of qualitative research should be assessed (Thomas and Harden, 2008), and in this review no quality assessment was undertaken. However, the majority of sources included in this review were published in peer-review journals (n=53), as peer-reviewed guidelines (n=2), working papers (n=3), conference papers (n=1) or commissioned reviews (n=1) meaning that there was some level of quality check prior to inclusion. This broad inclusion criteria reflects the aim of the review: to identify sources that identify and discuss ethical principles applied to MHPSS research conducted in emergencies.

As the purpose of this review is to explore a range of perspectives – academic and practitioner - and to identify areas of consensus and debate relating to the ethical conduct of MHPSS research in emergencies, these limitations are deemed both acceptable and necessary for the present exercise. As a unique contribution and the first known attempt at systematically reviewing evidence on the application of ethical principles to MHPSS research in emergencies, this review fills an important gap in existing knowledge. Furthermore, the insights from this review have been applied to the development of evidence-informed recommendations for the ethical conduct of MHPSS research in emergencies (Inter-Agency Standing Committee (IASC) Reference Group for Mental Health and Psychosocial support in Emergency Settings, 2014), resulting in “real life” outputs.

Summary and recommendations

This review of multidisciplinary literature has identified and discussed evidence on ethical principles applicable to conducting MHPSS research with adults in emergencies. Through searches on academic and practice databases applying broad inclusion criteria, 59 sources were identified and reviewed.

Discussion has revealed a systemic tension between procedural ethics and ethics in practice (Guillemin and Gillam, 2004). For some this is an attempt to straightjacket ethics (Hoeyer *et*

al., 2005), forcing complex social realities into procedures where the attainment of moral responsibility can end up playing second fiddle to quasi-legal standards (Benatar, 2002). Behind many of the debates raised is the desire to ensure the protection of participants exposed to emergencies and in need of evidence-based MHPSS services. However, there is a lack of consensus on how to achieve ethical research practice. A recent proposal for balancing the strict procedural “one-size-fits-all” against a relative approach that lacks common underlying normative foundations is to adopt a situated approach that prioritises contextual interpretation of ethical principles prior to their application (Chiumento *et al.*, 2016). This approach recognises the uniqueness of each emergency context and each research encounter, with active and continual consideration of the application of ethical principles essential to ensuring research protects and promotes the rights of participants whilst making valuable contributions to the evidence base. This overarching consideration requires attention to direct future efforts to strengthen the ethical foundations of emergency MHPSS research.

Conclusion

This review fills an important gap in knowledge relating to the ethical conduct of MHPSS research, identifying some key current debates. Through a broad literature review, we have sought to provide an overview of academic and field perspectives on the applicability and operationalisation of ethical principles when conducting MHPSS research in emergencies. This has been presented through the lens of five themes under which a number of ethical considerations have been identified, and their cross-cutting and mutually dependent nature demonstrated. These findings are important for understanding how the ethical challenges inherent to the conduct of MHPSS research in emergencies are responded to, identifying consensus approaches to achieving ethical research conduct in emergency settings.

A central principle underpinning the reviewed literature is a desire to ensure the protection of participants exposed to emergencies and in need of evidence-based MHPSS. However, there is a lack of agreement on how to contextualise guidelines and procedures to effectively maximise the perspectives of researchers, participants and ethical review boards. This is a tension that the field must address to strengthen ethical MHPSS research in emergencies.

It is hoped that this exercise will encourage further documentation of research experiences from an ethical perspective, continuing to build evidence about appropriate procedures and practice to inform how ethical principles are interpreted and applied in a challenging research field.

References

Ager, A., Burnham, G., Checchi, F., Gayer, M., Grais, R. F., Henkens, M., Massaquoi, M. B. F., Nandy, R., Navarro-Colorado, C. and Spiegel, P. (2014) 'Strengthening the evidence base for health programming in humanitarian crises', *Science*, 345(6202), pp. 1290-1292.

Allden, K., Jones, L., Weissbecker, I., Wessells, M., Bolton, P., Betancourt, T. S., Hijazi, Z., Galappatti, A., Yamout, R., Patel, P. and Sumathipala, A. (2009) 'Mental health and psychosocial support in crisis and conflict: report of the Mental Health Working Group', *Prehospital and Disaster Medicine*, 24(Suppl 2), pp. s217-s227.

American Anthropological Association (2009) *Code of Ethics*. [Online] American Anthropological Association http://www.aaanet.org/cs_upload/issues/policy-advocacy/27668_1.pdf (Accessed 03.03.2016).

Association of Social Anthropologists of the UK and the Commonwealth (ASA) (2011) *Ethical guidelines for good research practice*. ASA: UK. [Online]. Available at: <http://www.theasa.org/downloads/ASA%20ethics%20guidelines%202011.pdf>. (Accessed: 03.03.2016)

Aube, N. (2011) 'Ethical Challenges for Psychologists Conducting Humanitarian Work', *Canadian Psychology-Psychologie Canadienne*, 52(3), pp. 225-229.

Bäärnhielm, S. and Ekblad, S. (2002) 'Qualitative research, culture and ethics: A case discussion', *Transcultural Psychiatry*, 39(4), pp. 469-483.

Benatar, S. R. (2002) 'Reflections and recommendations on research ethics in developing countries', *Social Science and Medicine*, 54(7), pp. 1131-1141.

Benatar, S. R., Daar, A. S. and Singer, P. A. (2005) 'Global health challenges: The need for an expanded discourse on bioethics', *PLoS Medicine*, 2(7), pp. 587-589.

Benight, C. C. and McFarlane, A. C. (2007) 'Challenges for Disaster Research: Recommendations for Planning and Implementing Disaster Mental Health Studies', *Journal of Loss & Trauma*, 12(5), pp. 419-434.

Bhan, A. (2010) 'Ethical issues arising in responding to disasters', *Asian Bioethics Review*, 2(2), pp.143-7

Black, R. (2003) 'Ethical Codes in Humanitarian Emergencies: From Practice to Research?', *Disasters*, 27(2), pp. 95-108.

Brown, N., Boulton, M., Lewis, G. and A., W. (2004) 'Social Science Research Ethics in Developing countries and contexts', *ESRC Research Ethics Framework Discussion Paper*, 3(2). Available at: https://www.york.ac.uk/res/ref/docs/REFpaper3_v2.pdf. (Accessed: 10.02.2014).

Call, J. A., Pfefferbaum, B., Jenuwine, M. J. and Flynn, B. W. (2012) 'Practical legal and ethical considerations for the provision of acute disaster mental health services', *Psychiatry*, 75(4), pp. 305-22.

Chiumento, A., Khan, M. N., Rahman, A. and Frith, L. (2016) 'Managing Ethical Challenges to Mental Health Research in Post-Conflict Settings', *Developing World Bioethics*, 16(1), pp. 15-28.

Citraningtyas, T., Macdonald, E. and Herrman, H. (2010) 'A Second Tsunami? The Ethics of Coming into Communities following Disaster', *Asian Bioethics Review*, 2(2), pp. 108-123.

Contractor, Q. (2008) 'Fieldwork and social science research ethics', *Indian Journal Of Medical Ethics*, 5(1), pp. 22-23.

Council for International Organisations of Medical Sciences (CIOMS) (2002) *International ethical guidelines for biomedical research involving human subjects*. Geneva: CIOMS. [Online]. Available at: http://www.cioms.ch/publications/layout_guide2002.pdf. (Accessed: 12.02.2014).

Curry, D., Waldman, R. and Caplan, A. (2014) *An Ethical Framework for the development and review of health research proposals involving humanitarian contexts*. [Online]. Available at: http://www.elrha.org/wp-content/uploads/2015/01/FINAL-R2HC-Ethical-Framework_Final-Report_24-January-2014_0.pdf (Accessed: 03.02.2014).

de Graaff, D., Jansveld, E. and de Jager, A. (2008) 'A reaction to Mikus Kos', *Intervention.*, 6(1), pp. 69-72.

Del Ben, K. S., McLeish, A. C. and Elkin, T. D. (2006) 'Research and Ethics Following a Natural Disaster: From the Public's Point of View', *The Behavior Therapist*, 29(6), pp. 128-131.

Department of Health and Human Services. (2009) *Code of Federal Regulations: Part 46, Protection and Human Subjects*. Department of Health and Human Services: US. [Online]. Available at: <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.102>.

Economic and Social Research Council (2015) *Framework for Research Ethics*. [Online]. Available at: <http://www.esrc.ac.uk/funding/guidance-for-applicants/research-ethics/our-core-principles/> (Accessed: 25.02.2015).

Emanuel, E. J., Wendler, D., Killen, J. and Grady, C. (2004) 'What makes clinical research in developing countries ethical? The benchmarks of ethical research', *Journal of Infectious Diseases*, 189(5), pp. 930-937.

Fitzgerald, D. W., Marotte, C., Verdier, R. I., Johnson, W. D. and Pape, J. W. (2002) 'Comprehension during informed consent in a less-developed country', *Lancet*, 360(9342), pp. 1301-1302.

Goodhand, J. (2000) 'Research in conflict zones: ethics and accountability', *Forced Migration Review*, 8, pp. 12-15.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.

Harper, I. (2007) 'Translating ethics: Researching public health and medical practices in Nepal', *Social Science & Medicine*, 65(11), pp. 2235-2247.

Hastings Centre (2004) 'Moral standards for research in developing countries - From "reasonable availability" to "fair benefits"', *Hastings Center Report*, 34, pp. 17-27.

Hobfoll, S. (2014) 'Resource caravans and resource caravan passageways: a new paradigm for trauma responding', *Intervention*, 12, pp. 21-32.

Hoeyer, K., Dahlager, L. and Lynoe, N. (2005) 'Conflicting notions of research ethics. The mutually challenging traditions of social scientists and medical researchers', *Social Science and Medicine*, 61(8), pp. 1741-9.

Hunt, M. R. (2008) 'Ethics beyond borders: How health professionals experience ethics in humanitarian assistance and development work', *Developing World Bioethics*, 8(2), pp. 59-69.

Hynes, T. (2003) *The issue of 'trust' or 'mistrust' in research with refugees: choices, caveats and considerations for researchers*. Geneva: UNHCR. [Online]. Available at: <http://www.unhcr.org/3fcb5cee1.html>. (Accessed: 16.01.2014)

Iltis, A. S., Misra, S., Dunn, L. B., Brown, G. K., Campbell, A., Earll, S. A., Glowinski, A., Hadley, W. B., Pies, R. and Dubois, J. M. (2013) 'Addressing risks to advance mental health research', *JAMA Psychiatry*, 70(12), pp. 1363-71.

Inter-Agency Standing Committee (IASC) Reference Group for Mental Health and Psychosocial support in Emergency Settings (2014) *Recommendations for Conducting Ethical Mental Health and Psychosocial Research in Emergency Settings*. IASC: Geneva. [Online]. Available at: https://interagencystandingcommittee.org/system/files/1._iasc_recommendations_for_ethical_mhpsr_research_in_emergency_settings_0.pdf.

Jacobsen, K. and Landau, L. (2003) *Researching refugees: some methodological and ethical considerations in social science and forced migration*. Geneva: UNHCR. [Online]. Available at: <http://www.unhcr.org/3f13bb967.html>. (Accessed: 26.02.2014)

Jesus, J. E. and Michael, G. E. (2009) 'Ethical considerations of research in disaster-stricken populations', *Prehospital and Disaster Medicine*, 24(2), pp. 109-14.

Juntunen, C. L. (2011) 'Reflections on the opportunities and challenges of disaster response', *Counseling Psychologist*, 39(8), pp. 1182-1192.

Kieling, C., Baker-Henningham, H., Belfer, M., Conti, G., Ertem, I., Omigbodun, O., Rohde, L. A., Srinath, S., Ulkuer, N. and Rahman, A. (2011) 'Child and adolescent mental health worldwide: evidence for action', *The Lancet*, 378(9801), pp. 1515-1525.

Kilpatrick, D. G. (2004) 'The ethics of disaster research: A special section', *Journal of Traumatic Stress*, 17(5), pp. 361-362.

Kinard, E. M. (1996) 'Conducting research on child maltreatment: Effects on researchers', *Violence and Victims*, 11(1), pp. 65-70.

Kortmann, G. (2008) 'From being assessed to self assessment. A brief comment from an external evaluator and former field worker.', *Intervention.*, 6(1), pp. 79-81.

Kos, A. (2008) 'The pitfalls of psychosocial evaluations: a critical perspective from a field worker', *Intervention.*, 6(1), pp. 57-65.

Lavery, J. V., Green, S. K., Bandewar, S. V. S., Bhan, A., Daar, A., Emerson, C. I., Masum, H., Randazzo, F. M., Singh, J. A., Upshur, R. E. G. and Singer, P. A. (2013) 'Addressing Ethical, Social, and Cultural Issues in Global Health Research', *PLoS Neglected Tropical Diseases*, 7(8), pp. e2227-e2232.

- Leaning, J. (2001) 'Ethics of research in refugee populations', *Lancet*, 357(9266), pp. 1432-3.
- Levine, C. (2004) 'The concept of vulnerability in disaster research', *Journal of Traumatic Stress*, 17(5), pp. 395-402.
- Lohr, J. M., Devilly, G. J., Lilienfeld, S. O. and Olatunji, B. O. (2006) 'First Do No Harm, and Then Do Some Good: Science and Professional Responsibility in the Response to Disaster and Trauma', *The Behavior Therapist*, 29(6), pp. 131-135.
- Mackenzie, C., McDowell, C. and Pittaway, E. (2007) 'Beyond 'do no harm': The challenge of constructing ethical relationships in refugee research', *Journal of Refugee Studies*, 20(2), pp. 299-319.
- Madianos, M. G. and Evi, K. (2010) 'Trauma and Natural Disaster: The Case of Earthquakes in Greece', *Journal of Loss & Trauma*, 15(2), pp. 138-150.
- Michael, M. and Zwi, A. B. (2002) 'Oceans of need in the desert: ethical issues identified while researching humanitarian agency response in Afghanistan', *Developing World Bioethics*, 2(2), pp. 109-30.
- Mollica, R. F., Cardozo, B. L., Osofsky, H. J., Raphael, B. Ager, A., and Salama, P. (2004) 'Mental health in complex emergencies', *The Lancet*, 364(9450), pp. 2058-67.
- Neugebauer, R. (1999) 'Research on violence in developing countries: Benefits and perils', *American Journal of Public Health*, 89(10), pp. 1473-4.
- O'Mathuna, D. P. (2010) 'Conducting research in the aftermath of disasters: ethical considerations', *Journal of Evidence Based Medicine*, 3(2), pp. 65-75.
- Perrey, C., Wassenaar, D., Gilchrist, S. and Ivanoff, B. (2009) 'Ethical issues in medical research in the developing world: a report on a meeting organised by Foundation Merieux', *Developing World Bioethics*, 9(2), pp. 88-96.
- Poudyal, B., Erni, T., Subyantoro, T. and Jonathan, A. (2008) 'Psychosocial programmes and evaluations', *Intervention.*, 6(1), pp. 73-74.
- Redfield, P. (2012) 'The Unbearable Lightness of Ex-Pats: Double Binds of Humanitarian Mobility', *Cultural Anthropology*, 27(2), pp. 358-382.
- Richards, W. (1989) 'A community systems approach to research strategies', *American Indian & Alaska Native Mental Health Research*, 2(3), pp. 51-7.

- Rosenstein, D. L. (2004) 'Decision-Making Capacity and Disaster Research', *Journal of Traumatic Stress*, 17(5), pp. 373-381.
- Schopper, D., Upshur, R., Matthys, F., Singh, J. A., Bandewar, S. S., Ahmad, A. and van Dongen, E. (2009) 'Research Ethics Review in Humanitarian Contexts: The Experience of the Independent Ethics Review Board of Médecins Sans Frontières', *PLoS Medicine*, 6(7), pp. 1-6.
- Siriwardhana, C., Adikari, A., Jayaweera, K. and Sumathipala, A. (2013) 'Ethical challenges in mental health research among internally displaced people: Ethical theory and research implementation', *BMC Medical Ethics*, 14(1), pp. 13-20.
- Sumathipala, A., Jafarey, A., de Castro, L., Ahmad, A., Marcer, D., Srinivasan, S., Kumar, N., Siribaddana, S., Sutaryo, S., Bhan, A., Waidyaratne, D., Beneragama, S., Jayasekera, C., Edirisingha, S., and Siriwardhana, C. (2010) 'Ethical issues in post-disaster clinical interventions and research: a developing world perspective. Key findings from drafting a consensus generation meeting of the Working Group on Disaster Research and Ethics (WGDRE) 2007', *Asian Bioethics review*, 2(2): 124-42.
- Sumathipala, A. and Siribaddana, S. (2005) 'Research and clinical ethics after the tsunami: Sri Lanka', *Lancet*, 366(9495), pp. 1418-1420.
- Tankink, M. (2007) 'My mind as transitional space: Intersubjectivity in the process of analyzing emotionally disturbing data', *Medische Antropologie*, 19(1), pp. 135-145.
- Thomas, J., and Harden, A. (2008) 'Methods for the thematic synthesis of qualitative research in systematic reviews', *BMC Medical Research Methodology*, 8(1), pp. 45-55
- Thornicroft, G., Cooper, S., Van Bortel, T., Kakuma, R. and Lund, C. (2012) 'Capacity building in global mental health research', *Harvard Review of Psychiatry*, 20(1), pp. 13-24.
- Tol, W. A., Barbui, C., Galappatti, A., Silove, D., Betancourt, T. S., Souza, R., Golaz, A. and van Ommeren, M. (2011) 'Mental health and psychosocial support in humanitarian settings: linking practice and research', *The Lancet*, 378, pp. 1581-1591.
- Tol, W. A. and Jordans, M. J. D. (2008) 'Evidence based psychosocial practice in political violence affected settings', *Intervention.*, 6(1), pp. 66-69.
- Tomlinson, M., Swartz, L. and Landman, M. (2006) 'Insiders and outsiders: Levels of collaboration in research partnerships across resource divides', *Infant Mental Health Journal*, 27(6), pp. 532-543.

Weissman, F. (ed) (2004) *In the shadow of 'just wars': violence, politics and humanitarian action / Médecins Sans Frontières. Translations from the French by Vincent Homolka, Roger Leverdier and Fiona Terry. English text edited by Fiona Terry.* London: Cornell University Press.

Wessells, M. G. (2008) 'Do no harm: Challenges in organizing psychosocial support to displaced people in emergency settings', *Refuge*, 25(1), pp. 6-14.

Wessells, M. G. (2009) 'Do No Harm: Toward Contextually Appropriate Psychosocial Support in International Emergencies', *American Psychologist*, 64(8), pp. 842-854.

Wissow, L. S., Rutkow, L., Kass, N. E., Rabins, P. V., Vernick, J. S. and Hodge, J. G., Jr. (2012) 'Ethical issues raised in addressing the needs of people with serious mental disorders in complex emergencies', *Disaster Medicine & Public Health Preparedness*, 6(1), pp. 72-8.

World Health Organisation (2003) *WHO Ethical and Safety Recommendations for Interviewing Trafficked Women.* Geneva: WHO. [Online]. Available at: <http://www.who.int/gender/documents/en/final%20recommendations%2023%20oct.pdf>. (Accessed: 03.02.2014).

World Health Organisation (2007) *WHO Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies.* Geneva: WHO. [Online]. Available at: http://www.who.int/gender/documents/OMS_Ethics&Safety10Aug07.pdf (Accessed: 03.02.2014).

World Health Organisation/War Trauma Foundation and World Vision International (2011) *Psychological First Aid: Guide for Fieldworkers.* Geneva: WHO. [Online]. Available at: http://www.who.int/mental_health/publications/guide_field_workers/en/ (Accessed 03.02.2014).

World Medical Association (2013 [1964]) *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects.* WMA General Assembly.

Yamout, R. and Jabbour, S. (2010) 'Complexities of research during war: lessons from a survey conducted during the summer 2006 war in Lebanon', *Public Health Ethics*, 3(3), pp. 293-300.

Zwi, A. B., Grove, N. J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D. and Tarantola, D. (2006) 'Placing ethics in the centre: negotiating new spaces for ethical research in conflict situations', *Global Public Health*, 1(3), pp. 264-277.

LINKING THE LITERATURE REVIEW WITH THE CASE STUDY

This section links the previous literature review paper with the Developing World Bioethics paper *Managing ethical challenges to mental health research in post-conflict settings* (hereafter “case study paper”) (Chiumento *et al.*, 2016). It does this by outlining how the case study builds upon the literature review by exploring some of the unresolved debates in a post-conflict setting, providing a rationale for the case study paper. It then outlines how the case study paper captures early thinking in relation to the topic of study which is revisited in the discussion in light of study findings. In addition, the chapter on epistemology, methodological, and ethical considerations draws together how the literature review and case study papers’ informed the research questions, aims, and methods of this thesis.

Case study: exploring some key unresolved debates raised in the literature review

The case study offered an opportunity to explore some of the key debates identified in the literature review, centrally the underlying tension about how to contextualise and operationalise research ethics guidelines and procedures to research practice. Some of the tensions identified in the literature review that are explored in the case study include:

- how “fair benefits” is operationalised, considering the role of funders and the importance of the community determining what benefits are meaningful in a given context;
- the impact of multiple levels of formal and informal ethical review, and how this can be a stimulus for specifying ethical principles to situated research contexts;
- how to operationalise voluntary informed consent in a specific context, including considerations of decision making capacity and the impact of recent conflict upon community (mis)trust;
- exploring risk management through the lens of risk to the research team; and
- the role of ethical reflection upon research conduct to promote the development of good practice in applying ethical principles to practice.

These are explored in the case study paper by identifying the procedural research ethics standards applicable to each consideration, and outlining and critiquing the procedural and in-practice approaches to managing each ethical consideration taken by the South Asian research team. At the end of the paper a proposed framework for “empirical ethical reflection” is developed, offered as a way to balance the gap between procedural and in-practice ethics that the literature review and this thesis identify. This is revisited in the

discussion chapter which critically assesses the proposed framework in light of research findings.

How the case study builds upon the literature review

The rationale for conducting the case study is to build upon the literature review to inform the research design, notably the development of research questions, aims, and methods (Hart, 1998), discussed further in the chapter on epistemology, methodology, and ethical considerations. Therefore, the case study was important for its content, for clarifying the research aims and objectives, and for informing the research methodology adopted for this thesis by illustrating what could be learnt from an exploration of research ethics in situated contexts and from the perspective of researchers.

As such the case study provides a focussed exploration that complements the broader review provided by the literature review paper. It is for this reason that these two papers are presented together here: the first providing a background to the study topic and identifying gaps in current understanding that further research can explore; and the second exploring an empirical case study which informed refinement of the research aims, objectives, and methodology. Both of these papers were therefore drawn upon when finalising research aims, questions, and research design.

Tracking evolving theoretical positions during the conduct of research

By developing the approach of “empirical ethical reflection”, the case study paper identifies early thinking in relation to how the gap between procedural and in-practice ethics could be managed. This provides a reference point for this study to build upon or agitate against, situating the ideological underpinnings to the topic under study (Silverman, 2013), and is revisited and critiqued in the discussion chapter. This approach is viewed as a strength of this research by transparently identifying my position in relation to the potential directions the field could move in to address the challenges identified in the literature review.

This section has outlined the rationale for conducting a case study to explore key tensions identified in the literature review to inform development of the research questions, study design, and methods, as described in the chapter on epistemology, methodology, and ethical considerations. The strengths and limitations of the approach taken both in relation to the literature review and the case study are discussed in the section linking the literature review and case study into setting up the research problem which is presented following the case study paper.

References

Chiumento, A., Khan, M. N., Frith, L. and Rahman, A. (2016) 'Managing ethical challenges to mental health research in post-conflict settings.', *Developing World Bioethics*, 16(1), pp. 15-28.

Hart, C. (1998) *Doing a literature review: releasing the social science research imagination*. London: SAGE Publications.

Silverman, D. (2013) *Doing qualitative research*. 4th edn. London: SAGE Publications.

MANAGING ETHICAL CHALLENGES TO MENTAL HEALTH RESEARCH IN POST-CONFLICT SETTINGS

Abstract

Recently the World Health Organization (WHO) has highlighted the need to strengthen mental health systems following emergencies, including natural and manmade disasters. Mental health services need to be informed by culturally attuned evidence that is developed through research. Therefore, there is an urgent need to establish rigorous ethical research practice to underpin the evidence-base for mental health services delivered during and following emergencies.

This paper discusses ethical challenges to conducting mental health research in a post-conflict setting and puts forward possible solutions. Drawing upon a South Asian case study we identify six ethical challenges that were encountered. Each challenge is discussed in relation to wider ethical standards of research practice, and the applicability of existing normative frameworks to a post-conflict context is critically assessed. Our discussion emphasises the situated nature of responses to ethical challenges encountered during the research.

We then explore recent proposals for managing ethical issues in global health research, identifying their relative strengths and weaknesses. We conclude by calling for documenting and reflecting upon empirical evidence of research practice to stimulate consideration of procedural ethics and ethics in practice. This process aims to promote a moral discourse that can contribute to the development of ethical research practice to underpin mental health research in emergencies.

Introduction

Emergencies include natural disasters, man-made disasters, and (protracted) refugee or internally displaced persons (IDP) settings. They create a range of problems at the individual, family and societal levels, including mental health and psychosocial problems (Inter-Agency Standing Committee (IASC), 2007). Given the exceptional nature of emergencies, mental health research is required to build evidence of effective, acceptable and feasible services for contexts where mental health conditions may be aggravated by experiences of disaster and displacement (Zwi *et al.*, 2006; Tol *et al.*, 2011). Such research, as with all human subjects' research, must be ethical and maintain high standards of researcher integrity

(Kottow, 2002; Brown *et al.*, 2004; Iltis *et al.*, 2013). Consequently, the need to confront the ethical challenges inherent to conducting mental health research in emergencies is clear.

Both human rights and research ethics are concerned with normative standards and make claims about how humans *ought* to be treated in certain situations. They emerged from a shared history of rights violations stimulating an international human rights regime (United Nations General Assembly, 1948), and guidance relating to medical ethics (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; World Medical Association, 2013 [1964]). These guidelines codify the normative standards which healthcare research must uphold.

Post-conflict mental health research is more likely to occur in low- and middle-income countries (LMIC). It is therefore important to acknowledge that ethical and human rights norms, arguably, are premised upon a Western Liberal tradition that prioritise individual rights (Swift, 2006) and may clash with non-western conceptions. Through increasing international collaborative - including interdisciplinary - research, standards are homogenised, typically through importing research ethics codes from developed nations to LMIC (Brown *et al.*, 2004). As Emerson *et al.* (2009) highlight: “the ‘is’ of those living in the developing world is not the same as the ‘is’ of those living in industrialised nations, and this is morally significant”. In light of this, this paper questions the uncritical application of Western ethical research standards to community-based emergency contexts in LMIC, arguing that a more nuanced view of what ethical research “looks like” is needed.

Whilst ethical research standards can be viewed as imported from another setting, they provide a useful starting point for critically considering existing norms of research practice. Drawing upon a case study we discuss the difficulties of importing standards and propose strategies for managing ethical issues in research conducted in a LMIC post-conflict context. We put forward a case for critical reflexivity when conducting research in emergencies, examining what “ethical research” entails procedurally and in-practice (Guillemin and Gillam, 2004). Procedural ethics denotes the processes involved in applying for and securing formal research ethics approval; whereas ethics in practice refers to day-to-day ethical issues that are often not addressed or anticipated when applying for ethical approval (Guillemin and Gillam, 2004). It has been observed that it is in the application of ethical principles that differences in the way they are interpreted and balance are revealed (Emanuel *et al.*, 2004), further highlighting the tension between procedural and in-practice ethics.

Considering ethical research through a procedural / in-practice lens is particularly illuminating in emergency settings where ethics in practice may be complicated by a range of political, ethnic, economic, social and cultural factors, and where specific procedural guidance on ethical research do not exist. An example of this is carrying out and documenting informed consent in cross-cultural post-conflict contexts where socio-cultural norms and a potential climate of fear must be appropriately responded to. This is often presented in procedural documents as ordered and unproblematic, whereas in-practice this process can be far more nuanced, requiring gatekeeper as well as individual consent, and overcoming privacy and confidentiality fears to documenting consent. The potential disjunction between procedural and in-practice ethics raises questions about the purpose of procedural ethics for aiding study preparation, as well as the implications when there are significant in-practice deviations from what is outlined in procedural documents. It is this tension that this paper seeks to explore and propose solutions to.

We argue for moving away from a procedural rose-tinted presentation of the implementation of ethical principles that obscures in-practice realities, instead encouraging engagement and debate on how ethical challenges inherent to mental health research in emergencies are managed. The approach, referred to in this paper as “empirical ethical reflection” proposes a process to support ethical decision making in which ethical norms are specified from abstract principles to applied contexts, clarifying and converting ethical theories into guides for action (Richardson, 1990; Frith, 2012). The empirical ethical reflection approach proposes a framework for active engagement with procedural and in-practice ethical issues that arise in post-conflict mental health research that is ongoing from research inception to dissemination (see figure 2). It is proposed as a potential way to address the procedural / in-practice tension that this paper draws out. It is important to note that the empirical ethical reflection approach outlined in this paper is under development and will be refined (and potentially renamed) over time.

This paper presents a mental health research case study conducted in a LMIC post-conflict setting. The key ethical challenges are identified and discussed in relation to existing normative frameworks, critically assessing their applicability to LMIC post-conflict settings, and by extension - emergency - research. In the final section of the paper a broad outline of the proposed empirical ethical reflection approach is provided, calling for integration of documenting and reflecting upon empirical evidence of research practice to foreground procedural ethics and ethics in practice.

Case study

This case-study outlines an exploratory mixed-method mental health research study conducted in a post-conflict setting in South Asia. It is drawn from reflections of the research lead (MNK), academic supervisor (AR), and local research team. Details have been abstracted to protect on-going research.

The mental health study targeted perinatal women through a community health centre in one district of a South Asia country. It involved a qualitative assessment, baseline quantitative survey, developing and delivering an intervention, conducting an exploratory randomised control trial and follow-up qualitative interviews. Research was conducted over two years by a local researcher and study team trained and supervised by senior mental health researchers from the South Asian country. The study received full in-country and UK University ethical approvals.

Military operations officially ended prior to study commencement, but a strong military presence remained with checkpoints and patrols. The community contained active non-state insurgents, with isolated incidents perpetuating instability. This post-conflict context produced a number of ethical challenges to research conduct.

The case study examines the management of six ethical challenges:

Table 5: Ethical challenges

Challenges	Ethical issues	How ethical issues were managed
<i>Who conducts the research?</i>	Affects access to participants, acceptability and accountability of the research team, participant paranoia and mistrust, and carries implications for research capacity-building.	<ul style="list-style-type: none">• Access, researcher accountability and local capacity building addressed by research led and conducted by a local research team comprised of community residents.• Research supervision conducted by nationals of the South Asia country experienced in mental health research in complex community settings.
<i>Who funds the research?</i>	Disclosure of research funders in research information is accepted ethical research practice. It is important to be aware of local perceptions of funders and the impact this may have upon research participation.	<ul style="list-style-type: none">• Funded by a national Higher Education body equipped with local knowledge, able to judge study appropriateness for the target population.

<i>Ethical review</i>	Ethical review is an accepted procedure to verify the ethical grounding of proposed research.	<ul style="list-style-type: none"> • Local in-country ethical approval secured prior to obtaining UK University approval, deferring to local assessment. • Protocol developed with full participation of the local research team acting as cultural brokers.
<i>Voluntary informed consent:</i>	Informed consent is a guiding norm of ethical research practice: human subjects <i>should</i> be informed about the nature and implications of research, their rights in the research process, and that participation is voluntary.	<ul style="list-style-type: none"> • Voluntary written informed consent of female participants was required. • Cultural norms require prior gatekeeper consent from families. • Cultural adaptations to the consent process sought to ensure consent was informed, voluntary, adhered to ethical standards, and was compatible with local cultural norms.
<i>Community mistrust:</i>	Mental health research requires unbiased data to guide design, delivery and evaluation of interventions.	<ul style="list-style-type: none"> • Research was shared and agreed with local community representatives to counter misinformation about the study. • Community re-engagement was conducted to address rumours and mistrust.
<i>Risk to the research team:</i>	Participant and researcher safety is a guiding principle of research: Do no harm.	<ul style="list-style-type: none"> • “Do no harm” was applied to research participants and the research team. • Risk to the research team was managed by “pauses” to research activities and community re-engagement.

This case-study highlights some everyday ethical challenges encountered when conducting research in a post-conflict setting.

Maintaining ethical standards

In this section we discuss the six challenges raised in the case-study, examining existing ethical research standards. We then outline proposed strategies for managing the ethical issues raised by conducting research in emergencies. We conclude by considering the benefit of empirically studying researchers’ experiences for contributing to ethical mental health research in emergencies.

Who conducts the research?

In social research gauging an appropriate distance between researcher and participant – neither too familiar nor too distant (Craig *et al.*, 2000) - is important for methodological rigour. Often the “appropriate” distance is enmeshed with adherence to cultural norms, and is therefore affected by who conducts the research. This is important in mental health research where effective interventions require attention to the cultural context in which participants are embedded (Bernal and Sáez-Santiago, 2006). A local research team who can advocate for culturally centred interventions (Bernal and Sáez-Santiago, 2006), and research processes that respond to cultural context can aid acceptability of services and research.

Who conducts research carries implications for research capacity building, defined as the ability to conduct, manage, disseminate, and apply research in policy and practice (Thorncroft *et al.*, 2012). Gaps in LMIC mental health research capacity have been identified at every level: individual, organisational and national (Sharan *et al.*, 2007). The lack of sufficiently trained and experienced local researchers carries ethical implications when research is conducted by those unfamiliar with local context or without sufficient expertise to maintain ethical research standards (Goodhand, 2000). Consequently, the benefits of building local capacity should not be underestimated (Benatar *et al.*, 2005; Perrey *et al.*, 2009), including better integrating LMIC perspectives into research agendas and practice in global health (Lavery *et al.*, 2013). Capacity building requires long-term investment and commitment – including recognising research as a viable career.

Developing local capacity and partnerships also provide routes for initial contact with communities that can increase the acceptability of those conducting research. The way communities are approached has been highlighted as critical to “ethical entry” (Citraningtyas *et al.*, 2010) appropriate to local cultural norms. Partnerships with organisations embedded within local communities also provides routes for researcher accountability to the community (Brown *et al.*, 2004). When negotiating access to communities, particularly in conflict or post-conflict situations, awareness of power relations and who is identified to represent a community are pertinent (Hynes, 2003). The potential for researchers to be perceived as supporting one side or another, or privileging certain accounts requires careful attention (Leaning, 2001; Hynes, 2003) and can be exacerbated by researchers working outside of local community systems. Researchers must remain mindful of who they are provided access to, and issues that might arise from only engaging those with the power to speak out, further disempowering those without a voice (Zwi *et al.*, 2006). Responding to

these considerations is contextual, favouring a situated approach to how ethical entry is managed.

Local research teams are well placed to manage researcher safety. Craig *et al.* (2000) identify race, gender and culture as potentially impacting upon researcher safety in violent contexts. They advocate addressing safety by matching these and other important characteristics of the research team with the community. The issue of researcher safety is discussed in more detail below.

Therefore, for a range of ethical reasons it is maintained that ethical research conduct requires the incorporation of local researchers within the project team.

In the case study researcher matching and ethical entry were ensured through a local research team, critically incorporating local females including two mothers. These female researchers shared important characteristics with participants and were widely respected within the community. Gender matching researchers and study participants increased the acceptability of the research, strengthening mutual trust and rapport. Appropriate distance between participant and researcher was assured by adherence to local cultural norms such as dress codes including observing purdah (the practice of females wearing a veil and being segregated from men who are not family) and speaking the local language. Researchers were not personally known to participants, but came from the same region, deemed important for building trust and ensuring confidentiality (Hynes, 2003). Ethical entry was achieved through partnership with a local organisation, and respecting cultural norms by discussing the study with community elders and health workers prior to its commencement. Negotiating access to female research participants required attention to gender power imbalances as well as cultural norms relating to decision-making authority (discussed under “informed consent” below). Ongoing activities in the research site continue to draw upon the skills and expertise of the trained research team, contributing to local capacity building and embedding local partnerships for future research.

Who funds the research?

The manner in which research is funded in emergencies carries at least two important ethical considerations: first, in post-conflict situations is the funding source, or country associated with the source, seen to be party to the conflict? This could put researchers and participants at risk of harm. Second, do funding structures enable research that leads to tangible improvements in participants’ lives in the short and long term?

In post-conflict settings who fund the research can lead to positive or negative views of the study depending upon local populations' perceptions of outside agencies. This is particularly pertinent when bodies perceived as party to the conflict fund research, and can impact upon researcher safety.

The question of disclosing research funding raises competing ethical duties. On the one hand there is a duty to develop mental health interventions by conducting research which requires funding, and there is an established ethical obligation to disclose funding sources to participants. On the other hand following this ethical obligation could potentially put researchers at risk. Therefore two ethical principles come into conflict – the disclosure of funding sources to participants, and the duty to ensure researcher safety. To address this we recommend conducting an assessment to consider the ways funding agencies may be viewed by the local community, and how this may impact upon researcher safety. Assessment findings should be shared with funders to negotiate an approach to funding disclosure, considering adjustments to the obligation for full disclosure. This approach is not without its problems. For example, could failure to fully disclose funding sources be viewed as deception, presenting a risk should it become known that researchers were not open with participants? Resolving these tensions requires an approach that accounts for local factors, and not a “one size fits all” ethical requirement (Richardson, 1990; Frith, 2012).

A further issue is the ethical obligations of funders. Schopper *et al.* (2009) highlight “reasonable availability” of an intervention post-research, defined as a commitment to deliver services for a minimum of two years, or that it remains available through other means. Similarly, the Council for International Organisations of Medical Sciences (CIOMS) (2016) identify as “morally praiseworthy” the sponsor funding services beyond the duration of research, with this commitment outlined in research protocols; guidance that is reflected elsewhere (Medical Research Council (MRC), 2004).

The issue of research funding should be included within ethical risk / benefit analysis. In the field of mental health research benefits typically include influencing the design and delivery of services. This is the aim of WHO's “Building Back Better” which advocates strengthening health systems in the immediate aftermath of emergencies for long-term benefits (World Health Organisation, 2013). However, policy process can be lengthy meaning participants may not see research impact. This is particularly the case where intervention delivery is tied to short-term funding rather than a commitment to embed services into routine care. Delays

in research impact or short-term services can create poor perceptions of research participation.

The Hastings Centre consider the duty of “fair benefits” from research participation as laid out in CIOMS (Hastings Centre, 2004). They argue that “fair benefits” is poorly operationalised, with lack of clarity over who is to benefit (research participants, the wider community, a whole country?) and who is responsible for funding this benefit (research funders, governments, international organisations?). They support the community deciding the value of fair benefits of research participation, and what these should entail. Therefore, ethical research is not tied to continued access to services, but could include benefits such as capacity building of local service providers or researchers, contributing to health infrastructure, or financial reward. This raises a duty for researchers and funders to engage with communities to determine how benefits can be ethically distributed, delivering immediate and long term benefits of value to the community.

In the case study the issue of who funds the research was minimised as funding came from a National Higher Education body and a recognised local NGO. These funding sources increased local acceptability of the research and were fully disclosed to study participants. Future research benefits included an intervention provided by embedded health workers which continued to be delivered beyond the research, and capacity building of both healthcare providers and researchers. These benefits were discussed informally with healthcare providers prior to research, exploring how to embed research into existing services. Capacity building was viewed as of particular benefit and involved training healthcare staff at two centres in the mental healthcare needs of perinatal women.

However, in light of community mistrust it is possible that some participants considered the local funding sources as a route for government authorities to extract information regarding involvement in insurgency activity. Therefore, it is maintained that an assessment of the socio-political context be conducted, including in internal conflicts where community allegiances may lead to local funders being viewed with suspicion.

Ethical review

Research ethics review is a procedural cornerstone of international guidelines on human subjects research (Medical Research Council (MRC), 2004; Economic and Social Research Council, 2015; Council for International Organisations of Medical Sciences (CIOMS), 2016). However, lacking or dysfunctional review boards in many LMICs contribute to inadequate ethical research standards (Thorncroft *et al.*, 2012). Challenges ranging from review boards’

legal status, workloads, and differences in expertise and procedures contribute to disparities in the review process (Perrey *et al.*, 2009).

Developing research ethics committee members' capacity is frequently highlighted as a way of ensuring reliable interpretation of international ethical guidelines for socio-economic and cultural conditions (Milford *et al.*, 2006). This concurs with calls for in-country review to judge "ethical acceptability of the research in accordance with the customs and traditions of the community", involving lay persons to review research against community cultural and moral values (Medical Research Council (MRC), 2004, p. 6).

Advocating formal ethical review is premised on the view that when conducted well feedback can be instrumental to ensuring research maintains ethical standards. A subsidiary aim is to stimulate a conversation between researchers and reviewers, seeking consensus on how to manage potential ethical issues. In the ethical review process it is important to recognise informal community-level procedures for reviewing research that operate alongside formal review, ensuring that the latter does not usurp the former: conversations with ethical review boards should not replace conversations with communities involved in research. An iterative process between ethical review boards and communities to identify, define and negotiate the ways ethical challenges will be resolved is recommended. This approach problematizes the priority of formal ethical review, with the strongest process being one that balances formal review with community-led processes. An iterative approach acknowledges that most ethical issues arising in research implicate a number of principles which requires a process of judging the relative weight to be accorded each principle (Emanuel *et al.*, 2004).

In complex contexts it has been suggested that those conducting ethical review are often in a "double-bind": they recognise the risks and potential for exploitation, but have little practical guidance to offer on the management of ethical issues (Zwi *et al.*, 2006). This suggestion concurs with recent research identifying the paucity of guidance from ethical review committees on a study conducted with IPDs (Siriwardhana *et al.*, 2013). Involving the community to collaboratively design research, including developing responses to potential ethical issues, as well as having community review of research, offer potential mechanisms to address this "double-bind".

Challenges to iteratively developing specified ethical standards for international mental health research are recognised, not least of all the time required. Another difficulty is the complexity of ethical review at multiple levels – community, in-country, international and increasingly funder review. However, these processes aid development of ethical standards

for specific studies that adhere to both local and international norms, and support researcher preparedness by thinking through ethical issues prior to data collection. Multiple levels of review can also stimulate ethical review committees cross-learning: educating international committees on country context, culture and moral values; in-country committees can see how international committees work; and both local and international committees can learn from community responses to potential ethical issues. Therefore, due to potential long-term benefits for specific research studies and a broader moral conversation we argue for using the opportunity of engaging with multiple levels of review and iterative development of ethical standards to build examples of best practice for managing potential ethical issues in a range of contexts.

Whilst this proposal could be charged with being idealistic, it is countered that researchers routinely engage with procedural demands which frequently entail multiple levels of ethical review, for example in the country where the study is to be conducted and in the sponsor country. This demonstrates that with sufficient planning and researcher commitment multi-level review is possible. A further challenge is presented when seeking to follow the process of multi-level review in settings where no local review structures exist. In this case we recommend a peer-review assessment of the protocol either by local academics, practitioners or community members to ensure research is critiqued from a local perspective.

In this case study formal ethical review was obtained both in-country and at a UK University. Community perspectives were represented by the locally-based researchers who took an active role in developing the study protocol and acted as cultural brokers, identifying potential ethical challenges and suggesting routes to manage these - such as the informed consent process discussed below. Additionally, sharing proposed research with community health workers and elders provided informal community-level review. Contrary to the above discussion on the opportunities for cross-learning through ethical review processes this was not experienced in this study. Approval at all levels was provided without comment on the potential ethical issues that may arise. Therefore, management of in-practice ethical issues relied heavily upon informal local review and comment, researcher integrity, and knowledge of the study setting rather than formal ethical review processes. It is not known if this missed opportunity is a result of those conducting review feeling they were in a “double-bind” or due to poor capacity and review procedures.

Voluntary informed consent

Informed consent is a guiding norm of ethical research practice: human subjects *should* be informed about the nature and implications of research, their rights in the research process, and that participation is voluntary (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979). Informed consent arose from legal standards of physician duty towards research participants, and contemporary moral theory which conceptualises the patient as subject (Faden *et al.*, 1986; Rorty, 1993). It is premised upon the moral notion that rational people will choose to do what is good for them (Rorty, 1993). Homan (1991) identifies four elements to voluntary informed consent:

1. All pertinent aspects of what is and might occur are disclosed;
2. The participant should be able to comprehend this information;
3. The participant is competent to make a rational judgement;
4. Agreement to participate should be voluntary, free from coercion and undue influence.

Research guidelines recognise informed consent in LMIC raises additional cultural considerations, including the issue of gatekeepers (Medical Research Council (MRC), 2004) and differing conceptualisations of ethics and rights (Economic and Social Research Council, 2015). Attending to power relations is also identified (Zwi *et al.*, 2006), with one study seeking to mitigate power hierarchies' related to religious, community and political leaders, as well as the status accorded to medical professionals and researchers, which can create undue inducement to participate (Siriwardhana *et al.*, 2013).

In this case study gatekeeper consent was conducted, respecting local cultural norms. This entailed obtaining prior consent from household males and elders to seek consent from the female participant. This can be viewed as taking consent from multiple levels or "spheres" (Weijer and Emanuel (2000) cited in Emanuel *et al.*, 2004), including whole communities, community leaders or elders, families, and individuals as appropriate in the setting. This process presents ethical risks as it is possible that gatekeepers may not allow an individual to participate. In this circumstance the participant is unable to exercise their right to make an informed choice to participate. This presents an ethically charged dilemma for researchers balancing adherence to cultural context with ethical and human rights norms.

Chambliss suggests informed consent "represents at best a polite fiction" (Chambliss, 1993), a view pertinent to emergency contexts (Ahmad and Syed Maum, 2010). In the case study before research assistants sought informed consent research was introduced by a

community health worker who provided a short explanation of the study and asked permission for a research assistant to meet with the individual. Through training, research assistants' self-awareness of the impact disparities in education and status could have upon making an informed choice to participate were raised, and the participants right to refuse to participate without penalty was reinforced. Therefore, each step in the informed consent process sought to protect participant rights whilst remaining compatible with local cultural norms.

Additional safeguards were also considered including taking repeated consent, an approach adopted through repeat verbal consent. This compromise aimed to minimise raising anxieties in relation to the research purpose, and formed one aspect of addressing community mistrust through consistent articulation of the research process, discussed below. A challenge to repeat consent is that it could promote higher attrition rates, something particularly relevant to randomised control trials.

Relating to procedural ethics, in the case study, due to high rates of illiteracy all research information was explained verbally in the local dialect with a thumb print accepted in lieu of a signature, following standard practice in the context. It is important to note that in different settings a thumb print can itself carry negative connotations. Other alternatives for recording consent with illiterate populations are to record verbal consent or have researchers witness and verify consent on behalf of participants. However, both strategies present ethical challenges. In some contexts, including the case study, recording is not acceptable to the local community or presents risks to confidentiality. Equally, to have researchers verify consent on participants' behalf can be considered insufficient protection against coercion. Consequently, decisions relating to how to record consent must be carefully examined with local researchers who can act as "cultural brokers" to ensure acceptability of consent processes.

In the case study despite providing information in the local language and attempting to overcome illiteracy through verbal explanations of the research, rumours of threats to the research team called into question how far confidentiality, anonymity, and protection of participant rights was understood. Difficulties translating concepts such as anonymity and confidentiality into the local dialect raise questions as to the meaning participants ascribed to them. Perceptions that interviews are collecting information to pass onto intelligence authorities are more likely to occur where the population feel threatened, such as conflict or

post-conflict settings. This indicates that whilst consent processes can be culturally adapted, they may be unreliable when undertaken with an illiterate population who feel threatened.

Accordingly, the case study consent process in some cases failed to meet Homan (1991) element 2: comprehension of research information. This raises a critical ethical dilemma: how to ensure information is fully comprehended at the time of obtaining consent? Moreover, what are the implications for consent should it transpire that information was not fully comprehended? These strike at the heart of the principle of informed consent, and have been discussed elsewhere (Iltis *et al.*, 2013). Strategies for managing this in LMIC have been proposed including: placing emphasis upon the process of information exchange over formal recording of consent (Harper, 2007); providing information in lay language appropriate to local literacy (Call *et al.*, 2012), where required including images or video to aid communication (Tekola *et al.*, 2009); and conducting an oral examination to gauge sufficient knowledge to make an informed decision about participation (Fitzgerald *et al.*, 2002). The first two strategies offer routes to enhance the quality of information exchange and are deemed appropriate in emergencies. An examination to verify comprehension is deemed inappropriate given the potential for disempowering potential participants. However, the principle of asking participants to reflect back in their own words their understanding of research has been recommended (Goodhand, 2000) and is considered a less formal approach to verifying study comprehension to make an informed decision about participation. Furthermore, relating to information, concerns about the way information is constructed and presented have been raised (Tekola *et al.*, 2009). This is important in emergencies where clear and unbiased presentation of information is critical for avoiding exploitation.

As this brief discussion emphasises, the practice of ensuring voluntary informed consent is frequently complex, requiring researchers to judge the quality of consent. It may only be once research is underway that it emerges to what extent the information provided during consent was understood by participants. Therefore, ethical standards may require acknowledgement of situations where it may not be possible to obtain fully informed consent due to contextual realities such as a climate of fear. In such circumstances a more nuanced view of consent may be appropriate with alternative guarantees of ethical research practice. In this regard the biomedical field could learn from the work of social scientists and anthropologists (Harper, 2007). The possibility of negotiated consent involving collaboration with the community and flexibility as to what consent “looks like” by research ethics review boards (i.e. not dependent upon signing a form), is believed to offer potential for more

culturally appropriate and robust consent processes. This more nuanced view is felt to be suitable for emergencies.

Community mistrust

Managing paranoia or mistrust over the way information collected during research is to be used requires careful handling in communities exposed to conflict. Craig *et al* identify that it can be necessary to equip researchers with tools to respond to strong feelings or angry reactions to research by participants and the local community (Craig *et al.*, 2000). This is particularly important in mental health research where stigma and discrimination are common, reinforcing the importance of a trained research team (Goodhand, 2000).

Promoting trust requires active communication and mutual understanding between researchers and the community. At a minimum communities should be consulted during the research planning stage, on an ad-hoc basis whilst the research is conducted, and provided with research findings in an appropriate format and timely manner (Collogan *et al.*, 2004; Schopper *et al.*, 2009). In addition, care should be taken to distinguish between routine care and participating in research in order to avoid therapeutic misconception (Appelbaum *et al.*, 1982). These measures are essential to reducing community misperceptions about research.

In the case study community mistrust was an important ethical concern. When going to homes in the community researchers were confronted with families fearful for their safety. On rare occasions researcher safety was threatened when rumours of threats against the research team spread as a result of questions relating to exposure to violence. With families active in the insurgency these questions were interpreted as collecting information to pass onto intelligence authorities, carrying implications for participant recruitment and increasing risk to the research team perceived as acting at the behest of the government.

These issues were managed by (a) integrating local community members into the research team, and (b) suspending research activities whilst mistrust was addressed by the study lead, a precaution designed to ensure researcher safety. The locally based study lead and researchers ensured an “ear to the ground”, seeking to anticipate community mistrust and respond accordingly. In the post-conflict study setting the integration of local researchers increased the credibility of claims that research was not collecting information for intelligence authorities.

During the suspension of research the study lead conducted repeated research information events with those making threats. This involved detailing the broad study topic, what participation entailed, how information would be used including protection of participant

anonymity, and that personal information would remain confidential to the research team. Opportunities for questions and discussion were provided. In addition, as identified above, researchers conducted repeat verbal consent, reinforcing key principles of voluntary participation and protection of participant rights. The presentation and re-presentation of information sought to counter community rumours and mistrust, re-engaging participants and the wider community in research. This strategy proved effective in this context. Therefore, the response to this ethical issue was locally specific, developed by embedded researchers in accordance with local cultural norms.

Risk to the research team

Research investigating sensitive topics need to assess the potential risks research poses to both participants and researchers (Economic and Social Research Council, 2015). This is equally important when researchers are working in sensitive contexts such as emergencies. Examples of safety risks include threats to physical safety; risk of psychological distress; potential for accusations of improper behaviour; and increased exposure to everyday risks such as infectious illnesses or accidents (Craig *et al.*, 2000).

Risk assessments are an integral element of developing a research protocol, including budgeting and planning to manage potential risks to participants and researchers (Call *et al.*, 2012). Managing risks to the research team is essential to ethical research which is dependent upon researcher competency to practice (Juntunen, 2011), including addressing stress and fear. Guidelines to support development of protocols to manage researcher safety have been suggested. These include steps to assess the situation, identifying and responding to threats, and developing preventative strategies and follow-up procedures (Paterson *et al.*, 1999), including addressing potential psychological harm (Dickson-Swift *et al.*, 2007). Psychological support referral pathways for research teams are essential when conducting research with populations exposed to violence or trauma, or where upsetting or difficult disclosure may arise. In addition, in emergencies processes for consulting local security experts (World Health Organisation (WHO), 2003) as well as those coordinating the emergency response are also essential.

Recognising the potential emotional and psychological impacts of discussing sensitive topics is important to preventing researcher burnout (Kinard, 1996). Mental health and trauma-related research may lead to researchers experiencing vicarious trauma: traumatisation through the act of bearing witness to the suffering of interviewees (McCann and Pearlman, 1990). Equally, failure to ask these questions results in an incomplete picture of mental

health status and may miss cases of abuse or degradation, hence can be viewed as unethical not to ask.

Adequate attention to personal and psychological safety of researchers requires specialist training of research teams that emphasises strategies for researcher self-care, supervision and support (Juntunen, 2011). Such training addresses the concerns of Dunn (1991) that “the novice researcher is usually taught that the research process is orderly and straightforward” (p. 388). They also offer an opportunity to bridge the gap between procedural ethics and ethics in practice, engaging with potential real-world difficulties that may arise in research conduct. Training therefore promotes a more nuanced approach to the way in which specific ethical challenges will be managed.

In the case study support was provided through daily meetings between the study lead and the research team. In these meetings the research team detailed the day’s field activities and reported any events that had happened. These collective meetings provided opportunities for peer support and raising concerns. They also ensured the study lead was aware of field challenges and could monitor researchers’ psychological wellbeing. In addition to these daily meetings the study lead was available via mobile phone for immediate contact in the cases of crisis.

One crisis arose during the case study where military raids of homes occurred whilst interviews were being conducted. This resulted in research team members becoming fearful for their safety, compounded by high profile insurgent activity targeting women and health workers. These threats to safety were managed through pausing the research for one week so as not to coincide with activities being targeted by insurgents. Given the similarity of the study to activities being targeted –a health campaign conducting house-to-house calls – this was felt to be appropriate, with research resuming only after the other activities had ceased.

This highlights the ethical duty to be flexible in the research schedule, suspending research to not coincide with activities of a similar nature being targeted in order to protect both researchers and participants. This carries ethical implications when projects are externally funded as hostile activity may prevent a study being concluded, including withdrawing when a mental health intervention is ongoing which may leave participants at risk, and the ethical implications of perceived wasted financial resources. Despite the potential risks it is important that mental health research with groups or in settings perceived high risk is conducted (Iltis *et al.*, 2013) which requires robust risk management. This necessitates an approach to ethical research practice that responds to risks inherent to different contexts,

employing culturally appropriate strategies to address and mitigate risk to ensure that research adheres to the principle “do no harm”. Sharing strategies for responding to risk in different contexts will promote a moral conversation to identify best-practice approaches to minimising risks.

Research ethics in emergencies: arguing for specified normative frameworks

Specific approaches and epistemological positions for responding to ethical issues encountered in the conduct of global mental health research have been proposed by various authors. These will be considered and suggestions made for incorporating greater empirical ethical reflection to support ethical research conduct in post-conflict and emergency settings. We argue for the development of a nuanced ethical discourse on research practice in emergencies that responds to specific issues that arise in certain types of studies or in particular contexts.

Siriwardhana *et al.* (2013) propose a post-study ethical audit to evaluate researcher integrity and decision making that could have compromised the ethical grounding of research. What this audit would entail, who would be involved and the degree to which this would deliver genuine critical reflection upon ethical issues requires further elaboration. However, this proposal could form a useful addition to the research cycle, promoting reflection upon management of ethical issues and evaluating procedural ethics against in-practice realities. This process offers the opportunity to stimulate wider learning by researchers, ethical review committees, and potentially communities.

An addition to the post-study audit could be pre-study reflection to promote preparedness. This would differ from existing approaches to research planning which focus upon procedural ethics, instead encouraging active engagement and reflection upon in-practice ethical challenges that may be encountered. This process should include the community to identify ethical considerations relating to context such as adherence to local cultural or religious norms. Open engagement with potential ethical issues is anticipated to increase research team preparation for in-practice challenges that may be obscured by a purely procedural approach to research planning.

The Ethical, Cultural and Social Program for Global Health proposes addressing issues “up-stream” in the research process through Consultation Services in Research Ethics (Lavery *et al.*, 2013). These committees of experts in research ethics at academic bioethics centres provide advice and guidance about ethical issues that arise in the design and conduct of research. In this process the role of local experts is privileged, and the overarching aim is to

build upon specific cases to propose solutions to cross-cutting issues. Such services can stimulate moral conversation and address issues of capacity in research ethics review. However, they remain abstracted from research-in-practice, and their success is largely predicated upon their ability to overcome the “double-bind” where risks and the potential for exploitation are recognised, but practice suggestions as to how these can be overcome are unavailable to the reviewer (Zwi *et al.*, 2006). Therefore, integration of the community into this process to promote knowledge about the way ethical principles are balanced in different settings is recommended, moving away from expert academic driven strategies and towards an ethos of co-learning.

Ittis *et al.* (2013) identify considerations relevant to risk communication and management to support the ethical conduct of mental health research. They focus upon both procedural management and communication of risks in ethical approval applications, as well as supporting active engagement with in-practice ethics through adequate training and preparation of researchers. They call for further research into risk communication and management, learning from critiques of research information, ensuring research information and consent processes accurately portray study risks and benefits and do not unduly bias views of the research. They cite the ethical imperative of justice as placing the duty upon the research community to “design ethically and scientifically sound research that does not ignore populations or kinds of research merely because of the difficulties involved” (Ittis *et al.*, 2013, p. 1364), a call relevant to mental health research in emergencies. Whilst a useful proposal that engages with the procedural / in—practice disjunction, we argued that the focus upon risk of harm should be balanced against potential benefit, and should be extended to include risks to researchers.

Addressing the ethical issue of who and what are studied and why has recently been considered through a social justice lens. Feminist approaches have been suggested as a framework for health research that attends to social justice, emphasising multiple and complex structures of inequality and power (Rogers and Kelly, 2011). These acknowledge the impact of keeping those affected by multiple forms of oppression on the margins of society, health, and research.

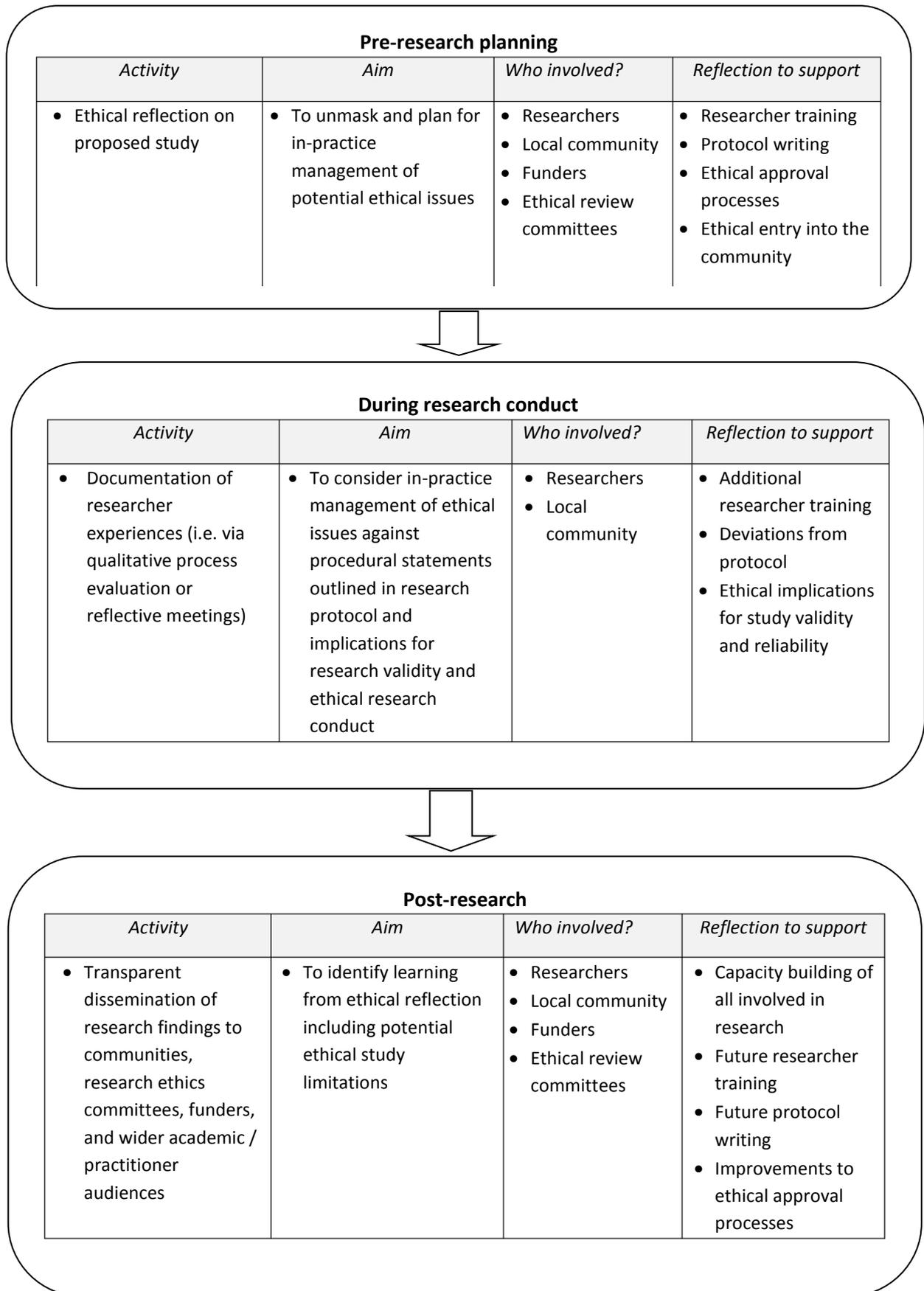
Rogers and Kelly highlight that researchers’ involvement in the subjective worlds of participants can reveal knowledge related to health disparities and systemic inequalities. This approach offers a useful critique of existing normative frameworks that can silence moral discourses emerging from local communities. It attends to research-in-practice,

foregrounding power, discrimination and social justice; as well as procedural ethical review, where Western norms and review processes frequently take priority over LMIC (Emanuel *et al.*, 2004) or informal community processes. Viewed through a social justice lens the extent to which normative frameworks of ethical research reify structures of inequality and power is emphasised. Adopting this approach to ethical research offers one response, recognising the non-absolute nature of ethical decision making and that norms are subject to contextual application (Richardson, 1990).

Each of these approaches emphasise ethical issues raised by conducting global health research. These issues are necessarily magnified emergencies in which problems of social justice and inequity are exacerbated, structures of dependency are prevalent, and existing family, community and societal support are disrupted (Inter-Agency Standing Committee (IASC), 2007). In such settings the imperative to ensure research is conducted ethically is paramount. It has been argued that the ethical conduct of research does not equate to importing ethical norms and standards of practice that may be inappropriate to culture and context. Ethical research practice is nuanced, premised largely upon researcher training, experience and above all integrity. To recognise this and to engage with the ethical issues raised by conducting mental health research in complex settings, moving away from rose-tinted protocols and towards addressing real world in-practice challenges, is a much needed bold step the research community must be prepared to take.

We propose that this process requires empirical ethical reflection. This entails active engagement with ethical issues procedurally and in-practice that is ongoing throughout the research process – from inception to dissemination. This should include pre-research planning involving local communities alongside researchers that seeks to unmask potential ethical issues that may arise to enhance protocol writing, researcher training and study preparedness. In research conduct and dissemination efforts should be made to capture and document researchers' experiences of applying ethics in practice, revealing potential deviations from what was outlined in procedural documents. Findings from this process should be used to consider potential implications for the validity and reliability of research findings. Learning from these processes should be disseminated, recognising that reliable research is a product of ethically sound research planning and conduct and that researcher's should report on all study limitations, including those that relate to ethics. This broad approach offers sufficient flexibility to integrate and address the shortcomings of the above proposals.

Figure 2: Aspects to the empirical ethical reflection model



We illustrate this proposed with the hypothetical example of disclosure of research funding. This hypothetical research is conducted in a post-conflict setting where military presence remains, including indiscriminate arrests, causing community mistrust and paranoia. Funding comes from a government / private funder collaboration known as GHR, which is managed and distributed by an internationally recognised charity, REGA. The research is conducted by a consortium involving a local NGO and international Universities and Health Organisations.

Funders require their sponsorship be disclosed to participants. Direct reference to GHR is therefore inserted into procedural documents (protocol and participant information sheet). This is discussed at a meeting prior to submission for ethical approval, and following advice from the local NGO that the funder is viewed with suspicion due to perceived involvement of the Government in the recent conflict, this is amended, stating “funding for this study comes via REGA”. This approach is discussed with local community representatives who feedback that the study would be more readily accepted through reference to a local body, such as the NGO implementing the research. Therefore, to strengthen local accountability further reference is made to the study being led by a recognised local NGO. This balanced approach is approved by ethical reviewers and research funders, who recognise the value of this compromise in the local setting.

This approach is discussed at field researcher training, and emphasis placed upon following the text in the information sheet. The question is raised as to whether the researchers should disclose the funder is GHR if participants ask the question. A detailed discussion sought to balance the need for transparency with the potential risk to researchers and the study if full disclosure were to lead to hostility towards the research. The compromise agreed to respond to the question by identifying the funder as “a western collaborative involving government and private funders”. This approach was recorded in notes about the training which formed one element of the process evaluation. It was applied by field researchers and found to be effective. However, in field researcher supervision it was discovered that those who asked for additional detail on study funding were more likely to decline participation than those who did not. This was documented in supervision records as part of the process evaluation. No further observations or issues relating to funder disclosure were raised during research conduct.

At the end of the research a reflective meeting was held, involving all research investigators and field researchers. At this meeting the approach taken to funding disclosure was critically

reflected upon, revisiting procedural documents and in-practice findings from the process evaluation which led to identifying competing ethical duties of accountability, transparency, and researcher safety. The higher levels of non-participation amongst those more aware of the funding source raised whether the research had misled participants. It was concluded the rationale for not fully disclosing the funding source was an overriding ethical duty to uphold the principle of “do no harm”. Furthermore, the information provided to participants was deemed accurate; it was just not as detailed as it could have been. It was also observed that the paranoia and mistrust of GHR was based upon misleading media coverage, and therefore difficult for researchers to counter. Finally, all agreed that the ethical duty of conducting needed research was implicated, with providing much needed intervention services and long-term community benefit through capacity building of local health workers and researchers justifying the compromise taken in this instance. This procedural / in-practice learning was documented along with other empirical ethical reflections in a short report to funders and ethical review committees who had approved the study; and was reported in more detail through a conference paper reproduced as a reflective article published in a peer-reviewed international journal.

As this hypothetical example illustrates, much of the in-practice ethical decisions are aspects of day-to-day research management. However, when identified as ethical issues and reflected upon from an ethical perspective the rationale and limitations behind ethical decisions is rendered explicit. The benefits of empirical ethical reflection therefore become clear: active reflection upon decisions relating to research conduct that carry ethical implications increases transparency and builds evidence of the way ethical principles are flexibly applied in specific settings.

Whilst this process requires additional resources and potentially time for the conduct of studies, it is argued that these are acceptable to achieve ethically robust research practice. A key limitation to these approaches when conducted as internal self-monitoring exercises is the willingness of researchers to actively reflect and identify potential limitations to ethical research practice. However, it must be observed that principles of transparency and critical reflection are central to all research conduct, therefore it is felt that this limitation could be overcome.

Conclusion

Some key ethical considerations when conducting research in emergencies have been highlighted through discussion of a relevant mental health case study. These are in no way

unique to the context in which the case-study was conducted, although the potential risks were higher than could be expected in peacetime. We suggest one response to ensuring ethical research practice is for researchers to engage in empirical ethical reflection entailing engagement with research practice on both descriptive and normative planes. Documenting and reflecting upon experience aims to promote the emergence of a moral discourse around the way ethical principles can be implemented and promoted in research conducted across cultural contexts.

As demonstrated in the case study, reflection upon empirical evidence of research practice can stimulate important ethical considerations. Through examination of research practice empirical ethics approaches aid critical consideration of background assumptions of moral principles, such as informed consent (Molewijk *et al.*, 2003). Given the range of ethical concerns raised in this paper, it is suggested that interrogation of research practice through an empirical ethics lens could support better understanding and management of the ethical implications integral to conducting mental health research in post-conflict and by extension emergency settings. To render explicit the practice of attaining ethical research in a given context will enhance learning. This recognises that “the effort to ensure that research is conducted ethically [necessitates] a thoughtful process of balancing ethical considerations [which] can be as important as any particular judgement” (Emanuel *et al.*, 2004, p. 936). Therefore, we call for moving away from rigid implementation of ethical principles and towards appreciating the fluid processes of ethical research in practice. This is not to reject existing normative frameworks, but to call for a considered approach to their application that recognises that ethical research conduct is not a product of adherence to a set of rules, but of a mutually respectful encounter.

Importantly, most frequently missing from research reports are the experiences of those on the ground, “too little attention is given to documenting the process of carrying out research” (Kinard, 1996, p. 69). We call for increased attention to documenting this process, building empirical evidence that critically considers the ethical difficulties in undertaking mental health research in complex contexts and with complex populations. In this way, global initiatives can contribute to development of an approach to applied ethics that responds appropriately to the specific issues raised in practice and promotes ethical standards to underpin research practice in emergencies.

References

- Ahmad, A. and Syed Maum, M. (2010) 'Philanthropic Misconception', *Asian Bioethics Review*, 2(2), pp. 154-161.
- Appelbaum, P. S., Roth, L. H. and Lidz, C. (1982) 'The therapeutic misconception: Informed consent in psychiatric research', *International Journal of Law and Psychiatry*, 5(3-4), pp. 319-329.
- Benatar, S. R., Daar, A. S. and Singer, P. A. (2005) 'Global health challenges: The need for an expanded discourse on bioethics', *PLoS Medicine*, 2(7), pp. 587-589.
- Bernal, G. and Sáez-Santiago, E. (2006) 'Culturally centered psychosocial interventions', *Journal of Community Psychology*, 34(2), pp. 121-132.
- Brown, N., Boulton, M., Lewis, G. and A., W. (2004) 'Social Science Research Ethics in Developing countries and contexts', *ESRC Research Ethics Framework Discussion Paper*, 3(2). Available at: https://www.york.ac.uk/res/ref/docs/REFpaper3_v2.pdf. (Accessed: 10.02.2014).
- Call, J. A., Pfefferbaum, B., Jenuwine, M. J. and Flynn, B. W. (2012) 'Practical legal and ethical considerations for the provision of acute disaster mental health services', *Psychiatry*, 75(4), pp. 305-322.
- Chambliss, D. F. (1993) 'Is Bioethics Irrelevant?', *Contemporary Sociology*, 25(5), pp. 649-652.
- Citraningtyas, T., Macdonald, E. and Herrman, H. (2010) 'A Second Tsunami? The Ethics of Coming into Communities following Disaster', *Asian Bioethics Review*, 2(2), pp. 108-123.
- Collogan, L. K., Tuma, F., Dolan-Sewell, R., Borja, S. and Fleischman, A. R. (2004) 'Ethical issues pertaining to research in the aftermath of disaster', *Journal of Traumatic Stress*, 17(5), pp. 363-372.
- Council for International Organisations of Medical Sciences (CIOMS) (2016) *International ethical guidelines for health-related research involving humans*. Geneva: CIOMS. [Online]. Available at: <https://cioms.ch/new-cioms-ethical-guidelines-for-health-related-research-involving-humans/>. (Accessed: 12.02.2104)
- Craig, G., Corden, A. and Thornton, P. (2000) 'Safety in Social Research', *Social Research Update*, (20). <http://sru.soc.surrey.ac.uk/SRU29.html>. Available at: <http://sru.soc.surrey.ac.uk/SRU29.html> (Accessed: 15.05.2013).

Dickson-Swift, V., James, E. L., Kippen, S. and Liamputtong, P. (2007) 'Doing sensitive research: what challenges do qualitative researchers face?', *Qualitative Research*, 7(3), pp. 327-353.

Dunn, L. (1991) 'Research alert! Qualitative research may be hazardous to your health!', *Qualitative Health Research*, 1(3), pp. 388-392.

Economic and Social Research Council (2015) *Framework for Research Ethics*. Available at: <http://www.esrc.ac.uk/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015/> - accessed 03.03.2017: (Accessed: 03.03.2017).

Emanuel, E. J., Wendler, D., Killen, J. and Grady, C. (2004) 'What makes clinical research in developing countries ethical? The benchmarks of ethical research', *Journal of Infectious Diseases*, 189(5), pp. 930-937.

Emerson, C. I., Upshur, R. E. G. and Daar, A. S. (2009) 'Empirical bioethics research in the developing world: when the 'is' is close to an 'ought'', *The American Journal Of Bioethics*, 9(6-7), pp. 101-103.

Faden, R. R., Beauchamp, T. L. and King, N. M. P. (1986) *A history and theory of informed consent*. . New York: Oxford University Press [electronic book].

Fitzgerald, D. W., Marotte, C., Verdier, R. I., Johnson, W. D. and Pape, J. W. (2002) 'Comprehension during informed consent in a less-developed country', *Lancet*, 360(9342), pp. 1301-1302.

Frith, L. (2012) 'Symbiotic empirical ethics: a practical methodology', *Bioethics*, 26(4), pp. 198-206.

Goodhand, J. (2000) 'Research in conflict zones: ethics and accountability', *Forced Migration Review*, 8, pp. 12-15.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.

Harper, I. (2007) 'Translating ethics: Researching public health and medical practices in Nepal', *Social Science & Medicine*, 65(11), pp. 2235-2247.

Hastings Centre (2004) 'Moral standards for research in developing countries - From "reasonable availability" to "fair benefits"', *Hastings Center Report*, 34, pp. 17-27.

Homan, R. (1991) *The ethics of social research*. Harlow: Longmans.

Hynes, T. (2003) *The issue of 'trust' or 'mistrust' in research with refugees: choices, caveats and considerations for researchers*. Geneva: UNHCR. [Online]. Available at: <http://www.unhcr.org/3fcb5cee1.html>. (Accessed: 16.01.2014).

Iltis, A. S., Misra, S., Dunn, L. B., Brown, G. K., Campbell, A., Earll, S. A., Glowinski, A., Hadley, W. B., Pies, R. and Dubois, J. M. (2013) 'Addressing risks to advance mental health research', *JAMA Psychiatry*, 70(12), pp. 1363-1371.

Inter-Agency Standing Committee (IASC) (2007) *IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings*. Geneva. [Online]. Available at: http://www.who.int/mental_health/emergencies/guidelines_iasc_mental_health_psychosocial_june_2007.pdf.

Juntunen, C. L. (2011) 'Reflections on the opportunities and challenges of disaster response', *Counseling Psychologist*, 39(8), pp. 1182-1192.

Kinard, E. M. (1996) 'Conducting research on child maltreatment: Effects on researchers', *Violence and Victims*, 11(1), pp. 65-70.

Kottow, M. H. (2002) 'Who Is My Brother's Keeper?', *Journal of Medical Ethics*, (1), pp. 24-27.

Lavery, J. V., Green, S. K., Bandewar, S. V. S., Bhan, A., Daar, A., Emerson, C. I., Masum, H., Randazzo, F. M., Singh, J. A., Upshur, R. E. G. and Singer, P. A. (2013) 'Addressing Ethical, Social, and Cultural Issues in Global Health Research', *PLoS Neglected Tropical Diseases*, 7(8), pp. e2227-e2232.

Leaning, J. (2001) 'Ethics of research in refugee populations', *Lancet*, 357(9266), pp. 1432-3.

McCann, L. and Pearlman, L. (1990) 'Vicarious traumatization: A framework for understanding the psychological effects of working with victims', *Journal of Traumatic Stress*, 3(1), pp. 131-149.

Medical Research Council (MRC) (2004) *MRC Ethics Guide: Research involving human participants in developing societies*. [Online]. Available at: <http://www.mrc.ac.uk/news-events/publications/research-involving-human-participants-in-developing-societies/> (Accessed: 12.02.2014).

Milford, C., Wassenaar, D. and Slack, C. (2006) 'Resources and Needs of Research Ethics Committees in Africa: Preparations for HIV Vaccine Trials', *IRB: Ethics & Human Research*, 28(2), pp. 1-9.

Molewijk, A. C., Stiggelbout, A. M., Otten, W., Dupuis, H. M. and Kievit, J. (2003) 'Implicit normativity in evidence-based medicine: a plea for integrated empirical ethics research', *Health Care Analysis*, 11(1), pp. 69-92.

Paterson, B. L., Gregory, D. and Thorne, S. (1999) 'A protocol for researcher safety', *Qualitative Health Research*, 9(2), pp. 259-269.

Perrey, C., Wassenaar, D., Gilchrist, S. and Ivanoff, B. (2009) 'Ethical issues in medical research in the developing world: a report on a meeting organised by fondation merieux', *Developing World Bioethics*, 9(2), pp. 88-96.

Richardson, H. S. (1990) 'Specifying Norms as a Way to Resolve Concrete Ethical Problems', *Philosophy & Public Affairs*, 19(4), pp. 279-310.

Rogers, J. and Kelly, U. A. (2011) 'Feminist intersectionality: Bringing social justice to health disparities research', *Nursing Ethics*, 18(3), pp. 397-407.

Rorty, R. (1993) 'Human Rights, Rationality, and Sentimentality', in Slate, S. and Hurley, S. (eds.) *On Human Rights*. New York: Basic Books.

Schopper, D., Upshur, R., Matthys, F., Singh, J. A., Bandewar, S. S., Ahmad, A. and van Dongen, E. (2009) 'Research Ethics Review in Humanitarian Contexts: The Experience of the Independent Ethics Review Board of Médecins Sans Frontières', *PLoS Medicine*, 6(7), pp. 1-6.

Sharan, P., Levav, I., Olifson, S., de Francisco, A. and Saxena, S. (2007) *Research capacity for mental health in low- and middle-income countries: results of a mapping project*. Geneva. [Online]. Available at: http://www.who.int/mental_health/MHRC_FullText.pdf (Accessed: 15.03.2013).

Siriwardhana, C., Adikari, A., Jayaweera, K. and Sumathipala, A. (2013) 'Ethical challenges in mental health research among internally displaced people: Ethical theory and research implementation', *BMC Medical Ethics*, 14(1), pp. 13-20.

Swift, A. (2006) *Political philosophy: a beginners' guide for students and politicians*. 2nd rev. and expanded edn. Cambridge: Polity.

Tekola, F., Davey, G., Farsides, B., Newport, M. J., Adeyemo, A., Rotimi, C. N. and Bull, S. J. (2009) 'Tailoring consent to context: Designing an appropriate consent process for a biomedical study in a low income setting', *PLoS Neglected Tropical Diseases*, 3(7), pp. e482-e489.

The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research (1979) *Ethical Principles and Guidelines for the Protection of Human Subjects of Research (The Belmont Report)*. Department of Health and Human Services. [Online]. Available at: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>. (Accessed. 12.02.2014).

Thornicroft, G., Cooper, S., Bortel, T. V., Kakuma, R. and Lund, C. (2012) 'Capacity building in global mental health research', *Harvard Review Of Psychiatry*, 20(1), pp. 13-24.

Tol, W. A., Barbui, C., Galappatti, A., Silove, D., Betancourt, T. S., Souza, R., Golaz, A. and van Ommeren, M. (2011) 'Mental health and psychosocial support in humanitarian settings: linking practice and research', *Lancet*, 378, pp. 1581-1591.

United Nations General Assembly (1948) 'Universal Declaration on Human Rights' *Resolution 217A*. Available at: <http://www.un.org/en/universal-declaration-human-rights/> (Accessed: 12.02.2014).

World Health Organisation (2013) *Building back better: sustainable mental health care after emergencies*. Geneva. [Online]. Available at: http://www.who.int/mental_health/emergencies/building_back_better/en/ (Accessed: 12.02.2014).

World Health Organisation (WHO) (2003) *WHO Ethical and Safety Recommendations for Interviewing Trafficked Women*. Geneva: WHO. [Online]. Available at: <http://www.who.int/gender/documents/en/final%20recommendations%2023%20oct.pdf>. (Accessed: 03.02.2014)

World Medical Association (2013 [1964]) *WMA Declaration of Helsinki: ethical principles for medical research involving human subjects*. Available at: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/> (Accessed: 12.02.2014).

Zwi, A. B., Grove, N. J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D. and Tarantola, D. (2006) 'Placing ethics in the centre: negotiating new spaces for ethical research in conflict situations', *Global Public Health*, 1(3), pp. 264-277.

DRAWING FROM THE LITERATURE REVIEW AND CASE STUDY TO SET UP THIS RESEARCH

This section connects the two previous papers *Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates* (hereafter: “literature review paper”) (Chiumento *et al.*, 2017a), and *Managing ethical challenges to mental health research in post-conflict settings* (hereafter “case study paper”) (Chiumento *et al.*, 2016) with the rest of this thesis. It does this by situating these papers in the context of the study, advancing an argument for how this thesis responds to gaps identified in the literature.

Following this a description of how wider literature continues to be drawn upon throughout this study is provided, situating the literature review as a process ongoing throughout research conduct. Finally, the strengths and limitations of this approach to the literature review is offered, and reflections on what has been learnt from this process shared.

Situating the literature review and case study in the context of this research

A literature review is conducted to justify the research topic, design, and methodology (Hart, 1998) by critically reviewing what is known about a given topic and identifying the value of additional research in the context of identified gaps (Murcott, 1997 cited in Silverman, 2013, p. 343). Conducting a literature review facilitates an assessment and critique of existing literature to set the stage for a given study, and provides an opportunity to enter into a dialogue with other researchers about a specific topic. It also supports development of specialist skills in conducting literature searches, reading the literature critically, and bringing together literature to develop arguments. It is argued that the literature review in this thesis, whilst circumscribed in its remit, achieved all of these objectives. Moreover, a description is provided of how the literature review is integrated as an ongoing process central to the development of each stage of this research.

The topic under investigation in the literature review was circumscribed to the identification and operationalisation of ethical principles applicable to mental health and psychosocial support research in emergency settings. As has been discussed in the introduction to the literature review, it was conducted to inform development of recommendations for the ethical conduct of mental health and psychosocial research in emergencies. The literature review paper moved beyond the limited remit of the literature review for developing the recommendations to critically engage with the literature and identify gaps in existing

knowledge to be addressed through further study. Importantly, the literature review moved beyond the identification and operationalisation of ethical principles to reveal the tensions and challenges when applying ethical principles to practice. This area of applying principles to practice is further explored through the case study paper, complementing the literature review by empirically investigating how researcher's operationalise ethical principles in a post-conflict setting.

Therefore, the literature review paper raises questions about procedural ethics, notably the role of ethical review boards; as well as revealing tensions surrounding how to operationalise principles to practice, for example what constitutes "fair benefits", or how to operationalise informed consent (Chiumento *et al.*, 2017a). Underpinning these debates was a systemic tension between procedural ethics on the one hand, and in-practice ethics on the other, signifying a gap in current knowledge. Adding to the knowledge in this area became a central aim of this thesis research, developing research questions to explore researchers' understanding and experiences of research ethics when conducting mental health research in post-conflict settings, exploring this topic from dual procedural and in-practice ethics perspectives. Alongside this the case study paper provided a working example of what can be learnt through empirical investigation of researchers' management of ethical issues in a situated post-conflict context. The conduct of this case study was important for its focussed attention on mental health research in post-conflict settings, demonstrating the ethical specificities that arise, and therefore confirming the utility of exploring this question in-depth through further research. Furthermore, the case study paper also provided an opportunity to develop a theoretical position for managing the tension between procedural and in-practice ethics through the proposed "empirical ethical reflection" approach (Chiumento *et al.*, 2017a). This approach is revisited in the discussion chapter of this thesis in light of research findings, and forms an important element of theory building in relation to this research topic.

Therefore, in combination, the literature review and case study paper's provide justification for the research questions and methodology (Hart, 1998) employed in this thesis research. Importantly, these papers are applied to advance an argument about a distinctive stance (Bryman, 2008) in relation to research ethics in mental health research in emergencies, calling for increased attention to a situated approach to ethics and prioritising the views of researchers to understand ethical research practice in context. This approach and the focus of this research recognises that to understand how research ethics operates in everyday

research practice requires engagement with the detailed, contextualised sites of practice and practitioners in situated contexts (Hammersley, 2009; 2015).

Literature review as a process ongoing throughout research conduct

Traditionally a thesis literature review chapter evolves during development of a thesis, updated throughout research conduct and finalised at the end of the study (Silverman, 2013). However, as Wolcott (1990) has noted, what is important in a literature review is not a knowledge “dump”, but demonstration of an ability to “draw upon the literature selectively and appropriately as needed” (p.17), particularly during the course of data analysis and presentation of research findings. This is the approach adopted for this research. Whilst the literature review and case study acted as springboards to the research by ensuring familiarity with current positions and debates about research ethics in mental health and psychosocial support research in emergencies, I remained cognisant that these debates continued beyond the literature included in the review and drawn upon for the case study. Consequently, as research progressed a continuous process of reading widely across disciplines (biomedicine, sociology, bioethics, and philosophy) was conducted, engaging with methodological, empirical, and theoretical literature. During the development of specific papers this reading became directed to advance potential ways to understand and interpret research findings. Consequently, whilst the literature review paper was a finite step in the research process, the principle of continuous engagement with literature relevant to the topic of study was actively applied, recognising the importance of a strong grounding in existing literature in order to situate advances in knowledge as a result of this study.

Tools to remain up-to-date on literature of relevance to my field of study included subscribing to e-mail alerts from key journals such as Biomedical Central’s “Medical Ethics” and “Conflict and health”, bioethical mailing lists such as “Bioethics”, Global Mental Health mailing lists such as the “Movement for Global Mental Health”, and the IASC-RG mailing list which includes information about policy and academic publications relevant to the field of mental health and psychosocial support in emergencies. Additionally, maintaining a profile on the social media platform Twitter (@achiumento) ensured topical debates on research ethics and mental health and psychosocial support research in emergencies could be followed and engaged with. These tools were complemented by the application of skills in conducting literature searches developed through the conduct of the literature review, which also increased a broad familiarity with sources to consult to remain abreast of

developments in the field. Attendance at relevant conferences and workshops¹⁰, as well as active networks with colleagues working in the field of mental health and psychosocial support research in emergencies and low and middle-income country settings, all offered informal connections to literature of relevance to the field. Finally, peer review feedback on papers submitted for publication included suggestions for strengthening papers through the addition of specific literature – notably occurring in relation to the paper on qualitative interviewing with interpreters (Chiumento *et al.*, 2017b); or to include/expand theoretical models such as in the case study paper.

Strengths, limitations and reflections upon the approach taken

The literature review provided an opportunity to cement skills in conducting literature searches, reading critically, and drawing selectively upon the literature to advance arguments. In the context of this study the review of the literature was an important first step in becoming familiar with current debates and areas of tension which this research could engage with and agitate against to address pressing questions facing the field (Silverman, 2013). Beyond this, active engagement with literature in response to emerging research results or the development of methodological approaches to conducting research ensured that the foundation established through conduct of the literature review continued to be built upon. Finally, through development of the proposed “empirical ethical reflection” approach to managing the gap between procedural and in-practice ethics, the case study paper situates early thinking in relation to the topic under study, and offers a model to be built upon or critiqued in light of research findings.

The approach adopted is not without limitations. Traditionally the literature review is an evolving element of a thesis that is updated and refined through the conduct of a study and in response to research findings. This approach has the advantage of providing an opportunity to integrate and critically assess all literature on a topic in one concise thesis chapter. Conversely, the approach taken here is more limited due to being finalised early in the conduct of this study. For a study such as this a literature review chapter may have explored for example literature from varying disciplines (philosophical, bioethical, sociological, anthropological, and biomedical) that addressed the management of ethical issues in research conduct. However, it is notable that whilst the content of the literature

¹⁰ This included for example participation in the two ESRC Conferences (including presenting on my experience of procedural research ethics at the annual conference in my third year); participation in a 2 day colloquium “Have we become too ethical?”; attendance at a 1 day workshop on “Social research in conflict affected areas”; and twice participating the bi-annual Oxford Global Health and Bioethics Conference, including presenting research findings at the 2017 conference.

review paper is circumscribed, it does include contributions from a range of disciplinary perspectives. Furthermore, the skills in critically reviewing and assessing literature from varying disciplines have continued to be applied and refined as this study was conducted. As has been described above and is demonstrated in the rest of this thesis, varying perspectives are drawn upon from diverse bodies of literature, applied to interpret and understand research findings, thereby demonstrating my ongoing engagement with the literature relevant to this research.

Therefore, whilst departing from the “traditional” approach to a literature review for the purpose of a thesis, it is felt that the literature review and case study papers fully demonstrate evidence of knowledge acquisition; development of skills in literature searching, synthesising, and developing an argument; and provide a firm justification for the research presented in this thesis.

Conclusion

This section has drawn together the role of the literature review and case study papers in the context of this research. It has provided an explanation for the relevance of the literature review and case study papers for setting up this research. Limitations to the approach adopted are acknowledged, and an explanation for why these limitations are deemed acceptable advanced. The role of these papers in supporting refinement of the research questions, design, and methods is provided in the next chapter on epistemology, methodology, and ethical considerations.

References

Bryman, A. (2008) *Social research methods*. 3rd edn. Oxford: Oxford University Press.

Chiumento, A., Khan, M. N., Frith, L. and Rahman, A. (2016) 'Managing ethical challenges to mental health research in post-conflict settings.', *Developing World Bioethics*, 16(1), pp. 15-28.

Chiumento, A., Rahman, A., Frith, L., Snider, L. and Tol, W. A. (2017a) 'Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates', *Globalization And Health*, 13(1), pp. 8-26.

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017b) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online early view, pp. 1-19.

Hammersley, M. (2009) 'Against the ethicists: On the evils of ethical regulation', *International Journal of Social Research Methodology*, 12(3), pp. 211-225.

Hammersley, M. (2015) 'On ethical principles for social research', *International Journal of Social Research Methodology*, 18(4), pp. 433-449.

Hart, C. (1998) *Doing a literature review: releasing the social science research imagination*. London: SAGE Publications.

Murcott, A. (1997) 'The PhD: some informal notes', School of Health and Social Care. South Bank University, London.

Silverman, D. (2013) *Doing qualitative research*. 4th edn. London: SAGE Publications.

Wolcott, H. F. (1990) *Writing up qualitative research*. Newbury Park, California: SAGE Publications.

EPISTEMOLOGY, METHODOLOGY, AND ETHICAL CONSIDERATIONS

Introduction

This chapter outlines the qualitative approach comprising the research epistemology, methods, and research procedures, including ethical considerations. These have been chosen as those most appropriate for addressing the gaps identified in the literature review and case study papers, which brought to the fore a focus upon the disjuncture between procedural and in-practice ethics which this study seeks to illuminate.

The chapter proceeds with an overview of the qualitative research approach and the role of qualitative research in empirical ethics. Following this is a brief introduction to the interpretivist epistemology and a description of the phenomenological orientation adopted for this study is provided, with a focus upon the phenomenological methodology of Schutz. These discussions are contextualised to how these epistemological considerations apply to this research. From this, the research aims and methods are outlined, including how these flow from the literature review and case study papers, and detailing the role of preparatory site-visits and document analysis in refining research methods and procedures. Next the research procedure and the researchers' positionality are outlined. Finally, some key ethical considerations are highlighted and discussed in the context of this study.

The two papers that follow this chapter take an in-depth methodological look at two specific facets of the research methodology: the methodological considerations when working with interpreters; and the methodological impact of conducting interviews online. Accordingly these aspects are only briefly considered in this chapter. Finally, the data analysis process is described after the two methodological papers and immediately before the research results papers.

Qualitative research

The field of qualitative research is broad and often contested, approached from a range of epistemological positions and applying varying research methods and forms of analysis. A unifying feature of qualitative research is privileging the perspectives of research participants. A qualitative stance is often recommended for exploring topics where little is known as it can provide descriptions of everyday life that illuminate the subject under investigation (Bryman, 1988). Qualitative research furthermore allows exploration of the situated nature of practice, situated both socially through cultural and institutional life of a community; and historically in shared traditions of knowledge production (Smith, 1998).

This study seeks to investigate how research ethics is understood and negotiated in researchers' everyday practice of mental health research in post-conflict settings. This is a topic that has not been systematically investigated to date¹¹, and for which qualitative methods provide the best approach for their ability to explore the topic. By privileging how researchers understand and apply "ethics" to their research practice, this approach facilitates thick descriptions and detailed elaboration of how ethics is understood and practiced (Rapley, 2007), including the mechanisms through which procedural and in-practice ethics relate to one another. Examining this intersection in the particular setting of mental health research in post-conflict settings, and privileging researcher's accounts, offer opportunities to expand an understanding of how research ethics both shape and are shaped by the social, normative, and geopolitical context in which they are applied.

Qualitative research in empirical ethics

It has been observed that:

"The social sciences see legal and ethical issues as primarily social issues and, because of this encompassing perspective, can contribute not only to the understanding of ethical issues but also to the understanding of the social processes through which those issues become constituted as ethical concerns" (Haines, 2002, p. 91).

This description aptly describes the function of this qualitative study which seeks to consider researchers' perspectives and experiences of research ethics as a lived-through phenomena inherent to research conduct. Through the empirical power of "thick descriptions" of the ethical dimensions of everyday research practice (Dunn *et al.*, 2012, p. 468), this study will consider the role of normative frameworks in shaping everyday ethical decision-making as viewed from the researchers' perspective.

Specifically, this study seeks to explore how research ethics is "done" in the everyday practice of researchers – how they conceptualise and identify research ethics; their reflections on the role of ethics in research; and how research ethics is acted upon and acted out in the course of research practice. This recognises that "bioethics comes into being when it is translated

¹¹ A notable closely related study is that of Renaud Boulanger who conducted a 2015 MSc study titled 'Ethics in humanitarian research: insights on the experiences of researchers' (available at: http://digitool.library.mcgill.ca/webclient/StreamGate?folder_id=0&dvs=1507811789666~415). This study focussed upon research following natural disaster, and encompassed a range of research topics including epidemiology, nutrition, maternal health, nursing, psychology and mental health. Therefore, whilst insights from this study are drawn upon, this study is not viewed as exploring the same topic as this thesis.

from the abstract into the local idioms of the places where it is enacted” (Kingori *et al.*, 2013, p. 262) Given the subject matter – that of research ethics – normative claims suffuse discussions with researchers, which invite initial bioethical analysis based upon lived experience (Draper and Ives, 2007). Within the field of bioethics this position has been described as a “social science of bioethics...[which] seeks to study the relationship between bioethics and the world, and explain how bioethical discourse interacts with, and impacts upon, both professional and lay institutions” (Draper and Ives, 2007, pp. 322-323).

This focus corresponds with increased attention to what applied social sciences can contribute to bioethics and philosophy (Haimes, 2002). It recognises that in order to understand how research ethics operates in everyday research practice requires engagement with the detailed, contextualised sites of practice and practitioners in situated context. This involves conducting “social science analysis of the social processes, meanings and institutions that frame and produce ‘ethics’ and ethical problems” (Haimes, 2002, p. 110). The means for achieving this are provided by the social sciences, offering approaches that seek to respond to and account for the messy complexity of the human world, and applying social science research and analysis methods to move beyond the particular to the general. Here, all applied social science analysis remains in conversation with overarching moral theories (Green, 1990), which in this study is focussed upon the analysis and critique of the principlist approach that underpins research ethics (Beauchamp and Childress, 1989).

It is important to recognise that this study does not apply the methodologies and techniques of bioethical analysis, which seek to mine qualitative data for the normative foundations that underpin it (Dunn *et al.*, 2012). Instead, this thesis engages in “*empirically driven, broad-conception empirical ethics* [which makes]...empirical claims that describe or explain the world as it is....to make sense of the relevant experiences, understandings, judgements, or intuitions of individuals” in relation to research ethics (Dunn *et al.*, 2012, pp. 467, italics original). The empirical ethical value of this study is encapsulated in the social scientific engagement with prescriptive normative claims made by researchers – depictions of right or wrong practice, or highlighting sites of practice that are ethically problematic (Dunn *et al.*, 2012) - to examine the ethical dimensions of practice. Analysis seeks to move beyond surface descriptions of the lived experience of conducting research to engage with the extent to which these descriptions conform to or agitate against a principlist research ethics framework which was the framework ascribed to by participants in this study (Chiumento *et al.*, in preparation). However, whilst engaging with the overarching normative framework of

principalism, this study does not take the methodological step of applying specific empirical ethics methodologies¹² to the qualitative data.

From a bioethical perspective this approach is critiqued for being limited to a social science of bioethics which does not engage in critical normative theorising (Green, 1990). Dunn *et al.* (2012) advance an epistemological critique, arguing that the philosophical foundations of epistemologies such as phenomenology which ascribe to situated moral knowledge and judgement are incompatible with empirical ethical epistemologies which function as external philosophical reference points upon which normative theoretical arguments are based. These critiques speak to contrasting views over the role of empirical social science knowledge in empirical ethics. In the present study the approach remains limited to the description and analysis of empirical data about researchers experiences of ethics from a sociological viewpoint. It therefore does not seek to engage in philosophical theorising beyond identifying sites of dissonance between normative frameworks and participant's accounts of their lived-experiences. Consequently, this study remains a social science study of research ethics and draws upon epistemologies, research methods, and approaches to data analysis that are congruent with this focus.

Epistemology

This section briefly outlines the rationale for adopting an interpretivist epistemology and details the phenomenological orientation selected to explore the subjective experiences of research ethics from the point of view of researchers. The points considered here are further developed in subsequent papers and chapters in this thesis as the epistemological stance informs decisions about research methods and approaches to data analysis.

Research adopts an interpretivist stance which prioritises subjective understanding of the organisation, understanding, and interpretation of experience (Smith, 1998). Interpretivism views knowledge as the application of ideas to organise human experience, emphasising the subjective position where the empirical world around us is not distinct from our social interaction with it. One of the founding influences is the work of Kant who problematized the relationship between the phenomenal world of appearances and senses; and the noumenal world of things independent of our senses (Kant, 2007 [1781]). Kant highlighted the mediated nature of contact with the world, prioritising the role of the human subject in

¹² Examples of such methodologies include reflective equilibrium (van der Burg and van Willigenburg, 1998); Integrated Empirical Ethics (Molewijk *et al*, 2004); Symbiotic empirical ethics (Frith, 2012); Pragmatic hermeneutics (Widdershoven, Abma and Molewijk, 2009); or Critical Bioethics (Hedgecoe, 2004)

acquiring and shaping knowledge which is understood through lenses of prior norms and theories to understand the world around us. This critiques the empiricist traditions tendency to reify or produce a “thingification” of the world, people, and human experience which leads to a “phantom objectivity” that obscures the fundamental role of human social relations (Taussig, 1980, p. 3). As this study seeks to foreground subjective experience and understanding within situated and relational contexts the interpretivist stance is considered most appropriate.

Research adopts a broad phenomenological approach (Schutz, 1944; 1945; 1967). Literally understood, phenomenology is the study of “phenomena” or the way experience is understood from a first-person point of view. Phenomenology therefore seeks to provide an unprejudiced, descriptive understanding of whatever appears to consciousness, precisely in the manner in which it appears (Moran and Mooney, 2002). It involves “the descriptive study of lived experience (phenomena) in the attempt to enrich lived experience by mining its meaning” (van Manen, 1990, p. 38).

Phenomenology attends to the structure and quality of objects and situations as they are experienced by the subject (Moran and Mooney, 2002). The focus is placed upon the structure of the appearance of the phenomena as it comes into consciousness, the “how”, followed by the lived-through meaning of that phenomena (Moran and Mooney, 2002). Therefore, it moves beyond the natural attitude of the everyday manner of being in the world, to attend to the lived-through nature of experience. This is achieved through probing taken-for-granted and common-sense assumptions to attend to tacit knowledge and everyday context which shape subjective experience. These features must be reflected in the chosen research methods ability to embrace the complexity of intuitive human experience which depends upon spheres of human understanding, judgement, and reasoning processes (Moran and Mooney, 2002).

The phenomenological stance incorporates an active mode of intentionality of experience and a consciousness of or about phenomena – “consciousness is always consciousness of something, and experience is directed upon objects, both real, imagined, material, and ideal” (Wagner (1975) in Schutz, 1975, p. 5). Intentionality therefore is understood as directedness towards or in reference to an object of investigation (Brentano, 1973), and encompasses consciousness in a qualitative sense of the what-it-is-like dimension to experience (Portc, 2013). Therefore, the subjective, practical, and social conditions of experience are considered to combine to create the meaning of a given experience in the everyday life-

world. It is these features of experience that this study attends to in the context of research ethics.

Schutz's phenomenological methodology

Schutz (1944) proposes a phenomenological methodology for research. He asserts: "the observational field of the social scientist,... namely the social reality, has a specific meaning and relevance structure for the human beings living, acting, and thinking therein" (Schutz, 1975, pp. 272-3), reaffirming a subjective orientation. Here the actions of social actors are founded upon pre-selected and pre-interpreted common-sense constructs of their social world, which the social scientist seeks to observe and explain. "Social phenomena,...we cannot understand...otherwise than within the scheme of human motives, human means and ends, human planning – in short – within the categories of human action" (Schutz, 1975, p. 282). This stance emphasises the extent to which subjective understanding of the world is guided by the instruction and interpretation of others in a historical process of a received way of understanding the world (Schutz, 1975). When applied to social science research this orientation requires the researcher to draw upon research participants' subjective understanding, and to this add a layer of scientific constructs, understood as ideal type constructs of theoretical systems that seek to explain and comprehend subjective experience (Schutz, 1975). In Schutz's methodology this is understood as a reciprocity of perspectives, where understanding of a single shared reality is crucial to the communication and coordination of action (Hammersley and Traianou, 2012). This requires methods that facilitate inquiring of what happens in the minds of individual actors in relation to the phenomena under investigation, seeking to understand these in light of wider theoretical positions that enhance our understanding of a given experience.

Schutz's methodology encompasses intentionality in the orientation towards the phenomenon of study. This can be achieved both by apperception – understood as the mental process by which a person makes sense of an idea by assimilating it into their schema for understanding the world; and as an intentional act whereby an individual experiences an object – whether physical or ideal (Schutz, 1975, pp. 318-19). Here Schutz emphasises a methodological concern for estrangement where the phenomena under investigation is approached not as a fixed, known object, but is explored from the viewpoint of the research participant. The concept of estrangement is developed in his essay *The Stranger* (Schutz, 1944) which emphasises the outsider position experienced when an individual is exposed to a different context where their assumptions about norms of behaviour fail to apply. To acclimatise the stranger must observe and adapt to a new set of norms and expectations.

Therefore, the world around the stranger is constructed from observation, interaction, and interpretations offered to him by others. The essay *The Stranger* encapsulates the estrangement Schutz felt should be pursued when conducting social science research.

Another important aspect of the phenomenology methodology of Schutz is the way the experiences of individuals can be bounded together into collective ideal types (Schutz, 1975). This is important in this study where the methods facilitate considering the experiences of individual researchers in relation to one another; to the collective entity of the research organisation they work for; as well as to the generalised “research enterprise” understood to encompass all post-conflict mental health research undertaken globally. Methodologically, this research seeks to engage with the subjective meaning-contexts of the organisational collective, understanding the extent to which the collective offers a scheme of objective norms or standards that aid understanding the actions of the individuals which comprise it. This involves unpacking the organisational norms, operating standards, and attitudes common to each research organisation and that apply across the organisations involved. In this way the subjective meaning of a social collectively is exposed and the actions of those who belong to the collective can be understood in context (Schutz, 1975). Another ideal type that is drawn upon in this study are tools engaged with as “a-thing-in-order-to” (Schutz, 1975), considering procedural ethical documentation through the lens of means-ends relations. These tools are considered in relation to the actors that use them to contribute to the typification of the role of research ethics for researchers.

Consequently, the phenomenological orientation in this research emphasises the lived-through quality of researchers’ experiences of ethics. The phenomenological focus is upon individual researchers’ perceptions of ethics, the meaning this carries for them, and the actions taken when “doing” ethics. Intentionality is encapsulated through a purposive orientation towards how “ethics” is understood, applied and managed in everyday research practice – all features of the what-it-is-like experience of ethics. Considering the subjective experience of researchers in the context of the organisational collective seeks to unpack how ethics is encountered and negotiated in everyday situated research practice shaped by organisational norms and routines. By typifying the features of individual action and experience and the tools used in routine research conduct (such as procedural ethical documentation), this study presents generalisable research findings that become available for further exploration and testing (van Manen, 1990). To achieve this, this study focuses upon perceptions of ethical practice that lie within the researchers remit, exploring

individual scope for ethical decision-making and the making of ethics within situated practice.

RESEARCH AIMS

The literature review revealed tensions in the literature when operationalising ethical research principles to research practice. It is this tension that this research aims to examine and explore through the empirical investigation of the construction and management of ethical issues raised by conducting mental health research in post-conflict settings, from the perspectives of researchers active in this field. Construction here is used to refer to how researchers' define and understand the concept of research ethics procedurally and in the course of their everyday practice, and management refers to the application of research ethics to practice, including how situational considerations and contextual challenges are responded to. Taking research ethics as the point of departure aims to question the essential nature of the phenomena of research ethics as a concept and an intuitive action in the everyday lives of researchers, given meaning through their reflections upon their lived experience.

Research question

Research questions flow from the literature review which clarified the research aims, and bear direct relation to the research epistemology and research methods. The primary research question is:

How do researchers construct and manage ethical issues experienced in mental health research with post-conflict humanitarian populations in three countries in South Asia?

In line with the phenomenological orientation, what constitutes an "ethical issue" and how this could be understood will not be defined as a primary study aim is to explore how researchers define, understand and apply "ethics" to their research practice (Frith, 2009; Frith *et al.*, 2011). This encompasses exploring researchers' views on how:

- "ethics" is defined and understood;
- situations stimulating "ethical considerations" are identified;
- "ethics" is applied and managed;
- procedural ethics are interpreted and applied to ethics in practice (Guillemin and Gillam, 2004);
- ethics in practice and procedural ethics relate to one another, synthesising insights from the above.

The procedural and in-practice ethics distinction is drawn from Guillemin and Gillam (2004) who use procedural ethics to refer to the processes involved in applying for and securing formal research ethics approval - such as developing the research protocol, informed consent form, and other research procedures. In contrast, in-practice ethics refers to the day-to-day ethical issues that arise during the conduct of research that are often not anticipated or addressed in procedural ethical documentation or processes prior to commencing data collection.

Research setting

This study was conducted in three countries in South Asia. Due to anonymity procedures, the countries will not be named, and will instead be referred to as C1, C2 and C3. In order to situate the study in context however a broad overview of the research settings is provided here, focussing upon key socio-demographic information that provides a sense of the setting in which research was conducted.

All three countries have experienced conflict within the last decade, and are therefore defined for the purpose of this study as “post-conflict”. They all currently host refugee and / or internally displaced populations, and continue to experience political instability and natural disasters. Each country is culturally diverse, with a multiplicity of ethnic, religious, and language groups. Two countries are classified by the World Bank as lower middle income, and the third as a low income country (World Bank, 2017). The 2015 Human Development Index - a composite statistic of life expectancy, education, and per capita income indicators - ranks one country as high and the other two as low human development (United Nations Development Program (UNDP), 2015). Literacy rates in all three countries continue to improve, particularly for younger generations, although in two countries the literacy rates for the population over 65 years remain at around 40% (United Nations Educational Scientific and Cultural Organization (UNESCO), 2015).

All three countries have free government healthcare facilities as well as private healthcare practices (World Health Organisation, 2017). The population in each country uses multiple biomedical and religious / traditional healthcare systems (World Health Organisation, 2001). Mental health in all three countries is recognised as a Government priority, with two countries having recently passed Mental Health Acts and the third frequently mentioning mental health in policy frameworks. In all three countries mental health stigma, often founded upon religious or traditionally-informed understanding of the causes of mental ill-health, remains a significant barrier to treatment (Thorncroft, 2006; Patel, 2007).

All organisations participating in this study were engaged in or had recently been conducting research with conflict-affected populations. The organisations involved in research included: in the first country a dedicated psychosocial and research NGO; in the second country a research and training NGO; and in the third country a tertiary hospital. In both the first and second countries the organisations operate country-wide, have multiple projects operating concurrently, and offer support with the mental health aspects of disaster response when required. In the third country the project explored in this study was the only community-based research the organisation were conducting, with clinician-researchers overseeing the work of non-clinician research assistants. In all three countries research assistants were employed, trained and supervised as short-term hires for the duration of a specified project, with opportunities for transferring to other projects / for research career progression in countries one and two in particular.

All three settings have formalised procedural ethics structures including requirements to obtain ethical approval prior to research conduct. Additionally, all three organisations were in receipt of international funding which mandated adherence to ethical review mechanisms and ongoing ethical oversight of research. All organisations had developed their own programme of research assistant training which included key principles of research ethics, conceptualised according to principlism (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; Beauchamp and Childress, 2013), with an additional research methods focus, emphasising interviewing skills that recognise the sensitivity of discussing mental health in all three countries. When exploring researcher's approaches to and experiences of ethics therefore, the ethical governance mechanisms and organisational approaches to ethics-in-practice including research ethics training, supervision, and support are considered sufficiently similar for multi-site analysis.

Method

This section outlines the research methods chosen to empirically investigate the construction and management of ethical issues that arise in mental health research in post-conflict humanitarian settings, from the perspectives of researchers active in this field. The methods have been selected for their ability to address the research aims and questions from a phenomenological perspective.

Briefly, research follows a multiple-case study method (Yin, 2009), involving in-depth interviews with researchers. Interviews facilitate access to the phenomenology of individuals, and provide a high degree of control to the participant (Frith and Gleeson, 2012).

Conducting interviews with many researchers aims to produce generalizable theoretical propositions through incorporating multiple sources of evidence that allow converging lines of enquiry to emerge, supported by data triangulation through replication of the empirical study across three settings. This approach is appropriate when following a phenomenological epistemology which recognises that the diversity of human experience is infinite, meaning subjective human experience will be structured differently for each individual; but that adopts an orientation to the essence of ethics as a phenomena which facilitates moving from particular accounts to a plausible interpretation of the totality of researchers' experiences of ethics (van Manen, 1990).

Multiple case-study method

The multiple multi-site case study method involves three embedded case studies. All case studies comprise individual in-depth interviews with researchers. The approach of exploring research ethics with researchers at all levels, discussed in detail under "sampling" below, enables exploration of findings across the case studies either by country, or by category of researcher. This versatility enhances potential directions for interview conversations, allowing pursuit of questions relevant to a specific setting as well as to a particular role, as well as opening up potential avenues for data analysis.

In choosing the multiple case-study method the aim is to produce generalisable theoretical propositions which therefore means that the selection of cases is theoretically informed (Yin, 2009; Silverman, 2013). As Yin (2009) describes: "in doing a case study, your goal will be to expand and generalize theories (analytic generalizations)" (p. 15). Consequently, sampling decisions do not seek to quantitatively "make-up" the numbers in the sample, but to ensure representation from all categories of respondents who may have something to say about their experiences of research ethics which can then be analysed to make theoretical judgements.

Qualitative interviewing

Insights into researchers' sense-making of "ethics" and "ethical issues" will be achieved through in-depth interviews, allowing the interviewee to reveal an account of their experiences. In this process both method and data are captured in the meaning of participants' words accessed through interview talk and interactions (Green and Thorogood, 2014). Conducting qualitative interviews in which the participant reflects upon their experiences accords with the phenomenological perspective that temporality can only be appreciated reflexively (van Manen, 1990). In this orientation factual accuracy is not the

primary concern, rather, the focus is upon the ways researchers understand and make-sense of their experiences (Harper, 2012). This is appropriate for the phenomena under investigation where the interest is in participants' behaviour and attitudes relating to research ethics, not in gathering verifiable data about what they know (Robson, 2011).

A semi-structured topic guide was developed to steer interviews, built around the research questions (a copy is provided as Appendix 2). The topic guide was not intended to be strictly followed, but provided areas for discussion, with potential questions and prompts to be drawn upon as appropriate (Frith and Gleeson, 2012). Interview guides employed a "tree and branch" approach where the research question was broken down into a series of main questions, each with their own follow-up questions and probes to be drawn upon according to the direction of interview discussions (Rubin and Rubin, 2005). Specifically, interviews commenced with broad opening questions about the participants background and a description of their current role. Beyond this, it was intended that each interview navigate its own path through the main interview topics which included procedural ethics, ethics in practice, the interrelation between procedural and in-practice ethics, and researcher integrity. Interviews closed by asking participants if they had anything further to add or if the interview had missed topics they felt it was important to discuss.

Therefore, the topic guide was complemented by attention to emerging meanings within interviews that present pertinent lines of enquiry (Rubin and Rubin, 2005; Robson, 2011), and iterative evolution of interview topics and questions (Rapley, 2007; Yin, 2009). This involved using probes to encourage additional detail, depth and vividness to participant responses (Rubin and Rubin, 2005), for example by deconstructing experiences step-by-step. Another technique employed was to use information from one interviewee as a prompt to explore similar experiences or perspectives in subsequent interviews (Rubin and Rubin, 2005). This presents a device for expanding discussion with participants who may provide briefer and more direct responses, offering a way to encourage a reflective attitude towards common experiences of researchers (Frith and Gleeson, 2012). This approach means interviews move between phases of interviewer-as-stimulus, collaborative production of knowledge, and participant-led discussion (Frith and Gleeson, 2012). Where each interview falls on this spectrum is determined by the levels of openness and responsiveness of interview participants, which is reacted to in-situ by the researcher who in turn guides the interpreter, where present.

The exact path of each interview was determined by participant responses to opening and main questions, as well as attention to lines of enquiry to be explored with specific participants or categories of participants that had emerged in previous interviews (Rubin and Rubin, 2005). Therefore, interviews were understood as reflexive processes where participants can actively reflect upon their experiences and understanding of research ethics, constructing an interpretation of their meaning in partnership with the researcher and where involved, the interpreter (Frith and Gleeson, 2012). This approach considers the interview environment as one in which meaning is co-produced between the researcher, participant, and where involved interpreter (Dunn *et al.*, 2012; Bramberg and Dahlberg, 2013). This co-production recognises that all participants in the interview setting take cues and ideas from one another to explore in a conversation, with the researcher seeking to steer the interview in anticipation of sought after possible future conversations (Wengraf, 2001).

Therefore, whilst all interviews covered the same broad topics, the way in which questions arose or were phrased differed according to the evolution of particular interview conversations. This approach maintained close orientation to the overarching research question, always asking how the phenomena of research ethics is understood, encountered, and responded to by researchers (van Manen, 1990). The essence of interviews were to pursue questions that open up, and keep open, possibilities for understanding the phenomena of research ethics (Gadamer *et al.*, 2004). The iterative approach to interviewing acknowledges the evolving trajectory of research, and is compatible with phenomenology in which '*analysis is always an ongoing process*' as meaning and understanding is built up through interaction with participants (Rapley, 2007, pp. 26 - emphasis original).

All interviews were digitally recorded on a Dictaphone to capture individual narratives and facilitate transcription. Written transcriptions containing the English narrative are used for the purpose of analysis. The process of transcribing interviews is detailed below.

Participants

Participant inclusion criteria are researchers active in mental health research with post-conflict humanitarian populations in three countries in South Asia. Research participants comprises three embedded categories:

1. Primary Investigator / supervisor;
2. Mid-level researcher managing a field research team; and
3. Front line data-collector involved in administering questionnaires and conducting qualitative interviews.

Broad classification of researcher recognises that experiences of “ethics” arise at all stages of the research process and impact upon researchers at every level. As discussed above, embedded units of analysis allow for corroboration and contrasting of experiences, as well as facilitating analysis of the data by case study setting, or by category of researcher.

Sampling

Sampling is theoretically informed to reach researchers with experience of the phenomena of research ethics in three post-conflict settings. With an interest in the social and normative processes that underpin experiences of research ethics, a conscious decision was made to focus upon researchers who are most able to provide data that allow a direct and deeper analysis of the phenomena of interest (Gobo, 2008). Alongside this sampling is driven by an element of convenience by recruiting from participating organisations willing to open up their practice to outside scrutiny.

Purposive sampling will be employed, with potential participants identified by in-country partners based upon the inclusion criteria and embedded units of analysis. Taking this approach involves actively seeking out the setting, organisations, and individuals who have experience of the phenomena of interest (Silverman, 2013). Sample size will where possible be determined by theoretical saturation, comprised of researchers from each country and representing each embedded unit of analysis. Due to the limited number of senior researchers, sampling will be determined by the conduct of interviews with all available senior researchers with the aim of reaching theoretical saturation. Therefore, the final sample size was not determined at the outset of research, but was instead determined by the theoretical aims of the study.

Interview preparation: site visits and document analysis

Preparatory site visits were conducted before the submission of ethical approval to finalise logistical arrangements and agree procedures for hiring interpreters and approaching research participants. In addition, content analysis of documents shared by organisations that were identified as relating to research ethics was undertaken. These aspects of interview preparation are briefly discussed in turn.

Site visits

Site visits to each organisation were conducted in advance of data collection. These provided an opportunity for face-to-face meetings with key contact persons at each organisation to finalise ethical approval documentation, and plan for fieldwork logistics. This included planning broad timelines for interviews to determine the length of time required in each

country for data collection, and identifying appropriate times of year for data collection that took into consideration religious festivals and holiday periods. Additionally the procedure for recruiting interpreters was discussed and agreed, adopting a process that remained broadly consistent across all three countries.

Preparatory site visits provide an opportunity for the researcher to become familiar with each research organisation, including a brief history of the organisation and overview of current and previous research projects. They offer an opportunity for the researcher to become familiar with sociocultural norms in country, for example being informed about local customs, appropriate dress, and national foods. This background acculturation and organisational understanding was felt to be important for the conduct of subsequent interviews, providing the researcher with a broad understanding of the opportunities and potential directions for interviews, as well as an introduction to sociocultural norms that may be important in the interview setting. These visits also offered an opportunity to obtain documents for subsequent document analysis to provide further insight into the organisational context and approaches to research ethics.

Document analysis

Document analysis was undertaken following site visits and prior to data collection. The primary aim of this was to gain a background understanding of the way organisations conceptualised ethics in procedural documentation. This information provided a contextual perspective on the way research ethics arises and is applied in specific socio-cultural and organisational case-study contexts, providing orientation to the potential subjective meaning-contexts of individual research participants important to the phenomenological orientation adopted by this study. This background understanding is drawn upon by revealing aspects of the phenomena of interest that could emerge and be explored in interviews (Robson, 2011), shaping topics and questions to be explored in interviews.

Subsidiary aims of document analysis were to:

- a) refine the topic guide for individual in-depth interviews;
- b) inform interpreter training with organisational terminology used to discuss research ethics, and provide a broad orientation to organisational approaches to procedural research ethics;
- c) provide an indication of what organisations viewed as ethical documentation and procedures; and

- d) allow data triangulation through the identification of potential codes to be deductively applied and explored in initial analysis of interview data.

The rationale for this step is that document analysis facilitates a deeper understanding of research participants' background context and shared meanings (Moran and Mooney, 2002; Vaismoradi *et al.*, 2013) that may be applicable to their understanding and management of research ethics. This is important for developing an awareness towards nuances in meaning and application of organisational schemas relating to the way ethics is conceptualised and understood. This "top-down" conceptualisation of ethics is complemented by interviews in which a "bottom-up" understanding of ethics is explored. When taking this approach it is accepted that "official" documents for ethical approval are limited in what they can reveal about approaches to research ethics as the process of writing in itself entails reflection and refinement which acts to constrain the content (van Manen, 1990). As a phenomenological study one aspect this research seeks to explore is the ways organisational procedural documents define research ethics and the management of ethical issues. Consequently, documents are viewed as telling both in what they do say - their specific presentations of "ethics" - their omissions, and for what these reveal about the ways "ethics" is understood and engaged with from an organisational and procedural perspective.

Therefore, document analysis supported the researchers' preparation for conducting interpreter training and interviews. For this reason it is not seen as a distinct research step, but as an element of methodological preparation that aided refining the interview approach.

Requests for sharing documents asked key contacts at each organisation for documents considered to be relevant to research ethics, identifying examples such as material used for training research teams, study protocols, and notes from supervision sessions. A limitation was that documents needed to be available in English. A summary of the documents shared is provided in table 6.

Table 6: Documentation for content analysis

	Country 1	Country 2	Country 3
Ethical approval	<ul style="list-style-type: none"> - Community survey protocol - Cohort study protocol 	<ul style="list-style-type: none"> - Study protocol* - Information sheets for survey and qualitative study* - Consent forms for survey and qualitative study* - Correspondence with ethical review boards to finalise approval* 	<ul style="list-style-type: none"> - Study protocol - Amendment to study protocol - Informed consent form for quantitative and qualitative phases of study - Appendices including interviewing guides - Report to ethical review boards
Researcher training	<ul style="list-style-type: none"> - Ethics training manual - Two sets of slides for training researchers - Ethics evaluation (short questionnaire about ethics) - Certificate of completion of CITI training 	<ul style="list-style-type: none"> - Researcher training manual 	<ul style="list-style-type: none"> - Schedule of researcher training for qualitative study - Researcher training slides for qualitative study
Other procedural documents	<ul style="list-style-type: none"> - Adverse events reporting procedure 	<ul style="list-style-type: none"> - Risk assessment checklist 	

* Multiple versions of these documents were provided as they were submitted to two different ethical review boards

Documents were analysed thematically (Vaismoradi *et al.*, 2013; Green and Thorogood, 2014). This approach supports identification and exploration of institutionalised schemas in relation to ethics, and is compatible with phenomenology. As part of the analysis, the following questions were asked for each document:

- What is the document i.e. a protocol, training material, instrument etc?
- Who produced it?
- For what purpose was the document produced, i.e. what is the goal of the document?
- From what perspective or mindset was the document produced (e.g. to standardise procedure; or to offer proof of ethical credentials etc)?
- Who are the end users of this document?

Additional focal points for analysis included identifying sites of conflict between and within documents. Analysis was conducted in NVivo 10 which supports thematic organisation of data.

By conducting analysis that mines the manifest and latent meanings within the documents (Robson, 2011), the phenomenon of “ethics” within the organisational environment is made visible (Moran and Mooney, 2002). In this study this process produced thematic categories that disclose the essence of “ethics” as it appears in documents. Here, thematic analysis aligns with the phenomenological aim of returning to “things in themselves” (Husserl, 1971), taking each document as a manifestation of the way ethics is categorised or defined procedurally by and for researchers.

This approach has some key limitations, namely that the researchers background knowledge of “ethics” – the way in which it is defined and applied – will be brought to bear on documentary analysis and may predispose a specific interpretation (van Manen, 1990). To manage this challenge transparency about emerging thematic categories is maintained through documenting the process by which categories arise from the text in a “common-sense” way. Furthermore, as mentioned above, the “official” nature of these documents is anticipated to limit what they can reveal. These limitations will be addressed through qualitative interviews with researchers and subsequent data triangulation.

Findings from this process of document analysis were drawn upon to refine the approach to interviews. Whilst no questions were explicitly revised as a result of document analysis, the way in which questions were posed for each organisational setting was informed by this background understanding. This included for example being cognisant of researchers’ exposure to different types of research methods which could be explored in interviews; or being aware that researcher training conceptualises ethics as a fundamentally procedural concern which may be reflected in understandings of ethics by field research assistants in particular.

Key findings from this process were also summarised for the purpose of interpreter training. This included a focus upon the use of technical research terminology to familiarise interpreters to terms that may be used in interviews (e.g. RCT); summarising current research organisations were conducting that was likely to be discussed – for example if a project is a single site study or part of a larger multi-country study. This background was then jointly reflected upon with interpreters to consider how it may inform interview questions and the direction of conversations. It is also important to note that in the interpreter training the limited nature of what could be learnt from procedural documents was reinforced, highlighting why interviews with researchers were important to learn how these documents are drawn upon in everyday research practice.

Interview procedure

This section provides a description of the interview process, detailing steps taken before, during, and after interviews. This is presented as a narrative account of the research process as it happened, citing the nuances and shifts required to accommodate the realities of fieldwork. This addresses the critique that “too little attention is given to documenting the process of carrying out research” (Kinard, 1996).

Prior to interviews

Where possible, informed consent was obtained in advance of interviews through group information sessions with potential research participants and where required, the interpreter¹³. Where this wasn't possible – for example due to travel commitments meaning only one meeting with the participant was possible - informed consent was obtained immediately before the interview commenced. All participants were encouraged to ask questions to ensure they fully understood why they were being asked to participate in the study, and their right to decline participation was reinforced. If in agreement, informed consent was documented on a paper signed informed consent form. Participants were asked if they would like to have a scanned copy of the signed informed consent form and an electronic copy of the information leaflet e-mailed to them at a later date. Where requested, an e-mail address was added to the consent form to facilitate this and e-mails sent upon return from fieldwork.

Interview topic guides were piloted in each country as part of interpreter training¹⁴. Where possible these pilot interviews were conducted with research staff not participating in the study, and were used as an opportunity to gather feedback on the informed consent process and broad interview topics and questions. In C2 due to the remote field research site where interpreters were recruited piloting with research staff was not possible. Instead, pilot interviews were conducted with interpreter's taking turns to play the role of research participants. This approach was more limited for the purpose of training, in particular it is

¹³ Prior to piloting interviews interpreter recruitment and the theoretical and research methods aspects of interpreter training had occurred. The procedure for interpreter recruitment and information about the topics covered in interpreter training are addressed in Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017b) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online early view, pp. 1-19.

¹⁴ The interview guide is provided in Appendix 2. The role of pilot interviews in interpreter training is discussed in more detail in Chiumento *et al* (2017b).

felt that mistakes made by the interpreter during the first interview (discussed in Chiumento *et al.*, 2017b) may have been avoided had piloting with research staff been possible.

During interviews

Interviews were conducted in a range of locations according to the participants' convenience. These included office meeting rooms, café/restaurants, in outside spaces, and online via Adobe Connect or Skype¹⁵. When in public settings every effort was made to sit away from other people to maintain confidentiality and ensure minimal background noise for digital recordings.

All interviews were recorded on a digital Dictaphone which was placed on the table between the researcher and participant. When interpreters were involved the Dictaphone was placed so that the microphone was facing them to ensure their translations were fully audible. This was important for subsequent interview quality checks¹⁶ and transcription.

Interview seating involved the participant and researcher sitting opposite one another; or when the interpreter was present sitting in a triangle to ensure all participants could maintain eye-contact with the others. For online interviews the interpreter and researcher sat next to one another, both visible on the video and both able to talk to the participant¹⁷. Refreshments were available at all interviews, including water and tea and snacks, served according to local customs and the time of day.

Interviews commenced with the researcher introducing herself and where present the interpreter, outlining the interpreters' role in interviews. At this point the Dictaphone was put in place and participants were informed about the purpose of recording interviews for accurate transcription. This included reiterating anonymity procedures where all identifiable information such as place names or people's names would be replaced with pseudonyms in the transcription process. Participants were also requested to turn off mobile 'phones as these could distort interview recordings.

¹⁵ Online interviews are discussed in Chiumento, A., Machin, L., Rahman, A. and Frith, L. (submitted) 'Online interviewing with interpreters in humanitarian contexts', *Submitted to International Journal of Qualitative Studies in Health and Well-being*.

¹⁶ Quality checks are discussed in Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017b) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online early view, pp. 1-19.

¹⁷ The impact of seating and availability of visual cues when conducting interviews online are discussed in Chiumento, A., Machin, L., Rahman, A. and Frith, L. (2018) 'Online interviewing with interpreters in humanitarian contexts', *International Journal of Qualitative Studies in Health and Well-being*, 13(1), pp. 144487-144496.

Following these practicalities, a brief overview of the interview was provided. Participants were informed that the interview sought to explore their views and experiences, and that there were no right or wrong answers to the questions that would be asked. Sharing of specific examples was encouraged as a way to illustrate points through reference to situated practice, with standards of anonymity and the use of pseudonyms in the final transcript reinforced in this context. The participant was informed that both the researcher and interpreter may make notes during the interview, and that these were to help keep track of the conversation and remind of discussion points to follow-up later in the interview. Before commencing the main body of the interview participants were offered an opportunity to ask any questions they may have. Finally, the researcher informed the participant that interviews were expected to take between 60 to 90 minutes, and reconfirmed that the participant was available for this length of time. The researcher also committed to keeping an eye on the time to ensure interviews concluded promptly, and offered flexibility should interviews be interrupted and the participant called away.

During the interview the participant or interpreter could request to pause the interview at any time. Some participants had requested to keep their mobile phones on as they were expecting calls. When the participant did receive a call the interview was paused. Interview interruptions were minimal, including refreshments being brought in, and the occasional request for colleagues to speak to the interview participant or researcher.

To close the interview participants were asked if they wanted to add or clarify anything to what they had said, or suggest topics they felt interview questions had missed. For some participants due to unforeseen circumstances - for example when interviews were cut short, or where the participant had more to say than 90 minutes allowed - a second interview was scheduled for another date.

At the end of the interview the participant was asked if they would like a copy of the written English transcript. Where this was requested an e-mail address for sharing the transcript was added to the informed consent form, if it had not been obtained at the consent stage. Finally, the researcher thanked all participants for their time, identifying key points from the interview that had been particularly interesting or novel to reinforce the value of each interview to the overall study.

After the interview

For those who requested copies of transcripts and scanned copies of informed consent forms these were e-mailed once they were available upon the researchers return from fieldwork.

All transcripts were in password protected word files. The passwords were shared with a nominated individual within each organisation who then shared it with participants upon request, or for staff who had left the organisation were sent in a separate e-mail to the transcript itself. Participants were invited to comment upon, add to, correct, or refine what had been documented in an interview transcript, providing this feedback either via e-mail or through a skype discussion with the researcher (interpreters were not available at this stage)¹⁸.

Post-interview debriefing discussions with interpreters and the conduct of interview quality checks are described in the methodological paper on working with interpreters (Chiumento *et al.*, 2017b). Conducting debriefing immediately after the interview sought to search ‘for ‘communicative’ and ‘interpretive’ blunders and naiveté’ (Wengraf, 2001, p. 38). These reflective discussions, alongside discussions that occurred during interview quality checks, shaped subsequent interviews as questions were for example refined for ease of translation or explored in a different order. Additional post-interview considerations are covered elsewhere in this thesis, including transcription procedures detailed in the data analysis chapter; and the process for data security and handling which is described under “ethical considerations” below.

Positionality

Schutz emphasises that the social scientist is to detach themselves from their taken-for-granted biography to adapt to “being in a scientific situation” (Schutz, 1975, p. 276). To achieve this requires reflection upon positionality, understood as describing and assessing the impact of the researchers’ “role and presence, and...the values and theoretical orientation that have guided their research” (Spencer and Richie, 2012, pp. 231-2). This is important in qualitative research where it is accepted that “to orient oneself to a phenomenon always implies a particular interest, station, or vantage point in life” (van Manen, 1990, p. 40) including the researcher’s social, political and cultural positioning in relation to the research topic, as well as the historical context which makes it possible to ask particular questions at a particular time. Making explicit researcher positionality is seen as one aspect of maintaining research rigor by rendering prior assumptions transparent (Spencer and Richie, 2012), and recognises the inseparability of research methods and

¹⁸ As identified in Chiumento *et al* (2017b): to date, a third of participants have responded to thank the researcher for their transcripts, some confirming their accuracy, and one requesting a follow-up Skype discussion to share additional insights.

findings as researcher's consider their own role as actors in the research process (Emerson *et al.*, 1995).

This section will discuss the researchers' personal and disciplinary positionality such as how academic training shape the researchers' disciplinary and theoretical positions; and functional positionality in researcher-participant interactions. These are all discussed in the context of specific experiences and interactions, illustrating how these facets of positionality arose and shaped research.

Personal and disciplinary positionality

I will discuss some key aspects to my personal biography that are felt to have been significant in a cross-cultural study, namely my British nationality, and my gender and social role. Following this my personal and academic trajectory that influenced me to pursue this topic of study and allowed asking these research questions at this time are considered. Finally, some specific facets of my disciplinary positionality that were highlighted whilst conducting this study are discussed.

As a white British single female in my early thirties, my personal biography brings with it specific connotations when working in South Asian settings. My nationality was associated with British colonial histories, fused with contemporary global anti-terrorism narratives. These were evident when historically-rooted and current ethnic and religious tensions in each country were raised, with the role of the UK Government and Military in anti-terrorism operations often commented upon. Conversely however, being British facilitated my research as visa restrictions were minimal. The ease of my movement around the region contrasted with the experiences of the local researchers participating in this study who frequently faced significant barriers obtaining visas due to their nationality¹⁹. These examples highlight the disparities presented by my nationality and passport alone.

Being an educated white Western female travelling alone in South Asian settings brought attention to cultural differences in gender role expectations. For example, I was frequently asked about my marital status and how I balanced work travel and a personal life. These interactions reinforced my personal autonomy and socio-cultural values that allowed me to pursue a PhD over meeting normative assumptions about gender roles that it was perhaps more difficult for those I interacted with to overcome. Simultaneously my gender and Western nationality functioned as facilitators for my research by making me more accessible

¹⁹ The time and effort spent applying for and obtaining visas was notable in C2 and C3, with interview schedules planned around participants' trips to apply for visas in both countries.

to both males and females in the countries where I travelled. I was able to side-step gender norms in many settings due to my nationality to facilitate interactions with males; and in other situations was able to discuss gender norms with females – a topic that may have been closed to male researchers.

Having worked and travelled in South Asian settings over the previous 15 years I was equipped for encountering the challenges associated with gender norms. Furthermore, having established relationships with many of the senior male participants in this study facilitated informal discussion of topics such as gender roles which may have been more difficult for someone unknown to them. These informal interactions were important for exploring the religious and socio-cultural underpinnings to views of gender, challenging reified understandings of gender in each South Asian setting. I remained cognisant about these differences throughout research conduct, reflecting upon my gender positionality in research diary entries and discussing the implications of gender norms informally with researchers to better understand how these shaped their careers. These ensured an active socio-cultural awareness of the gender norms operating in each research setting which was informative for understanding gender considerations relevant to ethical research conduct, such as the importance of gender matching between interviewers and participants.

Conducting research in South Asian settings, including unstable countries with unfavourable profiles in the Western media, required careful consideration of safety issues. This was because as a White British female assumptions regarding who I worked for (often assumed to be the United Nations or a Non-Governmental Organisation (NGO)) brought specific safety implications. Recognising this, I was conscious of how I positioned myself in discussions with the general public, careful to distinguish my work from contentious activity such as UN War Crimes investigations in C2, and identifying myself as working with a Government Institution rather than an NGO in C3 where NGOs can be viewed with hostility and suspicion. It is important to note that at no point during my fieldwork did I feel unsafe or concerned about travelling alone. The phased development of repeated site visits, each involving careful planning and attention to issues of safety and logistics including an identified point of contact should problems arise, left me confident in the careful management of my personal safety.

Regarding my disciplinary positionality, my interest in the field of mental health research evolved during undergraduate study and a Human Rights Masters. My academic training has always been inter-disciplinary, involving the study of political, legal, philosophical, and sociological perspectives to forced displacement viewed through the lens of normative

claims relating to human rights and to medical and research ethics. This interdisciplinary theoretical orientation is viewed as both a strength by encouraging the integration of different perspectives upon the topic of study; whilst also being a weakness due to not having a firm disciplinary lens through which to approach research.

During both my Undergraduate and Masters Degrees I volunteered for charities supporting refugees and asylum seekers which raised my awareness of the mental health impacts of displacement. This was followed by volunteering with a human rights advocacy organisation in South East Asia, providing insight into advocacy efforts to support those marginalised in society. These experiences offered real life context to my evolving theoretical knowledge about the needs and rights of refugees and asylum seekers.

This exposure combined with a personal experience of trauma whilst living abroad which necessitated mental health support and sensitised me to the complex impact of traumatic events on interpersonal relationships and daily functioning, and the importance of actively managing distress. Receiving initial mental health support in a second language was particularly challenging, and brought to my attention the ethical dimensions of providing mental health services that are timely and respond to the needs of the individual receiving support. This experience as a user of mental health services gave me insight into their structure and functioning in the UK and abroad which has been brought to bear when seeking to understand the conduct of mental health research.

The timing of my PhD proposal coincided with a number of initiatives that focussed upon the ethical dimensions to research conducted in low resource contexts and emergency settings (Inter-Agency Standing Committee (IASC), 2007; Curry *et al.*, 2014; World Health Organisation, 2015). Therefore, the ethical dimensions inherent to research in low-resource settings was firmly on the agenda of a range of policy and research actors, as well as mental health practitioners. The focus of my thesis proposal was informed by discussions with an evolving professional network engaged in global mental health research and humanitarian practice, as well as being in-line with my interdisciplinary academic background and existing research skills. From these foundations a PhD to explore researchers' perspectives on the ethical conduct of research in post-conflict settings in South Asia was proposed and submitted for PhD funding. This focus effectively synergised my previous interests, drawing upon my cross-disciplinary academic training, personal experiences of mental health services, and the needs of communities affected by displacement, conflict, and disaster; as well as effectively responding to an area identified by colleagues as requiring further

investigation. Notably, my focus upon researchers' experiences of research ethics added a novel contribution, empirically investigating ethics to contribute both to the knowledge on ethical research conduct, as well as to the evolving field of empirical ethical research.

A final disciplinary consideration is the reflexivity inherent to conducting research into research ethics. This brought a certain level of pressure to be seen to be "doing" ethics "right", for example in the ethical review process or when enacting informed consent with participants. In this regard I identify my position at the start of this study as theoretically informed, grounded in a procedural understanding of ethics. This was challenged during research conduct, and evolved to become a position that embraced researcher flexibility to balance procedural requirements and responding to the situated context in which ethical procedures are enacted. For example, challenges encountered included adjusting the informed consent *process* from the Western formalised and legalised model, to something more appropriate to the socio-cultural norms and expectations in each South Asian setting. This included adjusting formal legalistic terminology about criminal behaviour and protection concerns to identifying the ethical responsibility to respond to concerns about "harm to participants or self". Adjusting the positioning of these statements arose through comments and discussion with local researchers about how they position such statements when conducting their research. Therefore, as well as gathering data on researchers' experiences of research ethics, I was also in a position where my own practice was being shaped and moulded by the experiences of my research participants who challenged my own conception of what "ethical practice" entails.

Functional positionality

This section briefly discusses key features of functional positionality, focussing upon the researcher-participant relationship. Functional positionality between the interpreter and researcher, and between the interpreter and participants, are discussed in the subsequent methodological paper on interviewing with interpreters (Chiumento *et al.*, 2017b), therefore will not be covered here.

Positionality vis-a-vis research participants was of a highly educated and privileged female with professional relationships with senior staff at each organisation. Balancing being a guest hosted by partner organisations alongside running my own project with dedicated staff and ensuring data collection progressed in a timely and efficient manner necessitated continual project management. This included responding to the availability of researchers for interviews, and adjusting travel plans according to considerations outside my control such

as severe weather or participants needing to travel. Therefore, research conduct required responsiveness to changing context, and was viewed as a collaborative endeavour in which hosting organisation facilitated the logistics in order that I focus upon the task of data collection.

Prior organisational narratives about who I was frequently prioritised my “expert” status above other characterisations such as “student”. Being presented to each organisation as conducting a study on ethics and an expert in research ethics may have led to interview bias. Efforts were made to minimise this preconception at the start of interviews when the aim of understanding the topic from the perspective of participants was emphasised. Equally prior relationships with some participants led to a more informal dynamic to interviews, often producing more candid responses. This informality also required attention to “taken-for-granted” shared understanding of topics, with efforts made to probe in interviews so that the participants spelt-out their thinking to make this explicitly available for analysis.

Finally, managing professional relationships in informal situations including sharing accommodation with researchers (in C2), and socialising at lunchtimes and in the evenings with researchers and interpreters in all three countries, created porous professional boundaries. In these informal interactions I was conscious to demonstrate cultural awareness, for example through adapting to local customs related to dress, food, and mealtimes. I also sought to acquire basic elements of the local language to be able to communicate with organisational staff and locals who did not speak English. These efforts were recognised to contribute to an overall impression of my approach as one of genuine interest in the views, customs, language, and culture of each country. These informal efforts were commented upon by participants and staff of hosting organisations, and were felt to support relaxed and open interview discussions founded upon mutual respect.

Tracking evolving positionalities

This section has sought to render explicit my positionality in relation to the PhD research topic from personal, disciplinary, and functional perspectives. Attention to shifting and evolving positionality throughout the conduct of research was achieved through the maintenance of a reflective research diary, and discussions with supervisors that stimulated reflexivity²⁰. Documenting reflections in this way has been important for writing

²⁰ An example extract from e-mail correspondence with supervisors reflecting upon the conduct of interviews in C1 is provided in Appendix 4.

methodological papers, as well as for shaping what was looked for and “seen” during the process of data analysis. In the methodological paper on working with interpreters (Chiumento *et al.*, 2017b), and in the discussion chapter, various challenges to the assumptions to, and evolution of, the researchers’ positionality are discussed. Therefore, efforts have been made to evaluate positionality at the study outset, and throughout the conduct of research, data analysis, and write-up.

Ethical considerations

For this study key ethical considerations include protecting the rights of research participants and the organisations which they represent, ensuring voluntary informed consent, maintaining confidentiality and anonymity, the management and storage of data, and research funding. Details of research risks and benefits, how participants were approached and recruited, obtaining informed consent, terms of reference with organisations hosting the study, and a position statement on ethical research reporting all form part of the research protocol (Appendices 1 and 5²¹) submitted alongside applications for ethical approval in all three countries, and will not be reiterated here.

This section discusses ethical considerations that were impacted during the course of research to detail how these were managed. These include obtaining and amending ethical approval for research, participant reimbursement for time and travel expenses, detail on the roles of interpreters and transcribers not covered in later methodological papers, evolving data management procedures, and the management of researcher safety. Therefore, this section considers the active management of emerging ethical issues as they evolved throughout the research process, recognising that ethics arises throughout study planning, conduct, and analysis (Hammersley, 2006); with decisions made in the context of practical factors and researcher prudence (Hammersley and Traianou, 2012). The discussion presented here is complemented by ethical reflections offered in the discussion chapter.

Ethical approval

Ethical review was conducted in each country, with approval from all three countries obtained in advance of applying for ethical approval from the University of Liverpool’s Institute of Psychology, Health and Society Research Ethics Committee, who have ultimate

²¹ Please note that in the original study protocol research was anticipated to involve individual in-depth interviews, followed by participatory workshops. Upon reviewing the depth and breadth of data collected through individual in-depth interviews, it was decided that workshop discussions were not required and would place unnecessary burden on both the participant’s and researcher. Therefore, these were removed from the study design.

oversight of this research. Having in-country review prior to institutional review aims to allow the University of Liverpool to defer socio-cultural considerations pertinent to ethical review to country-level Ethical Review Boards (ERBs) with local knowledge and experience to address these. This follows the University of Liverpool's routine practice (University of Liverpool, 2016b; University of Liverpool, 2016a).

Following approval for the original research protocol, it was decided to remove conduct of participatory workshops from the research process. This necessitated submission of amendment letters to all ERBs overseeing conduct of this study. This amendment was accepted and approved by all ERBs. Alongside this amendment a mid-point study report was provided to all in-country ERB's, detailing study progress and preliminary findings.

Reimbursement for time and travel expenses

Participants were provided reimbursement of travel expenses and time for study participation, to a maximum value of £25 per participant. This value was set through discussions with in-country representatives, and follows the anticipated loss of earnings in C2 which had the highest salaries of the three participating countries.

In C1 and C3 reimbursement was given in the form of a gift (a USB pen drive and a notebook) rather than as money, with the gift agreed with organisational representatives. In C1 the researcher travelled to field sites, whilst in C3 costs of participants travel to the city where the researcher was based were reimbursed. In C2 due to the research assistants having moved on to other job roles money was provided for travel expenses and time. For mid-level researchers in C2 a donation was made to a staff-fund for social activities, as per the request of participants. These differing approaches were considered acceptable as decisions were led by the requests and needs of participants, recognising that reimbursement for travel expenses and time to participate in research should be meaningful for the participant (Zwi *et al.*, 2006; O'Mathuna, 2010).

Refreshments were provided for participants during information events, interviews, and dissemination, according to the time of day and local customs. No further incentives were offered.

Interpreters and transcribers

The inclusion of interpreters brings with it specific methodological and ethical considerations (Chiumento *et al.*, 2017b). Here, the focus is upon the procedural ethical management of the role of interpreters in this study.

Interpreters were paid a locally appropriate salary agreed with in-country representatives (similar to the rates paid for research assistants in each country), and their daily lunches were paid for. When conducting fieldwork at sites other than the main office expenses for travel, accommodation, and subsistence were paid directly by the researcher.

Interpreter positions were publicised through advertisements on job websites in C1 and C2. In all three countries organisations promoted the interpreter positions through informal networks with which they were affiliated. The latter approach of informal networks was the most effective at identifying appropriate and motivated candidates from which all interpreters were drawn. The prior relationships between organisations and the selected interpreters also served to enhance the integration of interpreters into the daily functioning of organisations with which they were already broadly familiar.

All interpreters and transcribers were required to sign confidentiality agreements after being appointed to their role. Both interpreters and transcribers participated in a 3 day training in interpreting for research purposes, and transcribers received additional targeted training in their transcription role (Chiumento *et al.*, 2017b). Interpreters were supervised throughout data collection by the researcher. For the transcription team a team leader with prior transcription experience was appointed as the first point of contact for the transcribers to approach for support, with the researcher meeting regularly with the team leader to discuss progress and refine targets. Clear lines of supervision by those with the skills and training to provide support were crucial in this study employing lay interpreters and transcribers who may require additional guidance to carry out their roles effectively.

Interpreters and transcribers were provided letters attesting to their role in this study. The researcher also offered to act as a referee for subsequent job roles if appropriate. To date the researcher has been requested to provide references for two interpreters who participated in this study, and in C1 one interpreter continues to work for the organisation hosting the study.

Data transportation and storage

This section details additional considerations to those outlined in the research protocol (Appendix 1) that arose during research conduct.

Due to the sites of research conduct data was transferred across international borders, therefore concern for data security was paramount. All interviews were recorded on a digital Dictaphone and transferred onto a University laptop immediately after the interview had concluded. Where possible these recordings were uploaded onto the University's secure

M:Drive for storage. Awareness of challenges of internet infrastructures in the research settings were known in advance. Therefore, in coordination with the University of Liverpool it was agreed to encrypt the University laptop so that data could be temporarily stored on the laptop's C:Drive, to be transferred onto the M:Drive upon return to the UK. Files on the Dictaphone were deleted following transfer of the audio onto secure drives.

For transcription all files were put onto USB pens bought specifically for this project. Each interpreter and transcriber had their own USB pen that contained the files they were working on, and all agreed not to transfer files onto the hard drive of their personal or allocated work computers. Transcription in the third country continued beyond the time that the researcher was in-country, and therefore files of final transcripts were shared via e-mail. To protect documents in this transfer all files were password protected, with passwords agreed prior to the researcher leaving the country. All USB's were collected by the host organisation on behalf of the researcher and stored in a locked safe until a subsequent visit by the researcher, when they were collected and brought to the UK for storage alongside other digital data (see below).

All paper documentation including signed organisational agreements and informed consent forms; contracts of employments for interpreters and transcribers; and research diaries belonging to the researcher and the interpreters were transported in hand luggage when being brought back to the UK, ensuring data was not accessed by third parties. Once in the UK this data was placed in a secure locked cabinet on University campus to which only the researcher has a key. Digital data, including audio files, NVivo transcripts, and word files, were stored on secure University M:Drive, or USB pens in password protected documents.

Safety considerations

Conducting research in potentially unstable settings in South Asia requires attention to considerations of researcher safety. The primary consideration underpinning the approach to safety in this project is that the researcher "cannot always be expected to work in safety and security" (Kovats-Bernat, 2002, p. 210), and adopts a partnership approach that prioritises organisations contextual knowledge and experience of hosting external researchers (Emanuel *et al.*, 2004; Alden *et al.*, 2009).

Safety was incorporated as an ethical consideration in a Terms of Agreement with organisations in each country (as an appendix to the core research protocol, see Appendix 5). This addressed considerations such as accommodation, transportation, and moving around local settings alone. Safety was actively managed through deference to the

recommendations of local in-country organisations who provided advice on travel timelines, and accommodation and transportation choices. Furthermore, a risk assessment was completed for each research site, approved by organisational representatives and filed with the University as part of the process of obtaining ethical approval for study conduct. Due to terrorist activity shortly before the conduct of fieldwork in C3 an additional Protocol was developed with the hosting organisation which addressed considerations such as moving of accommodation half way through fieldwork visits, varying daily transportation routes, recommendations to only make essential journeys, and when in public to always be in the presence of a local staff member.

In addition to these procedural steps I participated in University risk seminar on planning for conducting fieldwork abroad, and ESRC seminars that consider and sensitise to the ethical and safety issues associated with conducting fieldwork in unstable contexts²². Having experience of working in these country settings, particularly C3 which was the most unstable, also provided important awareness to managing safety.

Funding statement

The researcher is fully funded by an Economic and Social Research Council (ESRC) +3 PhD Studentship. This award is for the period 01/10/2013 – 30/12/2017²³. Student number: 200863693.

Additional funding of £9428.00 was awarded by the ESRC Overseas Fieldwork Allowance. Fieldwork funding was supplemented by additional income obtained from other sources, for example through underspent funds provided for the researcher to attend a meeting. Expense claims for fieldwork with accompanying receipts (where possible) have been submitted and approved by the ESRC.

Conclusion

This chapter has examined the research epistemology and methods, complemented by an exploration of researcher positionality and evolving management of ethical issues that arose during research conduct. The epistemological, theoretical, and disciplinary orientations

²² These include “Social research in conflict affected areas” at Sussex University, attended in June 2014; an ESRC half-day on research ethics which included safety considerations; the University of Liverpool’s online Researcher Integrity course which addresses researcher safety, completed in February-April 2014; and a Fieldwork Coordinators Safety Training in February 2014.

²³ A 3 month extension was provided though additional ESRC funding for undertaking an internship with the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergencies.

identified in this chapter will continue to be drawn upon in subsequent papers that consider specific methodological considerations that arise when conducting qualitative research with interpreters, and when interviewing via online platforms. In the data analysis chapter many of the theoretical considerations discussed here are applied to the process of data analysis. Finally, the discussion chapter includes a reflexive analysis of my experience of the research process.

References

- Allden, K., Jones, L., Weissbecker, I., Wessells, M., Bolton, P., Betancourt, T. S., Hijazi, Z., Galappatti, A., Yamout, R., Patel, P. and Sumathipala, A. (2009) 'Mental health and psychosocial support in crisis and conflict: report of the Mental Health Working Group', *Prehospital and Disaster Medicine*, 24(Suppl 2), pp. s217-s227.
- Beauchamp, T. L. and Childress, J. F. (1989) *Principles of biomedical ethics*. 3rd edn. New York: Oxford University Press.
- Beauchamp, T. L. and Childress, J. F. (2013) *Principles of biomedical ethics*. 7th edn. New York: Oxford University Press.
- Bramberg, E. B. and Dahlberg, K. (2013) 'Interpreters in cross-cultural interviews: a three-way coconstruction of data', *Qualitative health research*, 23(2), pp. 241-247.
- Brentano, F. (1973) *Psychology from an empirical standpoint*, translated by Rancurello, A., Terrell, D.B, and McAlister, L. L. New York: Humanities Press.
- Bryman, A. (1988) *Quantity and quality in social research*. London: Unwin Hyman.
- Chiumento, A., Machin, L., Rahman, A. and Frith, L. (2018) 'Online interviewing with interpreters in humanitarian contexts', *International Journal of Qualitative Studies in Health and Well-being*; 13(1), pp. 144487-144496
- Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online early view, pp. 1-19.
- Chiumento, A., Rahman, A., Machin, L. and Frith, L. (in preparation) 'Writing to template: researchers' perspectives of procedural ethics in mental health research in post-conflict settings', *unsubmitted*.

- Curry, D., Waldman, R. and Caplan, A. (2014) *An Ethical Framework for the development and review of health research proposals involving humanitarian contexts*. [Online]. Available at: http://www.elrha.org/wp-content/uploads/2015/01/FINAL-R2HC-Ethical-Framework_Final-Report_24-January-2014_0.pdf (Accessed: 03.02.2014).
- Draper, H. and Ives, J. (2007) 'An empirical approach to bioethics: social science 'of', 'for' and 'in' bioethics research', *Cognition, Brain, Behavior*, 11(2), pp. 319-330.
- Dunn, M., Parker, M., Sheehan, M. and Hope, T. (2012) 'Toward methodological innovation in empirical ethics research', *Cambridge Quarterly of Healthcare Ethics*, 21(4), pp. 466-480.
- Emanuel, E. J., Wendler, D., Killen, J. and Grady, C. (2004) 'What makes clinical research in developing countries ethical? The benchmarks of ethical research', *Journal of Infectious Diseases*, 189(5), pp. 930-937.
- Emerson, R. M., Fretz, R. I. and Shaw, L. L. (1995) *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press.
- Frith, H. and Gleeson, K. (2012) 'Qualitative data collection: asking the right questions', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester: John Wiley & Sons., pp. 55-68.
- Frith, L. (2009) 'Process and consensus: ethical decision-making in the infertility clinic—a qualitative study', *Journal of Medical Ethics*, 35(11), pp. 662-667.
- Frith, L., Jacoby, A. and Gabbay, M. (2011) 'Ethical boundary-work in the infertility clinic', *Sociology of Health and Illness*, 33(4), pp. 570-585.
- Gadamer, H. G., Weinsheimer, J. and Marshall, D. G. (2004) *Truth and method*. London: Continuum.
- Gobo, G. (2008) 'Re-conceptualizing generalization: old issues in a new frame', in Alasuutari, P., Bickman, L. and Brannen, J. (eds.) *The SAGE handbook of social research methods*. Los Angeles, California: SAGE Publications [electronic book], pp. 193-213.
- Green, J. and Thorogood, N. (2014) *Qualitative methods for health research*. 3rd edn. London: SAGE Publications.
- Green, R. (1990) 'Method in Bioethics: A Troubled Assessment', *Journal of Medicine and Philosophy*, 15(2), pp. 179-197.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.

Haimes, E. (2002) 'What can the social sciences contribute to the study of ethics? Theoretical, empirical and substantive considerations', *Bioethics*, 16(2), pp. 89-113.

Hammersley, M. (2006) 'Are ethics committees ethical?', *Qualitative Researcher*, 2, pp. 4-8.

Hammersley, M. and Traianou, A. (2012) *Ethics in qualitative research: controversies and contexts*. SAGE Publications [electronic book].

Harper, D. (2012) 'Choosing a qualitative research method', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester: John Wiley & Sons., pp. 83-97.

Husserl, E. (1971) "'Phenomenology" Edmund Husserl's Article for the Encyclopaedia Britannica (1927): New Complete Translation by Richard E. Palmer', *Journal of the British Society for Phenomenology*, 2(2), pp. 77-90.

Inter-Agency Standing Committee (IASC) (2007) *IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings*. Geneva: IASC. [Online]. Available at: http://www.who.int/mental_health/emergencies/guidelines_iasc_mental_health_psychosocial_june_2007.pdf.

Kant, I. (2007 [1781]) *Critique of pure reason*. Revised second edition. Translated by Smith N. K. Edited by Caygill, H., Banham, G. and Smith, N. K. Springer [electronic book].

Kinard, E. M. (1996) 'Conducting research on child maltreatment: Effects on researchers', *Violence and Victims*, 11(1), pp. 65-70.

Kingori, P., de Vries, R. and Orfali, K. (2013) 'Introduction: Special issue introduction: Bioethics in the field', *Social Science & Medicine*, 98, pp. 260-263.

Kovats-Bernat, J. (2002) 'Negotiating Dangerous Fields: Pragmatic Strategies for Fieldwork Amid Violence and Terror', *American Anthropologist*, 1, pp. 208-222.

Moran, D. and Mooney, T. (2002) *The phenomenology reader*. London: Routledge.

O'Mathuna, D. P. (2010) 'Conducting research in the aftermath of disasters: ethical considerations', *Journal of Evidence Based Medicine*, 3(2), pp. 65-75.

Patel, V. (2007) 'Mental health in low- and middle-income countries', *British Medical Bulletin*, 82-81(1), pp. 81-96.

Portc, M. (2013) 'Phenomenology of Intentionality', in Fiset, D. and Fréchette, G. (eds.) *Themes from Brentano*. Amsterdam: Rodopi, pp. 165-188.

Rapley, T. (2007) 'Interviews', in Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative research practice*. London: SAGE Publications, pp. 15-34.

Robson, C. (2011) *Real world research : a resource for users of social research methods in applied settings*. 3rd edn. Chichester: John Wiley & Sons Ltd.

Rubin, H. J. and Rubin, I. S. (2005) *Qualitative interviewing: the art of hearing data*. 2nd edn. Thousand Oaks, California: SAGE Publications.

Schutz, A. (1944) 'The Stranger: An Essay in Social Psychology', *American Journal of Sociology*, 49(6), pp. 499-507.

Schutz, A. (1945) 'On multiple realities', *Philosophy and Phenomenological Research*, 5, pp. 533-576.

Schutz, A. (1967) *The phenomenology of the social world*. Evanston: Northwestern University Press.

Schutz, A. (1975) *Alfred Schutz on phenomenology and social relations: selected writings*. 3rd edn. Edited by Wagner, H. Chicago: University of Chicago Press.

Silverman, D. (2013) *Doing qualitative research*. 4th edn. London: SAGE Publications.

Smith, M. J. (1998) *Social science in question*. London: SAGE Publications in association with the Open University.

Spencer, L. and Richie, J. (2012) 'In pursuit of quality', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester John Wiley & Sons, pp. 227-242.

Taussig, M. T. (1980) 'Reification and the consciousness of the patient', *Social Science and Medicine*, 14(1), pp. 3-13.

The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research (1979) *Ethical Principles and Guidelines for the Protection of Human*

Subjects of Research (The Belmont Report). Department of Health and Human Services, U. [Online]. Available at: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>.

Thornicroft, G. (2006) *Shunned: discrimination against people with mental illness*. Oxford: Oxford University Press.

United Nations Development Program (UNDP) (2015) *Human Development Report 2015*. New York. [Online]. Available at: http://hdr.undp.org/sites/default/files/2015_human_development_report.pdf. (Accessed: 04.07.2017).

United Nations Educational Scientific and Cultural Organization (UNESCO) (2015) *eAtlas of Literacy*. Available at: <http://www.uis.unesco.org/data/atlas-literacy/en> (Accessed: 04.07.2017).

University of Liverpool (2016a) *Policy on ethical approval for research involving human participants, tissues or personal data*. Liverpool: University of Liverpool.

University of Liverpool (2016b) *Policy on the research ethics review of studies taking place at an overseas research site*. Liverpool: University of Liverpool.

Vaismoradi, M., Turunen, H. and Bondas, T. (2013) 'Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study', *Nursing & Health Sciences*, 15(3), pp. 398-405.

van Manen, M. (1990) *Researching lived experience: human science for an action sensitive pedagogy*. State University of New York Press [electronic book]. Available at: <http://ebookcentral.proquest.com/lib/liverpool/detail.action?docID=3408268>.

Wengraf, T. (2001) *Qualitative research interviewing: biographic narrative and semi-structured methods*. London: SAGE.

World Bank (2017) *World Bank Country and Lending Groups*. Available at: <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups> (Accessed: 04.07.2017).

World Health Organisation (2001) *Legal Status of Traditional Medicine and Complementary/Alternative Medicine: A Worldwide Review*. New York. [Online]. Available at: <http://apps.who.int/medicinedocs/en/d/Jh2943e/> (Accessed: 04.07.2017).

World Health Organisation (2015) *Ethics in epidemics, emergencies and disasters: research, surveillance and patient care: training manual*. Geneva. [Online]. Available at: http://apps.who.int/iris/bitstream/10665/196326/1/9789241549349_eng.pdf (Accessed: 04.06.2017).

World Health Organisation (2017) *Countries*. Available at: <http://www.who.int/countries/en/> (Accessed: 04.07.2017).

Yin, R. K. (2009) *Case study research: design and methods*. 4th edn. Los Angeles, California: SAGE Publications.

Zwi, A. B., Grove, N. J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D. and Tarantola, D. (2006) 'Placing ethics in the centre: negotiating new spaces for ethical research in conflict situations', *Global Public Health*, 1(3), pp. 264-277.

MEDIATED RESEARCH ENCOUNTERS: METHODOLOGICAL CONSIDERATIONS IN CROSS-LANGUAGE QUALITATIVE INTERVIEWS

Abstract

Given increasing globalisation, the continuing prevalence of emergencies, and the importance of rigorous research to ensure the mental health needs of populations exposed to emergencies are effectively met, cross-language research will continue to arise. Drawing upon the lead author's experience of conducting 35 interviews for a cross-language qualitative study in three post-conflict settings in South Asia, this article discusses methodological considerations raised when interviewing with interpreters. These include considering interpreter positionality and matching; the approach to cross-language mediation during interviews; and assessing the quality of interpreter facilitated interviews. Drawing upon approaches taken in this study, the important choices researchers face about how these are managed are examined, considering the roles of researcher and interpreter positionality, the research context, and the epistemological underpinnings of the research. The discussion further illuminates the interrelated methodological, practical and ethical considerations for other researchers embarking upon similar research.

Introduction

Acute and protracted humanitarian emergencies can have wide-ranging effects on mental health (Inter-Agency Standing Committee (IASC), 2007). To address these requires academic, operational, and policy oriented research. Cross-language research in emergencies arises for three primary reasons: first, technical research expertise is frequently found outside the settings where emergencies occur; second, emergencies are rarely contained to one country or population and commonly traverse national borders, for example earthquakes or conflicts; and third, research is increasingly international in nature. Under these circumstances research often needs multiple-language skills unlikely to be found in a single investigator, requiring interpreters to facilitate communication.

Recognising that a key principle of ethical research is to utilise sound research methods, this paper aims to extend methodological discussions, addressing the critique that researchers fail to adequately consider the implications of interpreter facilitated qualitative interviews (Squires, 2009; Williamson *et al.*, 2011; Shimpuku and Norr, 2012). Drawing upon the lead authors' (AC) conduct of a cross-language qualitative study in three post-conflict settings in South Asia, the study is outlined before raising methodological considerations when interviewing with interpreters. These are illustrated with examples and reflections from the

study before drawing conclusions about interrelated methodological, practical and ethical considerations for researchers embarking upon similar research.

The study: ethics in mental health research in post-conflict settings

This qualitative multi-site study (Yin, 2009) involved interviews with researchers engaged in mental health research in three post-conflict settings in South Asia. Adopting a phenomenological orientation (Schutz, 1945), the research emphasised the lived-through quality of researchers' experiences of ethics by empirically exploring how ethics is defined, understood, applied and managed in everyday research practice

Epistemologically, where the researcher is placed on the continuum between positivism and interpretivism/constructivism has implications for the interpreter's role (see Temple and Young (2004) for a discussion). In this study the phenomenological orientation calls for interpreters to occupy an active role, viewed as co-producers of research where translation is central to knowledge production (Temple and Young, 2004). Given multiple research sites that necessitate multiple interpreters, the interpreter was viewed as an extension of the researcher rather than joint-interviewer (Faller, 1985), with all interpreter-facilitated interviews led by AC.

AC is a white British female in her early thirties. Being British and conducting research in South Asia brought connotations of British colonial histories. AC's positionality vis-a-vis research participants was of a highly educated and privileged female with professional relationships with senior staff at each organisation. Prior organisational narratives frequently prioritised AC's "expert" status above other characterisations such as "student".

Thirty-five individual in-depth interviews were conducted at six field sites across three South Asian countries; and in the UK (see table 7). A semi-structured topic guide was developed to steer interviews, exploring participant's views of procedural and in-practice ethics from the participants' perspective (Guillemin and Gillam, 2004), complemented by remaining open to emerging meanings and the iterative evolution of interview topics (Rapley, 2007; Yin, 2009). Only one participant spoke English as a first language and the researcher did not speak the participants' languages making interpreters essential. 25 interviews were conducted with interpreters; the remaining participants spoke in English.

Table 7: Interview overview

	Country 1 (C1) September 2014		Country 2 (C2) December 2014		Country 3 (C3) January – February 2015	
Number of interviews	17		9		9	
Interview location						
UK	-		2		1	
In-country (no. of sites visited)	17 (3)		7 (2)		8 (1)	
Interpreter involvement	Without interpreter	With interpreter	Without interpreter	With interpreter	Without interpreter	With interpreter
All interviews	4	13	5	4	2	7
Primary Investigators	2	-	2	-	1	-
Research / field coordinators	2	1	2	-	1	1
Data collectors	-	12	1	4	-	6

Interpreters were hired in-country and, where possible, at the local field site. Selection interviews were conducted jointly with local organisations. Two interpreters were hired in each country, one to participate in interviews (“interview interpreter”) and the second to conduct a quality check (“quality check interpreter”). Attention was paid to the preferred national (C1) or regional language of participants (C2 and C3). Despite these efforts, in C2 difficulties arose in one interview due to the participants’ use of a sub-dialect; and in C3 an interpreter who spoke the participants’ regional dialect could not be found meaning interviews were conducted in the national language shared by interpreters and participants.

Ethics

Ethical approval was obtained from the University of Liverpool and each South Asian country. Voluntary written informed consent was provided by all participants. To protect confidentiality, all research sites and participant names have been anonymised. Interpreters were paid a local salary, provided certificates of participation in training, and a reference letter outlining their role in the research.

Cross-language interpreter mediated interviewing

This paper defines an interpreter as someone who translates from a source to a target language, transferring meaning based upon vocabulary, grammar, expression, context, and culture (Esposito, 2001; Regmi *et al.*, 2010). The interpreter is seen as an active co-constructor of data influenced by their intersubjectivities (Temple, 2002; Berger, 2015),

occupying a role that involves “seeking, contributing to, eliciting, or limiting the attainment of data” (Caretta, 2015). Consequently, interpretation is understood as reconstruction rather than the discovery of meaning (Temple and Young, 2004) where participants’ words are not *recreated* but *re-presented*. This paper discusses how the interpreter role was approached in this study, charted through research stages of prior to, during, and post-interviews, aiming to critically engage with methodological discussions on cross-language qualitative research with interpreters. The discussion then considers the interconnected nature of epistemological, methodological, and practical considerations when conducting interpreter-facilitated qualitative interviews.

Prior to interviews

Prior to commencing research, interpreters’ professional credentials and positionality, and the approach to training and supervision to ensure interpreter competency, must be considered.

Professional credentials and recruitment

Interpreters in this study were “lay” i.e. did not have interpreting qualifications or experience. All interpreters had a minimum of high school education (including English language), prior exposure to qualitative research methods, and a basic knowledge of and interest in mental health. In C2 whilst professional interpreters were available the remote research sites prevented their involvement. This reinforces that when conducting research in unstable settings the availability of professional interpreters can be limited, necessitating alternative approaches (Inhetveen, 2012). For this study conducted in countries with recent histories of conflict, being locally embedded was prioritised over formal interpreting qualifications (Wallin and Ahlstrom, 2006; Ficklin and Jones, 2009; Inhetveen, 2012; Shimpuku and Norr, 2012). A limitation to this approach is that the interpreter occupies a dual interpreter/gatekeeper role which carries methodological implications by actively or passively influencing the population research reaches, and potentially affecting narratives constructed in front of an interpreter perceived as a community “insider” or “outsider” (Hynes, 2003).

In C1 and C2 recruitment advertisements were placed on recruitment websites, and in all three countries partner organisations promoted the roles within their networks. Interviews were conducted with a partner organisation representative and involved an aural translation exercise, translating sections of an information sheet of an unrelated project from the source into the target language and vice versa. This provided a crude measure of each applicant’s

aural translation competency. Interviews also involved discussions about applicant's backgrounds, prior experience with qualitative research methods and the mental health field. Finally, availability for the study period (duration of employment, length of working days, and any required travel) were discussed. Decisions on who to hire for each interpreter role were made via consensus between the researcher and organisational representative.

Approach to equivalence across languages

A key consideration for interpreter mediated qualitative interviews is the approach to maintaining equivalence across the source and target languages (Squires, 2009; Sutrisno *et al.*, 2014). It is important to specify the approach in advance of interviews to ensure the interpreter places the correct emphasis upon translation of individual words or overall meaning. Sutrisno *et al.* (2014) define three types of equivalence: (1) lexical equivalence concerned with individual words; (2) conceptual equivalence focussing upon ideas or concepts; and (3) dynamic equivalence emphasising reproduction of the message in the most natural manner for the target language user. As dynamic equivalence is prominent in written translation rather than aural interpretation, and lexical equivalence has acknowledged limitations (Temple, 2002; Croot *et al.*, 2011; Sutrisno *et al.*, 2014), these will not be discussed further.

Conceptual equivalence involves: "remaining as close as possible to participants' words and being mindful not to embellish some points and/or omit others that are perceived by the interpreter as unimportant, irrelevant, or inappropriate" (Williamson *et al.*, 2011, p. 384). The interpreter moves beyond the 'correct' *word* towards the *meaning* embedded within language, recognising that this process may necessitate contracting or expanding the original meaning to achieve conceptual equivalence (Sumathipala and Murray, 2006). Consequently, the mediation of participant narratives by interpreters is privileged over exact replication of words which are not *recreated* but *re-presented* in context (Ficklin and Jones, 2009). This highlights the importance of discussing the choices made to maintain conceptual equivalence (Croot *et al.*, 2011) prior to, during, and post-interviews.

This study recognised that "all researchers in a sense 'translate' the experience of others and it is only possible to get as close to describing a phenomenon as language will allow" (Croot *et al.*, 2011, p. 1009). This contrasts with the view that interpreter-facilitated research cannot follow a phenomenological epistemology due to interpretation disrupting a focus upon language used to describe experiences (Squires, 2009). This studies' phenomenological

orientation emphasised conceptual understanding of participants' experiences of research ethics, analysing themes relating to experience and meaning rather than the use of language.

To enhance contextual understanding of organisational discourses regarding research ethics AC undertook documentary analysis of research materials and conducted preparatory visits. These supported training discussions about specific terms in each organisations context. For example in C1 the term "training" referred to accredited qualifications, whilst fieldwork training was termed "orientation"; and fieldworkers were given a "protocol" containing informed consent scripts and standardised questionnaires. These terms - "training" and "protocol" - were in the interview topic guide and their use could have distorted findings without this contextual understanding.

Whilst striving for conceptual equivalence, a challenge in this study was that translation of technical terms associated with mental health and research ethics central to the topic was impossible (Bolton and Weiss, 2001; Temple, 2002; Regmi *et al.*, 2010; Sumathipala and Murray, 2006), including the term "ethics". Here the English terms "ethics" or "interview" meant more to participant's than the closest local equivalent, with this reflected in their use of these English terms as a natural feature of speech.

Training

Borrowing from the "task-shifting" approach whereby lay people deliver mental healthcare in low resource environments (Murray *et al.*, 2011), AC provided targeted training and ongoing supervision to lay interpreters. A three day experiential training covered topics identified for effectively preparing the researcher and interpreter for cross-language interviews (outlined in figure 3) (Jentsch, 1998; Kapborg and Berterö, 2002; Ficklin and Jones, 2009; Croot *et al.*, 2011; Williamson *et al.*, 2011). Training emphasised that interpretation should minimise filtering or summarising, and introduced strategies for interpreters to negotiate the interview (Wengraf, 2001), such as requesting a pause to discussions whilst a segment of conversation was translated (Bolton and Weiss, 2001; Bramberg and Dahlberg, 2013).

Figure 3: Outline of interpreter training

- Researcher and interpreter introductions: games to get to know one another's family / educational background and previous experiences of research;
- Introduction to the research topic ;
- Introduction to key principles of qualitative interviewing;
- Guidance on the interpreter's role in interviews or quality checks;
- Guidelines on approach to interview interpreting, emphasising use of the third person, retaining conceptual equivalence, and reporting back to the researcher independent exchanges with participants;
- Exercises to translate the topic guide, exploring foreseeable interpretation difficulties;
- Key principles of research ethics, stressing confidentiality, professional conduct, and self-care.

To continue building competency peer supervision was conducted throughout interviews. This involved debriefings with the researcher and interview interpreter immediately after each interview, quality checks (discussed below), and informal discussions of research progress, all documented in field notes (Wallin and Ahlstrom, 2006; Williamson *et al.*, 2011).

Interpreter positionality

Interpreter positionality was explored during training, interview conduct, and in a closing discussion that considered the interpreter's backgrounds and views on the research topic prior to, during, and post-interviews. Drawing exercises during training included designing a flag with symbols to illustrate things of importance such as family, education, values, and religious beliefs; and illustrating personal and professional backgrounds. Drawings were undertaken by the researcher as well as the interpreters, and were used as a springboard for informal discussions about socio-demographic backgrounds and pathways to the study, including views on the research topic and qualitative interviewing. These activities provided cultural insights for the researcher, for example in C1 learning about the caste system and national dishes, and in C2 about subtle regional dialect differences and interpreter prejudices towards a specific religious minority and attitudes towards mental health. They also allowed interpreter's to understand the researchers personal and professional background.

Interview debriefing and supervision, an exit discussion at the end of the study, and ongoing discussions about study progress and everyday lives throughout data collection all provided opportunities to capture evolving positionalities. Conducting these activities informally has the advantage of allowing in-situ responses to how interpreter and researcher positionalities influence the data produced (Ficklin and Jones, 2009). Furthermore, from the researchers'

perspective, repeated conduct of these activities in each country over time facilitated self-reflection upon an evolving positionality when interviewing with interpreters (Caretta, 2015).

Whilst these efforts informed a sense of the various positionalities of each interpreter, when working with multiple interpreters across settings as short-term hires it remains impossible to gain a full understanding of each interpreter's positionality to fully account for the impact upon data. This is founded upon recognition of the inherent difficulties to situating one's own positionality as a researcher. Therefore whilst important to explore, efforts to understand the positionalities of interpreters can only ever be partial (MacKenzie, 2016).

Matching

Study participants were mental health researchers familiar with research interviews, many of whom regularly interacted with international researchers. Consequently, interviews were viewed as a domain in which all parties understood the norms governing the interaction (Wengraf, 2001). Participants' backgrounds enabled researcher-interpreter socio-demographic matching to be prioritised over participant-interpreter matching beyond shared language. This approach has been found to enhance interpreter-researcher working relations, whilst influencing participants' perceptions of the researcher's role (Jentsch, 1998).

All interpreters were females aged between 20 and 29, with the exception of one male interview interpreter in C3. As experienced by Jentsch (1998), when working with female interpreters the researcher felt more at ease, whereas the relationship with the male interpreter was more formal, resulting in subtle differences in interviewing style. For example, the researcher found the male interview interpreter would challenge the researcher when an alternative approach to interpreting in interviews was requested, suggesting that researcher-interpreter gender matching can be important in settings with strong patriarchal norms.

Additionally, in C2, where active conflict had recently ended, interpreter-participant ethnic matching was prioritised alongside interpreter-researcher matching. This factor was not present in C1 or C3 where intra-ethnic tensions were less prevalent. This reinforces the importance of an awareness of setting specific socio-cultural norms which inform how an interpreter's characteristics may affect access to participants and impact interview narratives (Ficklin and Jones, 2009).

During interviews:

When an interpreter mediates between people who do not share a common language, methodological and practical decisions must be made about the role they occupy during interviews. These are informed by the underpinning epistemological stance, and inform choices regarding recruitment and interpreter training.

Conduit or independent transmission role

Interpreters in this study occupied a conduit role as co-interviewer, and were requested to avoid filtering or evaluating responses prior to translation as far as this was possible. However, interpreters were given scope to clarify understanding and independently interact with participants: *I: And I ask if they do it, ... here in {Sevit florin} or not? But they said they don't....(RA: C1,114)*. As this example illustrates, interpreter's independently asked probing questions, but were requested to convey these interactions to the researcher to render transparent the interpreter's role in shaping interviews. This balance prioritised the content of translation, whilst recognising the limits to lay interpreters' topic knowledge and skills in qualitative interviewing.

During interviews there were instances that both raised concerns and built confidence in the lay interpreter's skills. For example, despite training on not influencing participant responses, in the first interview in C2 the participant did not understand the term "ethics" and the interpreter asked if she could provide a definition. When discussed in the interview debriefing the interpreter immediately recognised her mistake. As this was the interpreter's first interview this was attributed to nerves and a desire to be successful in the role, and was the only time this occurred. Similar difficulties in C1 led to discussing the strategies the interpreter used during an interview break:

R: Some of the questions he doesn't seem to be understanding.

I: Mmm.

R: Is that, because they're too complicated do you think?

I: No I, I tried to simplify. I tried to make him understand giving examples, but.

(RA: C1,18)²⁴

As the interpreter's investment in the study grew, their interpretation of what was heard evolved, indicated by the introduction of more technical or 'insider' language (Ballantyne *et*

²⁴ In all interview extracts R = researcher; I = interpreter; and P = participant.

al., 2013). For example, in C1 the interpreter would initially clarify her understanding of technical terminology such as “focus group discussion” and “cohort” which later became a natural feature of her speech. Moreover, due to being present in all interviews and surrounded by local languages, the researcher developed recognition of cues to ‘understand’ conversations and pick up the essence of what was said prior to translation (Jentsch, 1998), particularly evident when English technical terms were used by participants:

R: What, what did he say about psychological?

(...)

I: Psychological, it has mentioned something like that. ((R and I Laugh))

R: It's just a, it's one [word that I understood.

I: [Oh yeah he says that...

(RA: C2,I2)

These suggest that interpreters’ and researchers’ familiarity with technical and organisational terminology, local language, and cultural references evolves during the study. This reinforces the importance of monitoring evolving positionalities to consider the impact this may have upon data produced.

Interview as performance

In interviews the social roles of the researcher, interpreter and participant are negotiated in a setting in which impressions are managed by the various performers (Goffman, 1959). Whilst the researcher and interpreter roles can be pre-agreed, triple subjectivities (Temple, 2002), evolving competencies, and interactions with participants can lead to ruptures in role performance (Ficklin and Jones, 2009). Participants in this study utilised strategies to control or negotiate the interview, for example scrutinising the performance of the researcher-as-interviewer: “Yes it’s a good, good question” (Supervisor: C1,I12); “Well I’m thinking now,...of course your questions...make me think right...” (PI: C1,I1). Participants also commented on the interpreters’ performance:

R: Are you all right to continue for another, till 12 o'clock, is that okay?

P: Okay.

I: Yeah. ((All laugh))

I/P: #1:31:15-1:31:22#

R: Don't worry, she can cope. ((All laugh)) Umm.

P: Very skilful. ((I Laughs)).

R: It's a difficult job.

(RA: C1,I11)

Conversely, the interpreter role was established by the researcher during interview introductions:

R: {Interpreter} here, she will translate everything er, questions and answers and you can clarify anything with her. As before, if you understand and you want to respond after I've asked a question in English, feel free. It's up to you if you want to use {Florini}, English, a mix of the two, whatever feels comfortable.

(RA: C1,111)

Consequently, the interpreter's conduit role was established at the interview outset, defined as a static role whilst agency was conferred to participants. Reinforcing the agency of participants, Interpreters invited their comments, additions or corrections to translations:

I: ...if I miss anything please add, [or secondly

*P: [Yes, I can add or I can correct if you say
anything um, not, [not.*

I: [That would be (), yeah.

(RA: C3,18)

Finally, in C2 the interpreter occasionally remarked on the performance of participant-as-respondent: "*she is saying, she is saying good things*" (RA: C2,14). Whilst these comments could lead to concern for influencing participant responses, they are viewed as comparable to comments the researcher made showing interest in what participants' said: "Okay, no that's helpful, I like it a lot" (RA: C1,19).

Post-interviews

Methodological decisions regarding the interpreters' role extend beyond data collection into data analysis and write-up, and flow from the research epistemological stance.

Quality check

The methodological importance of assessing the quality of cross-language interviews is well established as one aspect of qualitative research rigour (Lincoln and Guba, 1985). Interpreter competency can be assessed by an independent interpreter performing a check on interpretation quality (Temple, 1997; Jentsch, 1998; Squires, 2009; Croot *et al.*, 2011; Shimpuku and Norr, 2012). Perspectives regarding the purpose of this check vary. Squires (2009) views it as an opportunity to validate the technical accuracy of translation, an approach critiqued for embodying a positivist notion of obtaining "truth" in translation (Croot *et al.*, 2011). When following an interpretivist epistemology, Croot *et al.* (2011)

recommend exploring the negotiation of meaning through discussion, proposing that those best positioned to undertake quality checks are interpreters with subject knowledge or involved in data generation, rather than with particular linguistic qualifications or skills.

Quality check interpreters for this study participated in training, thus were aware of expectations of the interview interpreter. The aim of the quality check was not to impose a positivist understanding of the “right” interpretation, but to transparently explore layers of interpretation of words and meaning in an effort to ensure faithful representation of underlying concepts intended by participants (Tsai *et al.*, 2004), and to interrogate the impact of interpretation upon the data produced (Temple, 2008). Quality checks assessed how far interpretation followed training, namely: (a) use of the third person to render explicit the interpreter’s role and signal the mediated nature of interviews (Edwards, 1998); and (b) maintenance of conceptual equivalence. The quality check interpreter listened to recordings of each interpreted interview and answered “yes/no” for whether the interpreter used the third person, and whether conceptual equivalence was maintained. Additional free-text space was provided for examples of deviation from what had been requested; to note segments of conversation that had not been translated; or where meaning had been changed through interpretation. The quality check interpreter also subjectively rated the quality of interpretation of each interview on a scale of 1 (poor) to 10 (excellent). Each aspect of the quality check was assessed for each interview third to attempt to capture the impact of interpreter fatigue upon interpretation quality. Adopting a structured approach aimed to ensure consistency of the quality check across multiple-sites.

Envisaged as an independent check on interpretation, the quality check became a collaboration between either the two interpreters independently or collectively with the researcher listening to interviews and pausing to discuss interpretation. This approach facilitated reflexive discussion of translation choices (Temple and Young, 2004; Sumathipala and Murray, 2006) and offered an opportunity for discussion of translations produced in-the-moment during interviews, allowing exploration of alternative possibilities for conveying meaning (Williamson *et al.*, 2011), and fully integrating the quality-check interpreter into the co-production of knowledge. Whilst time consuming, conducting this reflective exercise alongside interviews was felt to enhance data rigour. For example, the quality check facilitated identification of additional lines of enquiry for subsequent interviews, offered opportunities to educate the researcher to refine questions for ease of interpretation, and to educate the interpreter on technical terminology. Findings from the quality check have been carried over into written transcripts, highlighting the mediation of interviews and the

three-way construction of data. Consequently, the quality check evolved to encompass layers of (self-)reflection, peer-learning and capacity building alongside the intended methodological check on interpretation.

Despite these strengths, limitations are recognised, notably the subjectivity of the quality check. Attempts to objectively define what the 10 points on the rating scale corresponded to were ineffective, calling into question comparing interview quality across settings and quality check interpreters. Additionally, as with interview interpreters, the quality check interpreter's subject knowledge and technical terminology evolved throughout the study, potentially affecting assessments of interpretation quality. Moreover, views of translation quality will be determined by the subjective experiences of the quality check interpreter, including their relationship with the interview interpreter and perceptions of the quality check role. For this study these limitations are considered acceptable and in line with the interpretivist epistemology which recognises that both method and data are embedded within the meaning of participants' words filtered through social relationships. Rather than seeking an objectively verifiable "truth" for each interview, the quality check sought to ensure methodological transparency regarding the impact of interpretation upon the shared construction of interviews, viewing the quality check as a layer of interview co-production in a *four-way* construction of data.

Participant checking

Applying internal validity to interpretation, participant checking is one method of establishing that research is congruent with participants' perspectives (Crook *et al.*, 2011; Shimpuku and Norr, 2012). With this approach it should not be expected that participants and researchers share the same understanding of data (Green and Thorogood, 2014). However, for this study it offered an important opportunity to ensure confidentiality was addressed to participants' satisfaction, and provided participants with an opportunity to supplement or refine what was reported in an interview (Lincoln and Guba, 1985; Green and Thorogood, 2014).

All study participants were offered copies of their transcripts which contained the English narrative. All except three participants took up this offer, and three were unreachable. Participants were invited to comment on aspects of the interview that they felt may have been misrepresented in English, and to share additional reflections that arose when reading transcripts. To date, a third of participants have responded to thank the researcher for their

transcripts, some confirming their accuracy, and one requesting a follow-up Skype discussion to share additional insights.

Involvement in data transcription and analysis

Another aspect to qualitative research rigour is specifying the extent of interpreter involvement in data analysis (Squires, 2009; Shimpuku and Norr, 2012), whilst recognising that interpreters' lack of technical qualitative research skills limit how far they may engage with this (Croot *et al.*, 2011).

In this study all interpreters transcribed interviews and contributed to initial stages of analysis. An additional two transcribers were hired locally in C3. They participated in the interpreter training, received additional training on transcription, and were supervised by both the researcher and a local team leader with transcription experience (who was also the quality check interpreter in C3).

Transcription is a theory-laden process that should remain consistent with research epistemology and methodology (Lapadat, 1999). To remain in line with the phenomenological epistemology of this study it was considered important not to write-out the original language, losing spoken otherness in favour of textual sameness (Simon, 1996; Temple, 2002; Kohrt *et al.*, 2014). Due to anonymity procedures participants' words were not reproduced in written form (which would indicate the language of interviews), instead using a timestamp to identify when the participant or interpreter were speaking in their own language:

R: How did they, um, yeah preparing you for, for doing the qualitative assessment?

I: #26.07-26.12#

P: #26.12-26.36#

I: #26.37-26.43#

P: #26.43-26.49#

I: Okay, he said...

(RA: C3,14)

This format renders explicit the three-way construction of data by identifying interpreter-participant exchanges before translation to the researcher (Bramberg and Dahlberg, 2013), and also highlights the interview time "lost" to interpretation. These features emphasise the transcript as a contextual and theoretical construct designed for analysis purposes (Lapadat,

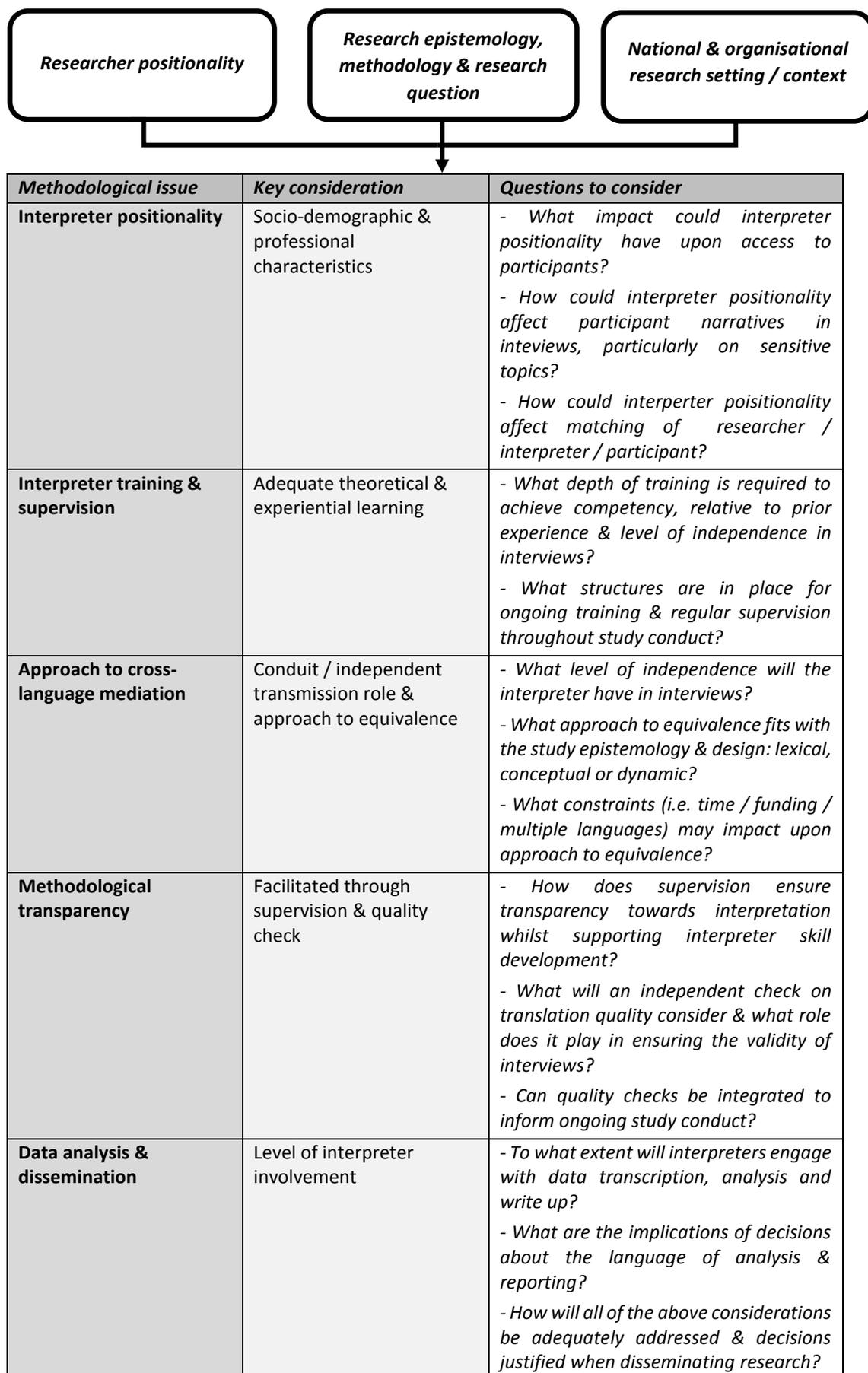
1999), and recognises that no transcript can objectively represent/re-present an aural interview (Chad and Witcher, 2010).

Involvement in transcription provided interpreters with immersion in the data and an opportunity to develop additional skills. Following involvement in data collection, quality checks, and transcription, it was appropriate to gather interpreters' perspectives on thematic analysis of data. To overcome the interpreters' lack of training or experience in qualitative data analysis (Croot *et al.*, 2011) an informal approach was adopted, requesting that interpreters and transcribers note things of interest or that connected to other interviews. These were discussed in reflective workshops facilitated by the researcher where preliminary thematic categories/maps for each countries data were developed. This analysis remained at the manifest, descriptive level (Green and Thorogood, 2014), providing a superficial review of emerging findings. However, this process provided insights that the researcher may not otherwise have seen, opening up new possibilities captured as "memos" and integrated into final data analysis conducted by the researcher.

Discussion

It has been established that interpreter-facilitated interviews give rise to a range of methodological considerations. Researchers face important choices about how these are managed, guided by epistemology, positionality, and the research context. In this study interpreters were central to the research design with their involvement underpinned by a broad phenomenological orientation focused upon participants' understanding and experiences of research ethics gathered via participants' "recollections of a phenomenon, directly and indirectly guided by the questions and prompts of the researcher" (Bramberg and Dahlberg, 2013, p. 246). Should research seek to probe deeply into participants' verbal utterances, the methodological challenges of interpreter facilitated interviews become more complex to surmount and would not be recommended.

Figure 4: Considerations for interpreter-facilitated cross-language interviews in cross-cultural contexts



Qualitative research is fundamentally dependent upon social relationships and narratives produced in-the-moment during interviews. How these relationships are established and maintained is guided by a specific epistemology which determines the research design, methodology, and approach to analysis. All of these elements are interrelated and require careful assessment, management, and transparent reporting, as outlined in figure 4.

Opting to work with lay interpreters departs from recommendations of professional interpreting credentials (Squires, 2009); although the practical, financial and logistical challenges of hiring professional interpreters are recognised (Croot *et al.*, 2011; Inhetveen, 2012; Sutrisno *et al.*, 2014). Professional interpreters may use formal language unfamiliar to participant's that could limit effective communication (Croot *et al.*, 2011) which is addressed by working with lay interpreters more likely to use participants everyday lexicon. In this study the research context required an alternative approach to working with professional interpreters, and a conscious choice was made to support early-career lay-interpreters who demonstrated an interest in mental health research and an aptitude for interpreting, as assessed at interview. This decision followed advice from organisations regarding the number of enthusiastic graduates and lack of employment opportunities; as well as the researcher's experience of successfully working with similar candidates on other projects. In taking this approach the ethical importance of supporting interpreter's full contribution to the co-production of research was recognised, whilst contributing to building research capacity.

When employing interpreters the researcher has to consider how they wish to co-construct researcher/interpreter/participant relationships, taking into account positionality, matching, and approach to training. There are a variety of perspectives on matching, often emphasising matching participant and interpreter socio-demographic characteristics to facilitate rapport building (Wallin and Ahlstrom, 2006; Bramberg and Dahlberg, 2013). However, this may lead to taken-for-granted assumptions (Murray and Wynne, 2001), questions regarding which characteristics should be prioritised (Temple, 2008), or participants limiting what they reveal (Ficklin and Jones, 2009). Furthermore practical difficulties can disrupt intentions - as demonstrated in C3 where being unable to find an interpreter who spoke the regional dialect of participants led to discussions being conducted in the national language. Equally the impact of factors affecting researcher-interpreter relationships should also be considered, such as patriarchal norms, which may affect interviews. In this study gender matching offered one way to promote transparency towards interpreter-facilitated interviews. This is

not to suggest researcher/interpreter gender matching in all studies, but to promote a contextual understanding of intersubjectivities that may influence relationships in each research setting.

Beyond affecting relationships, life experiences will shape what and how interpreters translate across languages, making it important to recognise their background, intersubjectivities, and perspective on the study topic (Temple, 2002; Ficklin and Jones, 2009; Bramberg and Dahlberg, 2013; Caretta, 2015). This study revisited these through training, supervision, contributions to emerging data analysis, and closing discussions, to capture evolving positionalities and interpreter skills. Exploring how interpreter's negotiate interviews can indicate evolving skills and the use of strategies that deviate from the professional interpreting conduit role such as independently investigating, filtering and evaluating information (Hsieh, 2008), reframing questions, offering examples, summarising or truncating responses (Inhetveen, 2012; Ballantyne *et al.*, 2013), and removing informal "rapport talk" to focus upon "report talk" (Wengraf, 2001). Interpreter-led interruptions can indicate interpretation distortions (Jentsch, 1998), or be viewed as exchanges that contribute to an informal interview context (Ballantyne *et al.*, 2013) and suggest the interpreters' desire to avoid inaccurate understanding and thus translation (Hsieh, 2008). Examples illustrate that the interpreters in this study practised these strategies, suggesting that the interpreter role - whilst pre-defined and rehearsed during training - remains fluid (Goffman, 1959; Ficklin and Jones, 2009; Croot *et al.*, 2011). Therefore, the interview interaction was viewed beyond language, seen as a social encounter in which layers of spoken and unspoken presentations were continually occurring and re-negotiated (Goffman, 1959; Wengraf, 2001; Wallin and Ahlstrom, 2006; Ficklin and Jones, 2009).

Recognising that interpretation is "a truly associative process, an ongoing appeal to memory, and to a private thesaurus, a pingpong of potentially infinite rebounds" (Godard [1995] in Simon, 1996, p. 23) it is important to assess interview interpretation quality. Conducting a quality check "illustrated how *what* we 'heard' in ... interviews was influence by not only what/how we asked, but also by how the interpreter 'heard' and conveyed dialogue to (and from) the study participants" (Ballantyne *et al.*, 2013, pp. 404, emphasis original). Researchers using similar approaches found checks revealed where the interpreter had adjusted participant responses to fit perceived expectations (Williamson *et al.*, 2011), or where researchers' questions were reframed or extended, and participants' responses summarised or truncated (Ballantyne *et al.*, 2013). For Jentsch (1998) quality checks are critiqued for being conducted post-interview meaning it is not possible to rectify missed

opportunities for probing or new lines of enquiry. In this study conducting this check alongside data collection addresses this critique, allowing new lines of enquiry or refinement of how questions were phrased or translated in subsequent interviews.

Examining methodological questions of language can open-up new avenues for research. In this study participants' comprehension and use of technical terminology was viewed as valuable learning rather than a study limitation (Sutrisno *et al.*, 2014), revealing that technical research or ethical language was filtered or simplified for fieldworkers. This led to examination of why this knowledge was imparted to or withheld from different categories of researchers, revealing the situated nature of organisational discourses and who are included or excluded from these (Haraway, 1991).

Relating to research dissemination, by having English as the language of data collection, analysis, and publication attention is called to its hegemony as the language used to speak *for* others, reinforcing power hierarchies in which White Western English-speaking researchers retain control in cross-language studies (Simon, 1996; Temple, 2002; Croot *et al.*, 2011; Kohrt *et al.*, 2014). In this study efforts were made to integrate the interpreters' perspectives into data analysis. However the short-term contract of interpreters prevented ongoing engagement with dissemination. Research dissemination events have been held in all countries, involving contributions and reflections upon the information presented from interpreters who continued employment with partner organisations. This approach is limited however, and efforts to consider how to fully retain interpreters' contributions through dissemination would be welcome.

Conclusion

It has been demonstrated that integrating interpreters into research requires careful consideration of the methodological complexities mediated research encounters entail. Failure to consider the pivotal role of interpreters in interview encounters will legitimately lead to concerns regarding research reliability.

Through implementing approaches such as those outlined in this paper it is considered possible to conduct rigorous research with lay interpreters. A range of methodological, practical and ethical considerations must be weighed when working with interpreters, and decisions about how to manage and account for them taken for each specific context, whilst remaining open to evolving competencies and changeable research settings. Given increasing globalisation, continuing prevalence of emergencies, and the importance of conducting research to ensure the mental health needs of populations exposed to

emergencies are effectively met, it is an ethical responsibility that researchers and interpreters share experiences of cross-language research from which others can learn.

References

Ballantyne, P. J., Yang, M. and Boon, H. (2013) 'Interpretation in Cross-Language Research: Tongues-Tied in the Health Care Interview?', *Journal of Cross-Cultural Gerontology*, 28(4), pp. 391-405.

Berger, R. (2015) 'Now I see it, now I don't: researcher's position and reflexivity in qualitative research', *Qualitative Research*, 15(2), pp. 219-234.

Bolton, P. A. and Weiss, W. M. (2001) 'Communicating Across Cultures: Improving Translation to Improve Complex Emergency Program Effectiveness', *Prehospital And Disaster Medicine*, 16(Special Issue 04), pp. 252-256.

Bramberg, E. B. and Dahlberg, K. (2013) 'Interpreters in Cross-Cultural Interviews: A Three-Way Coconstruction of Data', *Qualitative health research*, 23(2), pp. 241-247.

Caretta, M. A. (2015) 'Situated knowledge in cross-cultural, cross-language research: a collaborative reflexive analysis of researcher, assistant and participant subjectivities', *Qualitative Research*, 15(4), pp. 489-505.

Chad, S. G. and Witcher, M. A. (2010) 'Negotiating Transcription as a Relative Insider: Implications for Rigor', *International Journal of Qualitative Methods*, 9(2), pp. 122-132.

Croot, E. J., Lees, J. and Grant, G. (2011) 'Evaluating standards in cross-language research: A critique of Squires' criteria', *International Journal of Nursing Studies*, 48(8), pp. 1002-1011.

Edwards, R. (1998) 'A critical examination of the use of interpreters in the qualitative research process', *Journal of Ethnic and Migration Studies*, 24(1), pp. 197-208.

Esposito, N. (2001) 'From meaning to meaning: the influence of translation techniques on non-English focus group research', *Qualitative health research*, 11(4), pp. 568-579.

Faller, H. S. (1985) 'Perinatal Needs of Immigrant Hmong Women: Surveys of Women and Health Care Providers', *Public Health Reports*, 100(3), pp. 340-343.

Ficklin, L. and Jones, B. (2009) 'Deciphering 'Voice' from 'Words': Interpreting Translation Practices in the Field', *Graduate Journal of Social Science*, 6(Special Issue 3), pp. 108-130.

Goffman, E. (1959) *The presentation of self in everyday life*. London: Penguin.

Green, J. and Thorogood, N. (2014) *Qualitative methods for health research*. 3rd edn. London: SAGE Publications.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.

Haraway, D. J. (1991) *Simians, cyborgs and women: the reinvention of nature*. London: Free Association.

Hsieh, E. (2008) 'I am not a robot!' Interpreters' views of their roles in health care settings', *Qualitative health research*, 18(10), pp. 1367-1383.

Hynes, T. (2003) *The issue of 'trust' or 'mistrust' in research with refugees: choices, caveats and considerations for researchers*. Geneva: UNHCR. [Online]. Available at: <http://www.unhcr.org/3fcb5cee1.html>. (Accessed: 16.01.2014).

Inheteven, K. (2012) 'Translation challenges: Qualitative interviewing in a multi-lingual field', *Qualitative Sociology Review*, 8(2), pp. 28-45.

Inter-Agency Standing Committee (IASC) (2007) *IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings*. Geneva. [Online]. Available at: http://www.who.int/mental_health/emergencies/guidelines_iasc_mental_health_psychosocial_june_2007.pdf.

Jentsch, B. (1998) 'The 'interpreter effect': rendering interpreters visible in cross-cultural research and methodology', *Journal of European Social Policy*, 8(4), pp. 275-289.

Kapborg, I. and Berterö, C. (2002) 'Using an interpreter in qualitative interviews: does it threaten validity?', *Nursing Inquiry*, 9(1), pp. 52-56.

Kohrt, B. A., Upadhaya, N., Luitel, N. P., Maharjan, S. M., Kaiser, B. N., MacFarlane, E. K. and Khan, N. (2014) 'Authorship in Global Mental Health Research: Recommendations for Collaborative Approaches to Writing and Publishing', *Annals of Global Health*, 80(2), pp. 134-142.

Lapadat, J. C. (1999) 'Transcription in Research and Practice: From Standardization of Technique to Interpretive Positionings', *Qualitative Inquiry*, 5(1), p. 64-86.

Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic inquiry*. Beverly Hills: Sage, 1985.

- MacKenzie, C. A. (2016) 'Filtered meaning: appreciating linguistic skill, social position and subjectivity of interpreters in cross-language research', *Qualitative Research*, 16(2), pp. 167-182.
- Murray, C. D. and Wynne, J. (2001) 'Researching community, work and family with an interpreter', *Community, Work & Family*, 4(2), pp. 157-171.
- Murray, L. K., Bolton, P., Dorsey, S., Jordans, M. J. D., Rahman, A., Bass, J. and Verdeli, H. (2011) 'Building capacity in mental health interventions in low resource countries: An apprenticeship model for training local providers', *International Journal of Mental Health Systems*, 5, pp. 30-41.
- Rapley, T. (2007) 'Interviews', in Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative research practice*. London: SAGE Publications, pp. 15-34.
- Regmi, K., Naidoo, J. and Pilkington, P. (2010) 'Understanding the Processes of Translation and Transliteration in Qualitative Research', *International Journal of Qualitative Methods*, 9(1), pp. 16-26.
- Schutz, A. (1945) 'On Multiple Realities', *Philosophy and Phenomenological Research*, 5, pp. 533-576.
- Shimpuku, Y. and Norr, K. F. (2012) 'Working with interpreters in cross-cultural qualitative research in the context of a developing country: systematic literature review', *Journal of Advanced Nursing*, 68(8), pp. 1692-1706.
- Simon, S. (1996) *Gender in Translation: Cultural identity and the politics of transmission*. London & New York: Routledge.
- Squires, A. (2009) 'Methodological challenges in cross-language qualitative research: a research review', *International Journal of Nursing Studies*, 46(2), pp. 277-287.
- Sumathipala, A. and Murray, J., (2006) 'New approach to translating instruments for cross-cultural research: a combined qualitative and quantitative approach for translation and consensus generation', *International Journal of Methods in Psychiatric Research*, 9(2): 87-95.
- Sutrisno, A., Nguyen, N. T. and Tangen, D. (2014) 'Incorporating Translation in Qualitative Studies: Two Case Studies in Education', *International Journal of Qualitative Studies in Education (QSE)*, 27(10), pp. 1337-1353.

Temple, B. (1997) 'Watch your tongue: Issues in translation and cross-cultural research', *Sociology*, 31(3), pp. 607-618.

Temple, B. (2002) 'Crossed wires: interpreters, translators, and bilingual workers in cross-language research', *Qualitative health research*, 12(6), pp. 844-854.

Temple, B. (2008) 'Cross-cultural research', in Given, L. M. (ed.) *The SAGE encyclopedia of qualitative research methods*. Los Angeles, California: SAGE. pp. 180-182.

Temple, B. and Young, A. (2004) 'Qualitative research and translation dilemmas', *Qualitative Research*, 4(2), pp. 161-178.

Tsai, J. H.-C., Choe, J. H., Lim, J. M. C., Acorda, E., Chan, N. L., Taylor, V. M. and Shin-Ping, T. (2004) 'Developing culturally competent health knowledge: Issues of data analysis of cross-cultural, cross-language qualitative research', *International Journal of Qualitative Methods*, 3(4), pp. 1-14.

Wallin, A. M. and Ahlstrom, G. (2006) 'Cross-cultural interview studies using interpreters: systematic literature review', *Journal of Advanced Nursing*, 55(6), pp. 723-735.

Wengraf, T. (2001) *Qualitative research interviewing: biographic narrative and semi-structured methods*. London: SAGE.

Williamson, D. L., Choi, J., Charchuk, M., Rempel, G. R., Pitre, N., Breitzkreuz, R. and Kushner, K. E. (2011) 'Interpreter-facilitated cross-language interviews: a research note', *Qualitative Research*, 11(4), pp. 381-394.

Yin, R. K. (2009) *Case study research: design and methods*. 4th edn. Los Angeles, California: SAGE Publications.

ONLINE INTERVIEWING WITH INTERPRETERS IN HUMANITARIAN CONTEXTS

Abstract

Humanitarian emergencies raise logistical and safety considerations when designing and planning research. Internet communication technologies offer one way to address these by facilitating interviews online. This article presents reflections from a case study of a multi-site research project conducted in post-conflict settings. This study involved 35 qualitative interviews in total, of which 24 were cross-language, and six were conducted online. Although this project only involved a small proportion of online interviews (n=6), there is nevertheless a need to critically consider the impact upon data produced in this way. To achieve this, a range of practical and methodological considerations are discussed, illustrated with examples. Whilst online interviewing has methodological and ethical potential and versatility, there are inherent practical challenges in settings with poor internet and electricity infrastructure. Notable methodological limitations include barriers to building rapport due to partial visual and non-visual cues, and difficulties interpreting pauses or silences. Strategies for managing these logistical and methodological limitations are suggested, alongside recommendations for supporting future research practice.

Introduction

Unstable settings, such as those where humanitarian emergencies occur, give rise to logistical considerations when designing and planning research, including restricted access to sites and populations (Karray *et al.*, 2017). One way to overcome access difficulties is to use internet communication technologies, for example online interviewing. In choosing to integrate this solution into research, practical and methodological implications must be considered. When the interview process involves an interpreter, these considerations, and the accompanying methodological implications, increase in complexity.

The reflections, in the form of a case study, presented in this article are drawn from the lead author's (AC) experience of conducting online cross-language qualitative interviews as part of a multi-site study. Incorporating online synchronous interviews was necessary due to security considerations preventing travel to one of the research sites to conduct in-person interviews. Although in this multi-site case-study only a small proportion of interviews were conducted online, the impact upon data produced in this way needs to be critically considered. To this end, a range of practical and methodological considerations are identified and discussed, illustrated with examples and quotes. This small case study of

online interviews is valuable for the methodological reflections and learning that can be applied and extended through further research.

Case study: Researchers' construction and management of ethical issues in post-conflict mental health research

The case study from which this paper is drawn empirically examines how “ethics” is defined, understood, applied, and managed by mental health researchers working in post-conflict settings, focusing upon the interaction between constructions of procedural and in-practice ethics (Guillemin and Gillam, 2004). It is a qualitative multi-site study (Yin, 2009), involving interviews with mental health researchers in three post-conflict settings in South Asia. A phenomenological orientation was adopted to emphasize the lived-through quality of researchers' experiences of ethics (Schutz, 1945). The research aims to produce findings relevant to the conduct of ethical mental health research in post-conflict, and by extension humanitarian, contexts.

Between September 2014 and February 2015, 35 individual in-depth interviews were conducted across three South Asian countries and in the UK. All interviews were led by the researcher, with an interpreter involved when required. Interviews followed a semi-structured topic guide that explored participants' perspectives of the construction and management of procedural and in-practice ethics (Guillemin and Gillam, 2004), complemented by remaining open to emerging meaning and iterative evolution of interview topics to explore both within and between countries (Rapley, 2007; Yin, 2009).

Twenty-five interviews were conducted with interpreters, with the remaining participants choosing to speak in English. All interpreters were hired in-country following selection interviews, with attention paid to participants preferred languages. This article will focus upon six interviews that were conducted online in the third country, of which five involved an interpreter (see table 8). The focus of this case study is the interview format and methodological and practical considerations this posed for qualitative interviews, therefore the small number of interviews is deemed sufficient for these considerations to be explored. Attention is focussed on the online interview format, with the additional complexities of interviewing through interpreters discussed where relevant. For an in-depth discussion of the methodological approach this study took to integrating interpreters see (Chiumento *et al.*, 2017).

Table 8: Key characteristics of interviews conducted online

Interviewee*	Participant gender	Participant & researcher prior relationship	Interpreter involved	Interview location	Description of connection quality
Leslie (RA: C3, 11)	Female	Yes	Yes	Hospital	Call repeatedly dropped. Switching between Adobe Connect™ & Skype™ throughout interview.
Mollee (RA: C3, 12)	Female	No	Yes	Hospital	Some sections of overlapping speech
Fernanda (RA: C3, 13)	Female	No	Yes	Hospital	Multiple fade-outs of speech on both sides of conversation
Shaheen (RA: C3, 16)	Male	Yes	No	Hospital	Interviews conducted over 2 sessions due to power-cut. No problems during interviews.
Margareta (RA: C3, 17)	Female	No	Yes	Home	Unable to use Adobe Connect™, used Skype™ with video. Power-cut led to switching to mobile to continue conversation.
Tanika (Supervisor: C3, 18)	Female	Yes	Yes	Hospital	Interview conducted using Skype™ as Adobe Connect™ unable to connect. Repeated dropping of calls at beginning of interview.

**All names are pseudonyms allocated by the researcher, ensuring the protection of participant anonymity*

Setting description

Research was conducted in three countries in South Asia, with a one month period of data collection in each. All three countries have recent histories of conflict and disaster which meant the in-country internet and electricity infrastructures were poor, particularly in rural sites, including bandwidth limitations and unpredictable power-cuts. In the third country the security context deteriorated in the weeks leading up to planned fieldwork which necessitated the adaptation of interview formats to include online synchronous interviewing via Adobe Connect™ or Skype™.

Ethical oversight

Ethical approval was obtained from each South Asian country and the University of Liverpool. Online interviewing had been outlined as a possibility in the original ethical applications, recognising the potential instability of the research settings. When confirmed for Country 3, additional information on the online interview format and processes (i.e. addressing confidentiality) were approved by relevant country and Liverpool ethical review committees. All participants provided voluntary written informed consent prior to interviews. To protect confidentiality, data has been fully anonymized, including the use of pseudonyms for each

participant, and the replacement of all potentially identifying information with fictitious country / place / organisation names, denoted by { } brackets.

Online interviewing

The physical separation of researcher and interpreter from the participant raises both practical and methodological considerations. It is important to explore the consistency of online and offline interviewing with underlying research epistemology, use of methods, and how these ensure the desired research outcomes are attained (James and Busher, 2009).

To manage the shift in interviewing format, a brief review of literature was conducted prior to data collection to achieve methodological acculturation (Kovats-Bernat, 2002). Benefits of online interviewing were highlighted, including: limited ecological impact as compared to in-person interviews (Hanna, 2012); reduced time commitment due to eliminating travel (Deakin and Wakefield, 2014); and the increasing spread and advancement of technologies that make online interviews convenient and cost-effective (Sullivan, 2012; Deakin and Wakefield, 2014). Limitations were that these benefits require pre-requisites of high-speed internet access, and computer literacy of all parties (Janghorban *et al.*, 2014). Additionally, potential technical challenges include sound quality or webcam issues, a time-lag in the audio/video feed meaning sound and/or video is relayed slower than real-time, and potentially lost data as a result of technological failure (Sullivan, 2012; Saumure and Given, n.d.). Drawing upon reflections of the researcher, interpreter and participants documented during fieldwork, this article will critically engage with the methodological and practical considerations that need to be addressed when conducting online interviews.

Social construction of online interview spaces

In social science research, emphasis is placed upon the importance of the field, both epistemologically and methodologically, as a space where researchers and participants engage in the act of research (Clifford, 1997). When conducting research online, the *site* of research is displaced and the *sight* between researcher and participant interrupted (James and Busher, 2009).

In this study, the researcher and interpreter were based in the capital city, whilst participants were in a city in a different region. Based at a non-governmental research institution in the capital city meant the researcher had access to strong internet infrastructure, including multiple internet networks and a back-up generator for when the electricity supply ceased. By comparison, five participants conducted interviews from a Governmental Hospital with poor internet infrastructure, physically located in a shared office – with associated

interruptions and privacy limitations. The sixth participant conducted the interview from her home in a private room, with the only interruption being a family member bringing snacks. Power cuts affected the participants' home and hospital settings, with implications for two interviews: a computer running out of battery that required rescheduling an interview to continue 14 days later; and a participant switching to a mobile device to continue the interview after computer batteries had run out.

By conducting interviews via Adobe Connect™, the researcher was able to consciously construct a research environment for the study. Adobe Connect™ is subscription-based specialist web conferencing software frequently used in academic contexts. It has features to allow recording of video and audio within the software, with access to the meeting space and recordings password protected to ensure confidential information is safeguarded. It is for this reason that this platform was preferred to other options including Skype™ where the privacy of information cannot be guaranteed. Therefore, in choosing to use Adobe Connect™ for interviews the researcher was in a position of power, consciously constructing a professional site of research that afforded privacy protections and recording capabilities to facilitate the act of research (James and Busher, 2009).

It is important to note that AC is familiar with the use of online communication tools including regular use of Skype™ for meetings as well as personal use, and has used the Adobe Connect™ platform for teaching and meetings, ensuring familiarity with its features for application to this study. All research participants mentioned their familiarity with online platforms – notably Skype™ - for both professional and personal communication. However, to the researcher's knowledge only one participant had prior experience of Adobe Connect™. This lack of familiarity meant that for interviews conducted at the hospital a participant supporting the study's logistical arrangements and oriented to Adobe Connect™ by the researcher prior to study commencement was present at the start of each interview to set up the online space. Similarly, for the participant at home, the researcher provided guidance on setting up the connection prior to commencing the interview. This process of establishing a connection and introducing participants to the online space lasted around 10 minutes. Despite these brief orientations, there were instances during interviews where unfamiliarity with the software led to accidental muting of the microphone:

**R: We have lost your sound hang on one second. Ah, you've been muted,
hang on (.5) (Ask her)**

I: #37.24-37.28#

P: #37.29-37.30#

R: (.3) Oh you've muted it again, hang on, I'll unmute it.

I: #37.38-37.41#

R: (.2) ((to I)) I can do it for her, ((to P)) I don't want to do it and then you.

(.8) Okay I can hear you, oh no hang on, don't touch anything, let me do it.

I: #38.00-38.02#

R: (.7) You're touching it, so you're doing it at the same time. Okay we seem to have fixed it. Okay ((R laughs)), sorry.

Fernanda (RA: C3, I3)²⁵

Consequently, whilst the researcher, interpreter and participants all had prior experience of online synchronous communication technologies for professional and/or personal purposes, the use of Adobe Connect™ put the researcher in a position of power due to her familiarity with the software. Equally, to the researcher's knowledge none of the participants had engaged in interviewing or being interviewed via online platforms, and neither the researcher nor the interpreter had conducted qualitative interviews online before. Therefore, in engaging in online interviews the researcher, participant, and interpreter were drawing upon personal and professional micro-cultures that shape understandings of the personal and professional use of online communication tools (James and Busher, 2009).

The flexibility of online interviewing did facilitate the inclusion of one participant in the study because she was able to participate from home, meaning she could arrange the interview around other commitments. In this case, and in the re-negotiation of the timing interviews conducted from the hospitals, elements of the site of power between researcher and participant shifted to the participants who negotiated the timing and location of interviews around existing commitments. When compared to face-to-face interviews in other countries, it was felt that the online format made the adjustment of pre-arranged interview timing more likely than with face-to-face interviews. Similar experiences have been documented by other researchers who note that participants may feel less obliged to adhere to pre-agreed timings online than face-to-face (Holt, 2010). The fluidity of the physical interview site and associated power dynamics will continue to evolve as technology and

²⁵ In all interview extracts R = researcher; P = participant and I = interpreter. When the participant is speaking in their native language this is indicated by a time stamp i.e. #3.12-3.46#. This was felt to be in line with the study phenomenological epistemology, ensuring the native spoken word wasn't written out of transcripts, instead emphasising the three way construction of data involving translation by an interpreter.

Smartphones advance (Botha *et al.*, 2010), and is particularly relevant to conducting interviews in inaccessible locations such as after a humanitarian emergency.

Maintaining confidentiality / privacy

Two facets of the concepts of confidentiality and privacy will be discussed, the first relates to the researcher's ethical obligation to ensure the confidentiality of information shared via an online site of research conduct; and the second relates to privacy of conversations when the researcher has no control over the location from which participants conduct interviews (British Psychological Society, 2017).

Conscious construction of an online secure password-protected site ensured the researcher was able to achieve her ethical responsibility to ensure the privacy of information exchanged online (British Psychological Society, 2017). Critically, the choice to use Adobe Connect™ sought to minimize the risk of harm to participants by ensuring researcher and participant control over access to confidential data. Ess and The Association of Internet Researchers (2004) argue that consciously establishing a "safe" online environment can act to encourage participant disclosure in interviews. Equally, prior relationships between researchers and participants play a role in shaping trust, underpinned by a sense of the researchers integrity towards the protection of confidentiality and anonymity (Ess and The Association of Internet Researchers (AoIR). 2004; James and Busher, 2009). In this study, trust in the researcher's conduct was felt to have been established through prior relationships with some participants, which had led to internal narratives about who AC was, alongside perceptions of how a researcher conducting a study into research ethics would behave. This projection of the researcher as prioritising participant privacy is reinforced in the following text conversation when discussing a participant's request to switch from Adobe Connect™ to Skype™ to continue an interview:

P: The one thing to note with skype is I cannot guarantee the confidentiality of the conversation - skype have the right to record it if they want to.

Tanika (Supervisor: C3, I8)

This change in software occurred in a number of interviews, most frequently at the request of participants. Therefore, in proposing the use of Skype™, the agency of the participant to make an informed choice about the levels of privacy and security they are comfortable with is apparent (Ayling and Mewse, 2009).

Another issue encountered was the privacy of the site from which interviews were conducted. The researcher was able to ensure a private room for her and the interpreter to conduct interviews from. Conversely, due to the online format, the researcher is unable to control the participant's environment to ensure confidentiality. In this study, due to a lack of alternative options for the majority of interviews, participants were located in a shared office in a hospital. As experienced by other researchers, the lack of control over the physical setting in which participants were located led to interruptions or the presence of others in the background (Deakin and Wakefield, 2014). The impossibility of knowing when people were/were not present during interviews could lead to the misinterpretation of visual cues, such as smiles or turning of heads, which could be non-verbal cues relating to the conversation, or a response to the presence of others in the room (Seitz, 2016).

In an attempt to enhance the privacy of conversations, participants were encouraged to use earphones so only their responses could be overheard by others who may also be in the shared office. Despite this it is possible participants self-censored their responses for fear of saying the "wrong" thing in front of colleagues, which is likely to have impacted upon the depth of interview data.

Role performance

When interviewing, the social roles of those engaged in the interaction – in this case the researcher, interpreter and participant - are negotiated in a social setting in which the various performers engaged in impression management (Goffman, 1959). Sullivan (2012) argues that synchronous online environments are able to satisfy Goffman's (1959) criteria for assessing impression management including visual non-verbal cues such as smiles, frowns, shrugs etc., and paralinguistics such as stressing words or sighing. In this study, the research participants were researchers who brought their own understanding of the norms governing an interview encounter, including perceptions of the behaviour of a "good participant" (Wengraf, 2001; Frisoli, 2010) such as ensuring full attention to the interview and articulating their responses to questions as clearly as possible.

In capturing the projection of non-verbal cues a number of limitations were encountered. Low bandwidth meant even when available visual cues were limited or froze, and a time-lag in relaying the audio meant such cues were a-synchronous to verbal utterances. Additionally, even when available, video restricted physical presence by only displaying the participant's head and shoulders (Seitz, 2016) leaving absent other body language such as

positioning of hands and legs. Furthermore, simple non-verbal connections, such as eye contact, are impossible in online formats (Seitz, 2016).

To ensure transparency regarding this potential limitation, the researcher maintained notes in her research diary regarding perceptions of what was happening in the environment around the participant, for example: 'Participant looking at someone else in room and shaking head in response to a question/comment from them' (Mollee, RA: C3, I2); or 'Door opens in room P is in, can see her eyes go up to see who is coming in. Some background talking, then door opens and closes again – assume they left the room' (Mollee, RA: C3, I2). These were kept alongside general reflections about the interview environment from the researcher and interpreter, documented immediately after each interview.

Due to the impossibility of predicting connection quality in advance of interviews, flexibility in responding to the availability/unavailability of video was necessary. Once interviews move online, the ability to project and negotiate role performance is restricted, particularly in the absence of video. This includes limited access to cues regarding background demographics such as age; self-presentation for example through clothing; and subtle cues such as smiling, frowning or nodding. Additionally, in the context of this cross-cultural study conducted in South Asia, the availability of facial expressions could not be assumed as the research participants' cultures include females wearing veils that cover their face. This impacted upon the availability of non-verbal cues such as smiles, and occasionally the clarity of verbal utterances.

When working in cross-cultural contexts restricted visual cues, coupled with the involvement of an interpreter, reinforced the distance between the white, Western, English-speaking researcher and local interpreter and participants. This was reflected by participants who commented on the advantages of being able to see the researcher to "meet" who they were talking to:

I: ...the video conversation is very important because she wanted to know that who is Anna and how she looks like that er, that who is involved in {Rudo} programme so she just wanted to meet you so that's like. It's good.

Fernanda (RA: C3, I3)

This quote illustrates the importance the participant attached to "meeting" the researcher, emphasising the desire for face to face interaction. Whilst the extent to which this is achieved via the online format remains limited, it does offer a substitute to in-person interactions where required.

Rapport building

The researcher had prior relationships with some participants that were felt to aid online interviews, allowing the researcher and participant to build upon previous interaction dynamics. These prior relationships, alongside familiarity and comfort with online formats, were identified by a participant as a key factor in influencing the extent to which video supported rapport building and facilitated interview conduct:

P: ...actually it depends upon the person...how much another person is comfortable while dealing with a new person....normal level of anxiety is definitely there.

Leslie (RA: C3, I1)

As this indicates, a range of factors affect building relationships between researcher and participant. Of the interviews conducted in the third country, six were online and two were in-person. When reflecting upon the difference between the online and in-person interviews with participants the researcher had not met before, the suggestion that being comfortable with interacting with someone new is more influential than the interview format is supported. However, it is difficult to isolate factors that may have influenced this. It is possible the gender difference between researcher and participant may have been the critical factor influencing rapport building because the two in-person interviews were with males.

In interviews conducted with an interpreter, the presence of an additional unknown third party may also have impacted upon rapport building, as conversations and therefore connections between the researcher and participant are mediated by a third party. In this country, the interpreter was male whilst the majority of participants interviewed online were female, therefore patriarchal gender norms in the setting may potentially have influenced narratives. Equally, the researcher found that the relationship with a male interpreter led to a different style of interviewing than was experienced in the other countries when interviewing with female interpreters. This relationship between the researcher and interpreter may also have influenced rapport building between the participant and researcher/interpreter dyad.

Disembodied interview

Online interviews without video have been characterized as disembodied, with the removal of non-verbal cues acting to limit interview contextualisation and potentially reduce the impact of the interviewer on the interview encounter (O'Connor *et al.*, 2008). In this study,

disembodiment led to a more rushed interview flow, with a diminished emphasis upon rapport talk in favour of report talk (Wengraf, 2001). Interviews were also shorter, despite the online format requiring more time than in-person interviews, as a result of the conversation time-lag and additional level of clarification to ensure meaning had been understood. For example, after the first online interview, the researcher reflected that she felt she was unable to draw upon notes taken during the interview to consider the next question, with pressure heightened due to the lack of video. The result was an interview that involved question and answer exchanges, rather than an evolving discussion in which probes were organically pursued. This was felt to result from a sense that participants were waiting in anticipation for the next question, and was compounded by the lack of a clear visual connection between the researcher/interpreter and participant in which pauses accompanied by a smile or note taking can be taken as a cue to embellish or clarify response to a question. Therefore, this disembodiment led to a void between the researcher and participant that the researcher became concerned to “fill”, something others have reported when conducting online text interviews (Markham, 2004).

In an attempt to address this rush to the next question, the expectation of pauses in conversation was established at the outset of the interview when the researcher explained: ‘I have a notebook, {Interpreter} has the same ((both hold up notebooks to camera)), so we will probably take notes whilst you're talking, so if you see us looking down that's what we are doing...’ (Tanika C3, 18). Furthermore, the researcher in subsequent interviews narrated what was happening during silences or pauses – including when the video was on – for example:

R: ...Um, you’ve given me so many extra questions I want to ask you, er just give me a second to have a think.

P: Okay.

Margareta (RA: C3, 17)

The researcher would also clarify when the interpreter was finishing writing notes prior to translating what a participant had said:

P: #53:47-55:32#

R: (.4) Okay he's just finishing writing.

P: Okay.

R: Okay.

I: She said that....

Tanika (Supervisor: C3, I8)

This approach was effective in providing the space for more considered questioning and probing. Despite these efforts, the length and frequency of pauses as well as the depth of probing were felt to be less than occurred for in-person interviews, where the researcher can sense how comfortable a participant is with natural pauses in conversation. This approach also increased the sense of interview as performance, with the researcher providing cues akin to stage directions to ensure the participant remained informed about interactions that were out of sight.

Interview practicalities

When interviewing with an interpreter the time required for interviews necessarily increases, with interviews across the three countries involved in this study lasting on average 90 minutes. Online interviews brought additional considerations that impacted upon interview length, chiefly setting up the conversation at the outset, and interruptions to audio such as fading out or overlapping speech. When recording conversation within the Adobe Connect™ platform, as a result of the time-lag overlapping speech was a significant problem, leading to some lost sections of interview data where it is impossible to distinguish what is being said. By listening back to check recording quality this issue was quickly identified and addressed by using a Dictaphone to double record interviews.

Within the language-processing loop it is recognized that meaning can be lost, misheard, or misinterpreted (Frisoli, 2010). Difficulties conveying meaning can be compounded due to technological issues, in this study often resulting in repeated attempts to explain or clarify questions:

P: Um (.2) then the er (.3) consent, confidentiality, er patient comfort. I mean all these are everything.

R: **Patient comfort, what does that mean?**

P: Yeah.

R: **What does patient comfort mean?**

P: Sorry?

R: **What do you mean by patient comfort?**

P: It means that er patient

Tanika (Supervisor: C3, I8)

As a result of these difficulties, for all interviews conducted online the researcher had a heightened awareness of timing than with in-person interviews. For example, one interview

conducted online involved 22 minutes of recording in Adobe Connect™, during which 8 minutes of conversation took place; followed by 1 minute 15 Skype™ conversation before the connection went; and finally a 51 minute conversation in Adobe Connect™. At the end of this interview the participant reflected the frustrations that could arise as a result of technological difficulties:

R: ...how you found it in relation to the, the online setup?

P: Er actually I'm used to it before also but er sometimes, just like today a little exhausting because of the internet connection.

Leslie (RA: C3, I1)

The potential for frustration due to repeated connection issues led to a concern to keep interviews shorter both to limit the burden upon the participant, as well as to limit interpreter fatigue and potential impact upon translation quality. This resulted in interviews conducted online being shorter and therefore more limited in their depth than those conducted in-person.

Concept of safety

Physical safety is contested in unstable and unpredictable research environments (Hanna, 2012). In this study, whilst both the researcher and participants had opted for online interviews to increase safety and protect all parties from the risks presented by travel, this did not mean participants in particular were in a place where they were protected from potential safety threats.

This asymmetry in the relative safety of the researcher and interpreter versus that of the participant brings an additional dimension to the site of interviews (Karray *et al.*, 2017) that carries ethical implications (British Psychological Society, 2017). Notably, it raises a question around the first principle of ethical research practice – the protection of participants from harm (The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979) – as it can be the very inability to ensure a secure setting for interviews that lead to online interviews in the first place. When working in unstable contexts it has been highlighted that the researcher cannot always be expected to work in safety and security, with each of these concepts framed by knowledge of what constitutes danger in a given site (Kovats-Bernat, 2002). In this study, the decision to conduct interviews online was part of a co-produced approach to protection arrived at by the researcher and an organisational representative from the research site, with local knowledge and advice prioritized when making decisions about fieldwork conduct. As one participant noted:

P: ...um keeping in mind the availability and our own problems etcetera. So at times this kind of interaction is also okay.

Leslie (RA: C3, 18)

This construction, normalising an unstable context as “our own problems”, frequently arose during interviews that considered the impact post-conflict settings may have upon the application of ethics. In settings that are unstable, the concept of researchers protecting participants becomes less applicable, with the assumptions of ideal field sites where researchers are the ones in a position of control no longer holding true (Kovats-Bernat, 2002). Equally, the above quote highlights the appropriateness of online interviewing as an alternative format when the “ideal” of in-person interviewing becomes impossible.

Methodological considerations for managing online interviews

In this section, suggestions for managing key logistical and methodological considerations that arise when conducting interviews online will be made, drawing upon experiences in this case study (see table 9). These seek to address the lack of a precedent for online interviewing upon which researchers can build, and avoiding the imposition of in-person interviewing standards upon online interactions (Hine, 2004). Given the limited number of interviews on which these suggestions are based, they are intended to act as a springboard for further methodological and practical, reflection.

Table 9: Logistical and methodological recommendation for managing online research interviews

Logistical / methodological consideration		Suggested strategies to manage / account for these
<i>Social construction of interview space</i>	Internet, electricity and where applicable internet-enabled mobile phone infrastructure.	<ul style="list-style-type: none"> - Discuss strengths and weaknesses of local infrastructure with participants / contacts based in the participants setting. - Use this information to plan an interview schedule that is feasible and flexible within the identified constraints – for example would 3 shorter interviews be preferable to one longer interview if infrastructure is highly unreliable?
	Prior familiarity with online synchronous interviews, including software to be used for interviews.	<ul style="list-style-type: none"> - Gather information from participants about their previous use of online interviewing platforms, including the one to be used for interviews. - Develop instructions to share with participants in advance of the interview on how to establish a connection and use the interview software. - Account for the time required to set-up connections before interviews commence.

<i>Rapport building</i>	Prior relationships between researcher and participant	<ul style="list-style-type: none"> - Consider how prior relationships will set-up expectations of the interview encounter, in particular power relations and role performance. - What tools are available for the participant to “meet” the researcher & vice-versa (i.e. use of video; photo icons etc.) - Provide participants with a verbal overview of the intended progress of interviews, and any requests such as that the participant speak slowly and clearly.
	Presence of third parties (interpreters / chaperones)	- Ensure expectations about the role of any third party are established and agreed at the interview outset.
<i>Role performance</i>	Accounting for the interview environment	<ul style="list-style-type: none"> - As in any fieldwork, field notes are an essential tool to support contextual interpretation and analysis of interviews. - For online interviews including observations about the setting in which the researcher and participant are based is essential, including interruptions or presence of others in the participants setting. - Documenting facial expressions or hand gestures
<i>Disembodiment</i>	Managing silences	<ul style="list-style-type: none"> - Inform the participant during the interview overview of how non-verbal actions will be communicated (i.e. when writing field notes). - Consider all parties providing “stage directions” to narrate what is occurring during pauses in conversation.
	Inaudible segments	<ul style="list-style-type: none"> - As the researcher be prepared to ask the same question in different ways to avoid excessive repetition should connection problems cause difficulty in the participant hearing a question. - Use techniques such as reflecting back or incorporating language used by the participant into asking of questions to demonstrate responses have been heard, as well as to ensure correct understanding.
<i>Reflection</i>	Asking for participants experience of the online interview format	Asking participants for reflections on their experience of the online interview format can provide important feedback to (a) improve future interactions; and (b) complement field notes about a participants’ level of engagement during the interview.

In order to validate or refine these suggestions, continued documentation and sharing of experiences of conducting interviews online is encouraged, supporting future researchers who chose this interview format (Ferrante *et al.*, 2015).

Conclusion

As a result of the shift to online interviewing, this study entailed methodologically messiness where the researcher was learning the research process alongside generating data (Rossman and Rallis, 2003). This study views methodology 'not as a rigid or fixed framework for the research but, rather, as an elastic, incorporative, integrative and malleable practice' (Kovats-Bernat, 2002, p. 210) that is co-constructed between the researcher, participant and interpreter. In this context, reflexivity towards both the process and outcomes of interviews conducted online is a moral and methodological obligation of the researcher (Frisoli, 2010).

The reflections in this paper have identified a range of practical and methodological considerations that arose in the conduct of a cross-language qualitative research study that involved online interviewing. Notably the challenges of gaining depth of data collected via online interviews is a central consideration when using this interview format.

Online interviewing presents methodological and ethical potential and versatility, but should not be viewed as an easy option (James and Busher, 2009). Through providing practical tips for researchers to implement and evaluate, this paper aims to contribute to the development of qualitative research standards specific to online interviews, ensuring the same level of methodological transparency as is expected for in-person interviews.

References

Ayling, R. and Mewse, A. J. (2009) 'Evaluating Internet interviews with gay men', *Qualitative Health Research*, 19(4), pp. 566-576.

Botha, A., Makitla, I., Ford, M., Fogwill, T., Seetharam, D., CAbouchabki, C., Tolmay, J. and Oguneye, O. (2010) 'The mobile phone in Africa: providing services to the masses', *Science real and relevant conference*. Available at: http://researchspace.csir.co.za/dspace/bitstream/10204/4246/1/Botha_d1_2010.pdf. (Accessed 31.01.2015).

British Psychological Society (2017) *Ethics Guidelines for Internet-mediated Research*. Leicester: UK. [Online]. Available at: <http://beta.bps.org.uk/sites/beta.bps.org.uk/files/Policy%2020Files/Ethics%20Guidelines%20for%20Internet-mediated%20Research%20%282017%29.pdf>. (Accessed 28.04.2016).

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online early view, available at: <https://doi.org/10.1177/1468794117730121>

Clifford, J. (1997) *Routes: travel and translation in the late twentieth century*. Cambridge, Mass.: Harvard University Press.

Deakin, H. and Wakefield, K. (2014) 'Skype interviewing: reflections of two PhD researchers', *Qualitative Research*, 14(5), pp. 603-616.

Ess, C. and The Association of Internet Researchers (AoIR). (2004) *Ethical decision-making and internet research*. Available at: <http://aoir.org/reports/ethics.pdf>. (Accessed 28.04.2016).

Ferrante, J. M., Friedman, A., Shaw, E. K., Howard, J., Cohen, D. J. and Shahidi, L. (2015) 'Lessons Learned Designing and Using an Online Discussion Forum for Care Coordinators in Primary Care', *Qualitative Health Research*, 26(13), pp.1851-1861.

Frisoli, P. S. J. (2010) 'Assumptions, Emotions, and Interpretations as Ethical Moments: Navigating a Small-Scale Cross-Cultural Online Interviewing Study', *International Journal of Qualitative Studies in Education (QSE)*, 23(4), pp. 393-405.

Goffman, E. (1959) *The presentation of self in everyday life*. London: Penguin.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.

Hanna, P. (2012) 'Using internet technologies (such as Skype) as a research medium: a research note', *Qualitative Research*, 12(2), pp. 239-242.

Hine, C. (2004) 'Social research methods and the Internet: A thematic review', *Sociological research online*, 9(2), pp.10-17.

Holt, A. (2010) 'Using the telephone for narrative interviewing: a research note', *Qualitative Research*, 10(1), pp. 113-121.

James, N. and Busher, H. (2009) *Online interviewing*. Los Angeles, California; SAGE Publications [electronic book].

Janghorban, R., Roudsari, R. L. and Taghipour, A. (2014) 'Skype interviewing: The new generation of online synchronous interview in qualitative research', *International Journal of Qualitative Studies on Health and Well-being*, 9(1), pp. 1-3.

Karray, A., Coq, J.-M. and Bouteyre, E. (2017) 'Delivering online clinical interviews with NGO workers in humanitarian and cross-cultural contexts', *International Perspectives in Psychology: Research, Practice, Consultation*, 6(2), pp. 115-131.

Kovats-Bernat, J. (2002) 'Negotiating Dangerous Fields: Pragmatic Strategies for Fieldwork Amid Violence and Terror', *American Anthropologist*, (1), pp. 208-222.

Markham, A. (2004) 'The internet as research context', in Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative Research Practice*. London: SAGE Publications, pp. 328-344.

O'Connor, H., Madge, C. and Shaw, R. (2008) 'Internet-based interviewing', in Fielding, N., Lee, N. and Blank, G. (eds.) *The SAGE Handbook of Online Research Methods*. London: SAGE Publications, pp. 271-289.

Rapley, T. (2007) 'Interviews', in Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative research practice*. London: SAGE Publications, pp. 15-34.

Rossman, G. B. and Rallis, S. F. (2003) *Learning in the field: an introduction to qualitative research*. 2nd edn. Thousand Oaks: SAGE Publications.

Saumure, K. and Given, L. (n.d.) *Using Skype as a research tool: Lessons learned from qualitative interviews with distance students in a teacher-librarianship program*. [Online]. Available at: http://rsv.umd.edu/abstracts/Saumure_Given.pdf. (Accessed 31.01.2015).

Schutz, A. (1945) 'On multiple realities', *Philosophy and Phenomenological Research*, 5, pp. 533-576.

Seitz, S. (2016) 'Pixilated partnerships, overcoming obstacles in qualitative interviews via Skype: a research note', *Qualitative Research*, 16(2), pp. 229-235.

Sullivan, J. R. (2012) 'Skype: An Appropriate Method of Data Collection for Qualitative Interviews?', *The Hilltop Review*, 6(1), pp. 54-60.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (1979) *Ethical Principles and Guidelines for the Protection of Human Subjects of Research (The Belmont Report)*. Department of Health and Human Services. [Online]. Available at: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>. (Accessed: 12.02.2014).

Wengraf, T. (2001) *Qualitative research interviewing: biographic narrative and semi-structured methods*. London: SAGE.

Yin, R. K. (2009) *Case study research: design and methods*. 4th edn. Los Angeles, California: SAGE Publications.

DATA ANALYSIS

This section details the approach to thematic analysis of data, situated within the context of the underpinning research questions, epistemology, and methods, demonstrating a clear and coherent link between each. It traces the process of data analysis, commencing with the methodological choices made for transcription, which should be considered in light of the methodological considerations when working with interpreters, reported in Chiumento *et al.*, (2017b). This is followed by discussion of each stage of thematic data analysis, seeking to illustrate the key decisions made during this evolving process. Finally, strengths and limitations of the approach to data analysis are identified, and reflections on the approach taken offered.

Orienting to interview data

Interview data is approached from a standpoint that emphasises the situated nature of experiences of research ethics, privileging the participants' subjective views of the organisation, understanding, and interpretation of experience (Smith, 1998). Adopting a phenomenological stance means that interviews are viewed as accounts of objects and situations elaborated through descriptions and interpretations of the meanings these entail from the participants' perspective (Moran and Mooney, 2002).

As discussed in the section on epistemology, methodology, and ethical considerations (hereafter "epistemology section"), adopting a phenomenological orientation allows exploration of both to the contextual and the specific, as well as the identification and analysis of collective ideal types that are achieved by binding together the experiences of individuals (Schutz, 1975). To achieve this requires attending to both first order constructs which are those of the participant, and second order constructs which are those ascribed to the conduct of another person by an observer - in this case the researcher (Schutz, 1975)²⁶. Therefore, interview narratives are viewed as each participant's presentation of their first order constructs - the subjective meaning and interpretation of objects and situations. These narratives are promoted by the questions and prompts in interviews which act as opportunities to engage the participant in meaningful self-interpretation of their experiences to develop thick descriptions for analysis (Rapley, 2007; Dunn *et al.*, 2012). Overlaying this is the role of the researcher who builds upon wider theories and previous interviews to apply

²⁶ Wagner (1970) uses the terms "subjective meaning" and "objective meaning", however for clarity these have been described as first and second order constructs to distinguish them from the concepts of latent and manifest meaning discussed later in this chapter.

second order constructs by relating participants' experiences and understanding to pre-established and generalised typifications (Schutz, 1975).

This approach is encapsulated in *The Stranger* (Schutz, 1944) in which the outsider position – that of the researcher - provides a guide to orienting to data analysis. To achieve this the researcher adopts a postulate of adequacy where themes emerge from the data in a similar way to how the stranger acclimatises to being looked by an outsider. This requires weaving together first order constructs of the participant with the critical distance of second order constructs of the researcher. When applied to this study interviews are seen as participant's accounts of how they make sense of experiences of research ethics; whilst through data analysis the researcher makes sense of their experiences by drawing upon the common sense frames of reference embedded within participants descriptions, and melds these with second order constructs of typologies, schemas and theories to understand the world.

Two approaches to data analysis arise from this epistemological orientation. The first is descriptive phenomenology where the essence of participants' subjective experience is prioritised, as the researcher seeks to avoid imposing their own categorisation or understanding of phenomena onto the narratives (Palmer, 1971 [1927]; Harper, 2012). The second approach is interpretive phenomenology which seeks to move beyond the manifest account provided by participants to place these in broader social, cultural, and theoretical context (Harper, 2012). The data in this study is approached from an interpretive phenomenological position, bringing wider theories relating to research ethics and applying ethical procedures to practice to bear on the descriptions and interpretations of experience that participants have offered in interviews.

Interview as an account

Interviews in this study are seen as broadly tied to the context of their production. Rapley (2007, pp. 27-28) expands the elements that construct an interview, including:

- the here-and-now interaction of questions, answers, and probes that shape the discussion trajectory;
- the interview interaction where the researcher and participant present themselves in specific ways, as discussed in (Chiumento *et al.*, 2017);
- the broader research project and in particular the researchers motivation for conducting this study, and the background reading and theoretical understanding they inherently bring to the investigation of specific phenomena, discussed in the epistemology section.

For the purpose of this research it is considered appropriate to borrow some elements from Rapley's (2007) constructionist approach to recognise the social context of knowledge production. Rapley (2007) draws upon Seale (1998) to distinguish interview data as topic which views interviews as "reflecting a reality jointly constructed by the interviewee and interviewer" (p.16); and interviews as resource, where the data is seen as reflecting the respondents' reality outside of the interview. Viewing interview data as topic is inherent to the social constructionist position where all interviews are considered to be context specific and cannot be taken as representations of a reality beyond the situated interview (Miller and Glassner, 2011).

This study rejects this constructionist position for its incompatibility with a phenomenological epistemological orientation which assumes a shared reality and shared constructs exist outside of the interview itself (Schutz, 1944; 1975). Instead, each interview is viewed as a situated account that "describe, truthfully, delimited segments of real-live persons' lives" (Miller and Glassner, 2011, p. 136) that provide a window to their lived experience. Here the strength of the qualitative interviewing method is important, as it has the capacity to access the self-reflexivity of participants through the telling of stories and sharing of perspectives that facilitate researcher understanding and theorising about the phenomena of interest (Miller and Glassner, 2011). Therefore, interviews are seen as accounts of both the nature of research ethics – such as the contexts and situations in which "ethics" arises; as well as insights into the frameworks used to understand these experiences (Miller and Glassner, 2011).

This orientation to the phenomena of research ethics, and the corresponding perspective on the status of interview accounts, is consistent with a phenomenological epistemology. Following from these considerations, the approach to data analysis must encompass an ability to situate participant narratives in the wider context of frameworks underpinning them that shape and provide ways to understand the participants lived experience of research ethics. The ways that this has been achieved in this study are described under thematic data analysis below. Prior to addressing the stages of analysis, a description of interview transcription as key preparatory work for analysis is provided.

Transcription

This section outlines key decisions relating to how audio data was transposed into written transcripts. This discussion expands upon and is to be read in conjunction with (Chiumento *et al.*, 2017) which briefly addresses transcription decisions. In the discussion that follows

the focus is upon key decisions about the content of transcripts in the context of the theoretical underpinnings of this study, illustrated with transcript extracts where appropriate. Following this additional logistical information is provided about how the involvement of multiple transcribers was managed. Finally, some reflections on the approach taken are offered.

Transcription is a theory-laden process that must remain consistent with epistemological and methodological assumptions, and disciplinary perspectives (Lapadat, 1999; Bailey, 2008). It is recognised that “a transcript is a text that “re”-presents an event, it is not the event itself...what is re-presented is data constructed...for a particular purpose, not just talk written down” (Green *et al.*, 1997, p. 172). The act of transcribing is undertaken as a methodological process for an explicit purpose and requires the researcher to identify what is a useful transcript for the purpose of their study; and where to strike the balance between a desire to accurately reproduce the voice of participant’s, and the transcripts as a product independent of the audio conversation they re-present (Bird, 2005). In this study transcripts were designed for two purposes: firstly for methodological analysis of cross-language mediation of conversation, and secondly for the content of what was said for thematic data analysis.

A central consideration when starting out with transcription is how to represent/re-present verbal talk on the continuum between naturalism and denaturalism. At the naturalistic end of the spectrum transcripts seek to capture the “real world” represented via language, staying true to speech by signifying tools to coordinate conversation such as pauses, overlapping talk, and turn-taking; emphasising the *mechanics* of conversation (Oliver *et al.*, 2005). This approach is appropriate for detailed data analysis of the form of interviews, such as conversation analysis (Silverman, 2013). In contrast, the denaturalised approach is more interested in accurately capturing the *meaning* of conversation with a focus upon the words spoken rather than the how of speaking (Oliver *et al.*, 2005), and is appropriate for thematic analysis (Braun and Clarke, 2006; Silverman, 2013).

Therefore, a primary decision prior to transcribing is to identify the purpose of the written record – how will it be drawn upon for data analysis? As this study adopts a thematic approach that does not seek to analyse the intricacies of the mechanics of speech, the focus is upon the meaning of narratives – what was said rather than the how of speaking. However, this is balanced by methodological attention to the involvement of interpreters which requires attention to the mechanics of conversation and process of knowledge production

inherent to three-way interview conversations. Therefore, for the purpose of this study a balance was struck that sought to re-present the mechanics of the three-way construction of data between researcher, participant, and interpreter; whilst recognising that for data analysis the content of what was said was the primary consideration.

Whilst transcripts only include the English language conversation in full, it was also felt to be important not to write-out the original language (Simon, 1996; Temple, 2002; Kohrt *et al.*, 2014). This was achieved by using a timestamp to identify the segments of conversation conducted in languages other than English. This approach remains in-line with the study anonymity procedures which prevent the written script of the original language being used. Furthermore, discussions with interpreters in the first country about using symbols alongside timestamps to identify when the participant or interpreter were speaking in a language other than English led to agreement that this could be seen as offensive, as the language of participants would be identified as incomprehensible. This consideration was important given that transcripts were to be shared with participants for respondent validation (Oliver *et al.*, 2005; Green and Thorogood, 2014). Therefore, the approach chosen was to use timestamps, ensuring representation of the three-way construction of data by identifying interpreter-participant exchanges before translation to the researcher (Bramberg and Dahlberg, 2013) which highlights the interview time “lost” to translation.

Another important consideration in this study was how to incorporate information from the quality check performed on each interview by a second interpreter in each country²⁷. This meant having an additional column in the transcript where notes from the quality check and research diary were inserted. These notes were drawn from the quality check proforma which contained a time stamp of where the quality check interpreter felt there was a need for changes or additional clarification to what had been reported by the interpreter during interviews; and from the researchers’ research diaries which included contextual information such as participant gestures or interview interruptions, also approximately timestamped. Through the use of timestamps both the quality check and research diary information could therefore be inserted accurately into the transcript. When added \\ is used to denote the speech or section of interview that the additional notes relate to. An

²⁷ See Chiumento, A., Rahman, A., Machin, L., and Frith, L (2017b) ‘Mediated research encounters: methodological considerations in cross-language qualitative interviews’, *Qualitative Research*, online pre-print, for a full discussion

example transcript extract is provided in Table 10 to illustrate the insertion of quality check information and notes from research diaries.

Table 10: Extract from example transcript from Country 1

		Main text	Quality check / notes from research diary
(...)		(...)	
97	I	<i>So how do they benefit they arise such questions and so there's a need like they clarify about their</i>	
98		<i>objectives their research, and they try to \\convince people like unless they give them information how</i>	\\Participant actually said that “unless
99		<i>can they like really know, really know their real condition and how can they intervene. \\</i>	they do the research, they cannot know
100	P	Mmm. #12:19-12:40#	what the participants’ problems are.”\\
101	I	<i>Er, so he says that there's also a need to consider the personal relationships like er, to make them</i>	
102		<i>understand, to build good relationships and he says that it's research. Er, the good point about research</i>	
103		<i>is that to \\con, make, to convince people, to make them understand\\ so he finds this, thing interesting.</i>	\\Participant also said that: challenges
104	R	Okay. You've given me lots to get started there, lots of ideas that I want to, want to explore. Um so	and enjoying depends upon how they
105		that's really helpful and useful background how in terms of your experience, just to confirm you you.	coordinate with the participants, how
106		You have. Because I. Erg. You do direct data collection as well as the analysis so you kind of see the	much they can make them understand,
107		whole research process?	how much they are able to convince

108	P	Whole research process.	them and are able to make them clear
109	R	Right okay that's really helpful just for me to think about for how I position the questions. Um, so the	about consent. This was missed in the
110		next set of questions relate to the way in which ethics is understood and applied when conducting	translation.\
111		mental health research in post-conflict settings. As I've said no right answers, no wrong answers, just	
112		your experience that I'm interested in and how you manage ethics and ethical issues everyday. Um,	
113		it's really helpful if you give examples from your experience er, that really helps to bring it to life for	
114		me.	
(...)		(...)	
188	P	\#27:56-30:47#\	\When explaining one eye on ethics,
(...)		(...)	the other on questionnaires the
199	I	<i>And he says that in one part, while conducting research, in one part you are concerned about ethics, and</i>	participant gestures using papers in the
200		<i>in one part you are concerned about questionnaire ((To participant)) #32:21#</i>	room to demonstrate.\
201		Mmm.	
202	P	<i>Like, he said that in one eye, you are concerned about ethics, and in the other eye, you have your</i>	
203	I	<i>questionnaire.</i>	

Transcripts also included the “social talk” at the beginning and end of conversations; and a cover page containing a brief description of the setting in which interviews were conducted (Bailey, 2008). The non-verbal and paralinguistic features of speech identified in transcripts include pauses, overlapping speech, sighs, involuntary vocalisations such as coughs and sneezes, and response tokens including murmurs or sounds of agreement such as “mmhum” that encourage the flow of conversation or acknowledge what is being said. All of these were seen as potentially important for understanding the mechanics of conversations to consider the methodological implications of mediated cross-language interviews. The rationale for including these non-verbal and paralinguistic features is outlined below.

Length of pauses were felt to reflect the time taken to process questions or think about a response. For example, where a long pause was followed by asking for clarification of the question it was felt this could signal that the translation of the question required further consideration. Equally, overlapping speech was felt to identify swift comprehension of a question by answering prior to translation, or a desire to emphasise a point – particularly where the overlap was with a probe for the respondent to clarify or expand upon something previously discussed. Identifying murmurs or sounds of agreement were felt to demonstrate the use of these conversational tools across languages. Finally, sighs were seen as potential signs of frustration at the direction of interview questions, the length of interviews, or the three way process of discussion.

Additional depth of paralinguistic information such as intonation or stressing specific words was not included because these mechanical features of speech would not add to the methodological analysis of cross-language interviews, and are impossible to capture due to the translation process. The features that are identified emphasise the transcript as a contextual and theoretical construct (Lapadat, 1999), capturing specific features of speech for methodological analysis of the approach to cross-language mediation used as the basis for methodological papers (see Chiumento *et al.*, 2017; Chiumento *et al.*, 2018), and for thematic analysis of data. Consequently, the decisions made about transcription recognise that “transcriptions are not...neutral records of events, but reflect researchers’ interpretations of data” (Bailey, 2008, p. 129) produced for explicit purposes. The decisions made flow from a concern to remain in line with the phenomenological epistemology in which transcription is seen as an interpretive act, as the transcriber re-presents spoken word in written text (Bird, 2005).

The inclusion of multiple parties in transcription, as in this study, necessitates identifying conventions to be used to identify paralinguistic and non-verbal elements of the interview interaction. Transcribers were instructed that transcripts were to retain the original words, including grammatical errors made by the researcher and participant (Oliver *et al.*, 2005). However, for some such as when the interpreter mis-heard technical terms, for example “cohort” study, these were corrected through the quality check process, ensuring that the original meaning was retained²⁸.

All transcripts were produced in a standard matrix template document (Wengraf, 2001). At the beginning of this template a table was provided that outlined conventions to be used in transcripts, drawn from Silverman (1993, p. 118). This provided in Table 11.

Table 11: Transcription conventions

TRANSCRIPTION SYMBOLS	
Code for who is speaking	R = researcher (AC) I = interpreter P = participant
Overlapping speech	Put this bracket: [at the point the speech overlaps: i.e. R: hi, my name is [Anna P: [Hi Anna
Pauses	Use brackets and put the number of seconds that the pause lasts. These apply for all silences / thinking time i.e. R: So the first question I would like to ask you is (.3) how did you come to be a researcher?
Missed sections (i.e. can't hear)	If a section of speech is missed then just put empty brackets, i.e. I: So she is saying that () and then they had to - N.B: also put in the second column a note to say what is going on i.e. truck horn in background etc
Possible sections (i.e. hard to hear)	If a section of speech is hard to hear then insert it in brackets, i.e. I: So she is saying that (first they conducted informed consent) and then they had to
When speaking in local language	Put the time stamp denoting the beginning and the end of speech in the local language, using the hash symbol to identify these. i.e. #1:12:02 – 1:14:43#
Non-verbal / expressions	Use double brackets, i.e.: ((laughs)) or ((coughs))
Interruptions	Use double lines, i.e.: //tea// //phone call #1:13 – 1:26#//

²⁸ This example is discussed further in Chiumento, A., Rahman, A., Machin, L., and Frith, L (2017b) ‘Mediated research encounters: methodological considerations in cross-language qualitative interviews’, *Qualitative Research*, online pre-print.

These conventions were discussed during transcription training after being tested by the researcher who transcribed five interviews herself. All transcripts produced by transcribers and interpreters were checked by the researcher who listened back to interviews whilst reading written transcripts to ensure standardisation of the use of transcription conventions. Listening back also provided an opportunity to assess and where required address transcript accuracy, for example filling in speech that transcribers or interpreters had been unable to “hear” or understand, and to correct mis-heard terms. This checking process also formed the first aspect of data analysis, providing an opportunity for the researcher to re-familiarise herself with the content of interviews through full immersion in the data.

Prior to the transcription conventions, the first page of transcripts contained a cover page with a table which provided contextual information about the interview (see Table 12). This included the date of interview and of the finalising of transcripts, the country number and interview number, and the digital recording number to connect the transcript to the audio recording. It also contained notes about the setting in which interviews were conducted including factors that may have affected the quality of recordings, and reflections of the researcher and interpreter’s from interview debriefing. These were drawn from the researchers’ diaries and added during the process of checking the transcript, often with additions about the recording quality or difficulties with transcription.

Table 12: Example transcript cover page

Country number	1
Interview number	6
Interview date	09/09/2014
Date of transcription	20/01/2015
Digital recorder number	140908_0043
Interpreter involved? (Y/N)	Y - begins in English but switches to discussion through interpreter.
Participant gender	M
Room set-up	<ul style="list-style-type: none"> • Sat in back meeting room of organisation field office • Sitting on cushions on floor in middle of room, Dictaphone on ground in centre
Recording quality comments	<ul style="list-style-type: none"> • Some interruptions i.e. tea being brought in and phone calls • Electricity resumed and fan came on overhead about 10 mins into interview and continues throughout • Children playing outside nearby
Reflections from interview debrief:	<ul style="list-style-type: none"> • Participant has clear sense of duty to guide RA's • Differentiation between core principles of ethics and way in which they are applied as a coordinator versus how an RA applies them • Repetition of point that ethics should fit with the context • Clarification of consent process and training of RA's that was missing in prior interviews, and new examples i.e. use of flashcards • Main purpose of ethics from his point of view was to improve research quality • Long discursive responses indicated a strong desire to explore the topic. Participant largely understood translation and would add to / clarify / expand upon information as translation was happening. • Uses mix of English and {Florini} in most of his responses.
Other information	<ul style="list-style-type: none"> • Additional notes from conversation that continued after recorder had been switched off in bullet point format at end of transcript.

Transcripts were produced using the NVivo transcription function. This facilitated transcription through the features of keyboard shortcuts for playing, pausing, and jumping back or forward through audio. Once completed in NVivo transcripts were exported into Word files where they were formatted and finalised with quality check and research diary information. Data security considerations in the transcription process have been discussed in the epistemology section.

Reflections on transcription decisions

As with other methodological considerations, it is important to reflect upon decisions made when transcribing (Oliver *et al.*, 2005).

As a result of the range of accents in different interviews there were instances where those conducting transcription were unable to fully understand what was being said. This was true for the researcher as well as the interpreters and transcribers. Foreseeing this, the researcher made notes in research diaries when terms were obviously pronounced by participant's in ways that it was felt may lead to confusion when transcribing, for example in the first country one participant consistently pronounced the word "prior" as "preah". Equally, sometimes words were misheard by the transcribers, for example one transcriber had heard "she is working in the grass fruit label" whereas what had been said was "she is working at the grass roots level". In addition to mishearing's, transcription conventions were at times applied incorrectly, for example using double brackets rather than double forward-slashes. Where identified, these mishearing's and incorrect use of conventions were corrected by the researcher when checking the transcripts.

The process of listening back to transcripts produced by transcribers was illustrative of the different ways people hear and interpret talk into written text. It also illustrated that there was often no "right" way to re-present the spoken word in written transcript, and that some decisions were made at the discretion of the researcher not because of inaccuracies, but due to different interpretations of the word used. Here it is recognised that the "transcriber hears the interview through his/her own cultural-linguistic filters" (Oliver *et al.*, 2005, p. 1282). This highlights the interpretive nature of the act of transcribing, and the multiple possibilities for the final written transcript. One impact of the checking of transcripts by the researcher and efforts to ensure consistency is that written records may have become more ethno-centric as the researcher heard speech through the lens of her native English-language.

Once produced, the final transcripts were drawn upon both for methodological understanding of the mediation of conversations across languages, as well as for data analysis. However, the level of detail included in every transcript went beyond that required for the thematic approach used in this study. Equally, the extraction of data for methodological analysis could have been more efficiently achieved through selective transcription of illustrative examples of the mediation of conversations. Additionally, for the purpose of analysis the transcript format in a large table in Word could not be imported in

the NVivo, necessitating reformatting of transcripts and additional checking of data extracted for reporting results to ensure additional notes from quality check or research diaries weren't missed. This could have been addressed earlier on had more consideration been given to the use of software to aid data analysis. Finally, in the presentation of results detail included in transcripts was in some cases "written out". These included aspects such as repetition of words, response tokens, and correcting grammatical errors that made transcripts more difficult to read as a conventional written text (Wengraf, 2001). Therefore, when considering the transcript as a product for consumption by external audiences a concern for the clarity of the meaning of quotes to be accessible to readers and ensure illustration of the point being made came to the fore and in some cases displaced earlier theoretical considerations. This is seen as part of the process of striking a balance between theoretical concerns and practical considerations, reflecting the general theoretical model of representing meaning by selectively focussing upon aspects of speech that bear directly on the aims of research, whilst taking into account the practical constraints inherent to representing words in text (Mishler, 1986, p. 49).

Thematic data analysis

Thematic analysis of data sought to capture the essence of researchers' experiences of ethics, moving from particular accounts to develop plausible interpretation of the totality of participant's narratives (Van Manen, 1990). Through the multiple case study method research sought to capture the experiences of individuals and organisations felt to be able to provide experiences typical to the phenomena of understanding and applying research ethics in post-conflict settings (Silverman, 2013). This orientation contains a built-in theoretical approach to data collection and analysis to facilitate an understanding of the role and work that research ethics is doing in post-conflict mental health research (Mason, 1996). To achieve this, thematic analysis is appropriate as it aims to identify themes across and between case studies, moving across the data from an early stage in analysis to identify common themes to explore (Frith and Gleeson, 2012).

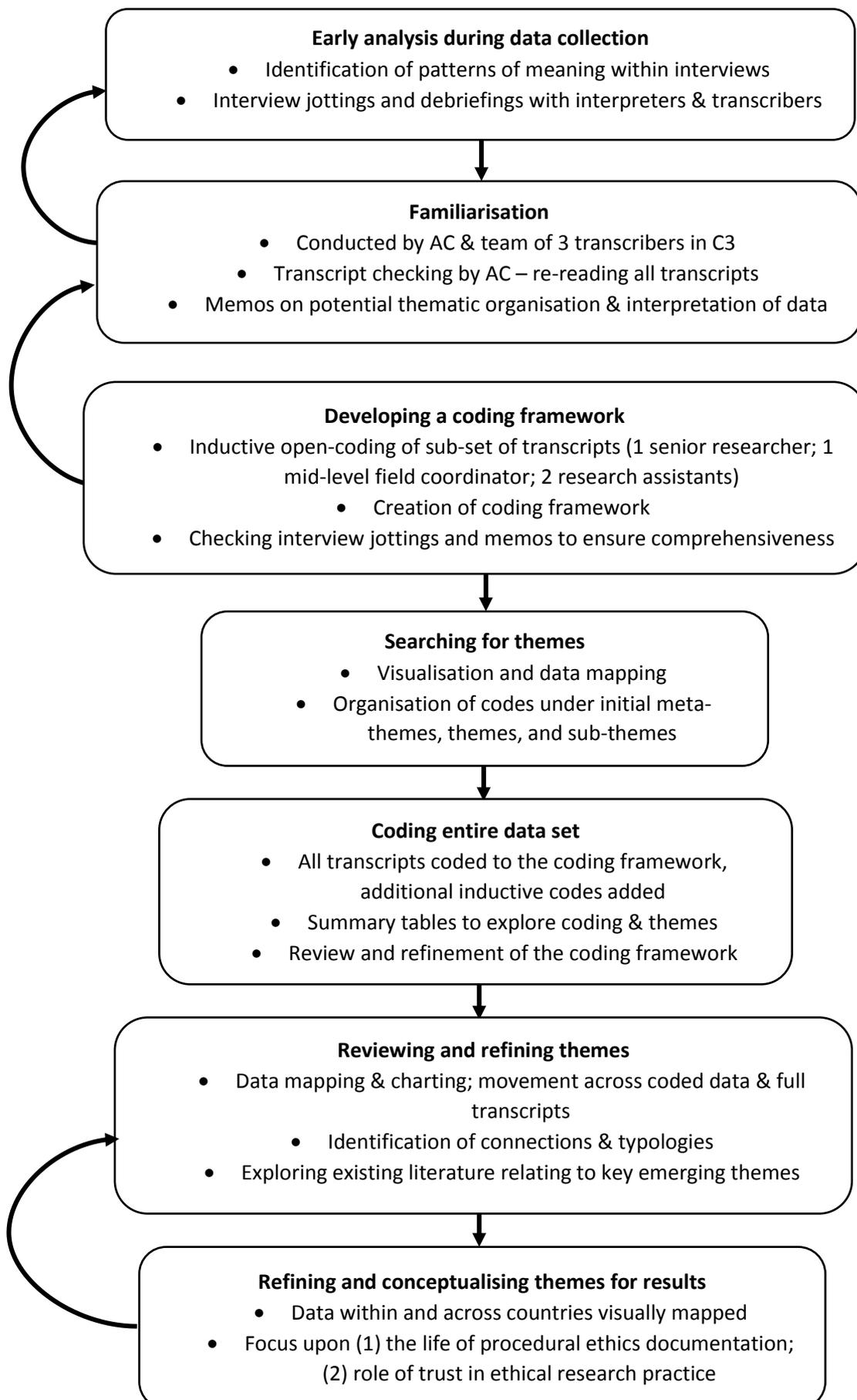
Thematic analysis seeks to produce theoretical propositions about researchers' experiences of research ethics built up through the explicit and implicit content within participant's narratives (Joffe, 2012). "Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data" (Braun and Clarke, 2006, p. 79). The stages to thematic analysis in this study include (1) familiarisation; (2) generating codes; (3) searching for themes; (4) reviewing themes; (5) refining and conceptualising thematic data organisation to produce research findings; and (6) Presenting and argument: writing up

research findings (adapted from Braun and Clarke, 2006). To aid management of the data in this study the framework approach was also drawn upon, specifically the use of charting and mapping to explicitly explore the relationships between concepts and typologies identified through analysis (Ritchie and Spencer, 1994; Green and Thorogood, 2014). This approach is appropriate for managing multiple-country data, encouraging explicit identification of key themes, and aiding movement from thematic codes to a theoretical interpretation of the data. In this sense the approach taken departs from the emphasis of the framework approach upon a more deductive approach to coding (Green and Thorogood, 2014).

Analysis was approached as an iterative and evolving process involving “constant moving back and forward between the entire data set, the coded extracts of data..., and the analysis of the data” being produced in written findings (Braun and Clarke, 2006, p. 86). Therefore, the “writing-up” phase of research is viewed as a final component of data analysis, as the coded data and theoretical propositions developed to explain the meaning of what participants have reported are refined into a coherent argument. What is provided below is a description of the phases of data analysis, including an introduction to the presentation of results. Whilst this is presented as a linear process, it is important to stress the recursive and iterative movement across and between these stages as data analysis evolved (Braun and Clarke, 2006).

Figure 5 summarises the process of data analysis.

Figure 5: Data analysis process



Early stages of analysis: data collection

Data analysis began prior to the formal “data analysis” phase of the study (Silverman, 2013), recognising that the process of data analysis begins when the researcher starts to notice and look for patterns of meaning in the data that may be of potential interest (Braun and Clarke, 2006).

In this study early analysis involved reviewing research diary notes taken during and between interviews to explore what had been reported in each case study country. These included jottings from interviews; specific thoughts arising from interview debriefing with the interpreter (where involved) and/or the researcher; and other notes of thoughts or things observed whilst based with organisations, including comparing and contrasting across countries as data analysis progressed. Early analysis involved reviewing these research diary notes to identify potential codes and themes to draw upon in subsequent stages of data analysis.

Early analysis also involved working with interpreters, and in the third country transcribers, to explore the key themes in the data from their perspectives. This was undertaken as a collaborative workshop activity where things of interest or that it was felt were reported often or rarely were identified and discussed²⁹. This stage of analysis encouraged the researcher to move beyond her own frame of reference to “see” the data from the perspective of interpreters and transcribers who came to the topic of study without prior theoretical frames of reference that the researcher carried. From each of these workshops thematic maps or brief summaries of the data were produced.

Due to the approach taken this early phase of data analysis remained at the manifest level of the explicit things participants said and viewed through a deductive lens in the context of the interview questions and interpreter / transcriber training on the topic of research ethics (Green and Thorogood, 2014) which included findings from the documentary analysis conducted to inform development of the topic guide. Therefore, this organisation of the data was revisited and refined through subsequent stages of data analysis that moved beyond the manifest descriptive level to an interpretive and theoretically informed understanding.

²⁹ See Chiumento, A., Rahman, A., Machin, L., and Frith, L (2017b) ‘Mediated research encounters: methodological considerations in cross-language qualitative interviews’, *Qualitative Research*, online pre-print, for a discussion of the involvement of interpreters and transcribers in data analysis.

Familiarisation

Familiarisation involves listening to and re-reading data to get a feel for what it contains, for example gaining an understanding of the breadth of accounts participants have shared, or to identify recurrent or outlying topics (Green and Thorogood, 2014). This was achieved through the transcript checking process described above, as the entire data set was listened to again (Braun and Clarke, 2006). Transcription as central to the familiarisation process is stressed by Bird (2005) who recognises it as a “key phase of data analysis within an interpretive qualitative methodology” (p.227).

In the familiarisation process memos were made on the content of interviews, as well as thoughts that arose about potential thematic organisation of the data that could be further explored during later stages of analysis (Braun and Clarke, 2006). The importance of making theoretical memos during transcription is stressed for building a holistic sense of the whole data set through its composite elements (Wengraf, 2001). As Wengraf (2001) notes “*The tape will always wait patiently to be transcribed; the ideas that spring from you as you write will vanish quickly*” (p.210 – emphasis original). As an integral aspects of familiarisation, the thoughts stimulated during transcription included jottings about overarching themes and connections between interviews, and the capturing of specific quotes that felt important or illustrative. These notes provided a resource for further exploration of the data set through revisiting and mapping the points that stood out.

As has been illustrated, the approach taken to transcription formed a critical step in the data analysis process. Importantly it acted to enhance familiarisation with individual interviews and the data set as a whole, and is seen as an important foundation for the interpretation and selection of data in subsequent stages of data analysis.

After familiarisation with the entire data set and identification of initial deductive codes through data analysis workshops with interpreters and transcribers in each country, it was felt important to return to the data anew to engage in open coding which seeks to inductively identify themes from the raw data itself (Joffe, 2012). To this end a sub-set of transcripts were open coded by reading them closely to identify inductive codes, organising these into a coding framework (Boyatzis, 1998). This process of identifying codes involves taking “the most basic segment, or element, of the raw data...that can be assessed in a meaningful way” in relation to the phenomena of interest (Boyatzis, 1998, p. 63).

Given that this study involves three case study countries, and different categories of researchers, it was decided that interviews for open coding should seek to be broadly

representative of the entire data set. This sought to take into account key aspects to sampling which may affect understanding of the phenomena including the country setting, relevant events that may have happened such as experiences of conflict and disaster, different categories of respondents (Boyatzis, 1998). A sub-sample of 4 transcripts were selected, including: one interview with a senior PI, one with a mid-level researcher, and two with research assistants. The interviews were selected for being broadly typical of the various categories of researchers, and to represent all three of the case study countries (see table 13).

Table 13: Sub-sample of transcripts for open coding

Category of researcher	Transcript no.	Rationale for selection
Senior researcher	C3, int 9 150219_0089 (male)	<ul style="list-style-type: none"> - Last interview of entire study, questions / focus therefore shaped by all data - Respondent was a “typical” PI based in one setting and researching in another - Captures organisational capacity building which features widely in other interviews with senior staff - Exploration of impact of setting, post-conflict context, and vulnerability which seem core to research topic - Also picks up on political economy systems and impact these have upon work on the ground - Respondent was considered open, honest, and engaged throughout
Mid-level researcher	C1, int 12 140915_0049 (male)	<ul style="list-style-type: none"> - First country, mid-way through interviews thus early in data collection but at a stage where had enough background information from previous interviews to be exploring the depth of the topic - Respondent responsible for staff training and development across the organisation thus provided a perspective that broadly conceptualises this countries organisational approach to ethics - Respondent had in-depth knowledge of specific practices of interest (i.e. use of the ethical questionnaire to test research assistants knowledge) which had been mentioned by others but could only be elaborated by this participant - Extensive field and management experience, able to draw on long history of considering how to promote ethics in research - Respondent considered frank and open in his responses, was reflective when discussing his views including recognising the limitations to the organisations approaches

Field RA 1	C2, int 5 (male)	<ul style="list-style-type: none"> - In-depth knowledge and experience of the topic, reflective thinking. Sense of confidence in ideas he was expressing – perhaps influenced by supervisors who are active in considering ethical research conduct - Similar ideas in this interview as expressed in the first country, especially of ombudsman - Explicit focus upon the post-conflict context, situation in the country closer to conflict than in the first country which led to more specific ethical considerations relating to this. - Participant provided outline of different levels of training for different categories of researcher. - Participant motivation / underpinning of ethics more unusual overall but typical of this country with a strong biomedical underpinning. - Responses were frank, considered, and consistent.
Field RA 2	C1, int 14 140916_0051 (female)	<ul style="list-style-type: none"> - Lots of examples of ethical and unethical practice direct from her experience. - Open about where she sees opportunities for improvement of practice. - Comparison of researcher and counsellor roles very useful, good to explore the clinical / researcher roles overlap - Links into research culture i.e. supervisor needing to set the right example

For open coding the unit of coding was at the sentence level (Boyatzis, 1998). This unit was selected to force attention to every aspect of what was said, opening up possibilities that could subsequently be refined and narrowed in later stages of analysis (Braun and Clarke, 2006). The generation of codes was aided by constantly asking of the data “what’s going on here?”, encouraging application of a conceptual code to each line (Green and Thorogood, 2014). As recommended by Charmaz ((2012) cited in Green and Thorogood, 2014), an effort was made to code in gerunds which can help focus analysis upon action and meaning rather than description. Furthermore, codes sought to explore both the manifest content of things explicitly stated or described by participants, as well as at the latent level of concepts or common-sense schemas underlying a particular description. Throughout this process attention was paid to the underpinning research questions, seeking to identify codes that explore the phenomena of research ethics from the participants’ perspective.

This stage of analysis was conducted manually on printed versions of transcripts that were annotated by hand. From this the codes generated were put into an excel spreadsheet. This stage of open coding 4 interviews generated 626 codes, which were then reduced through removal of duplicates or very specific codes applicable to one interview alone; and

reorganisation of codes into broader thematic categories, resulting in 495 codes. Following this and to ensure comprehensiveness, notes made during transcription and familiarisation were revisited to ensure they were captured in the coding framework. After this a second review was conducted to again eliminate overlapping and duplicate codes, which resulted in a final coding framework of 461 codes. During this process notes were made on potential thematic organisation of codes, which forms the next stage of data analysis.

The purpose of this stage of open coding and development of a coding framework was to develop ideas about the data and to identify potential avenues of inquiry through the generation of a large number of codes. It was recognised that this process will not result in a “true” representation of the data, but would generate a number of conceptual codes about the actions, meanings, and relationships within and between the data that could be further applied and refined in later stages of analysis (Green and Thorogood, 2014).

Searching for themes

As identified above, initial identification of thematic categories evolved naturally in the iterative process of refining of the coding framework. This process was aided through visualisation of the data including mapping and developing a table containing potential themes alongside a definition and description, and key codes that may belong with each theme (Braun and Clarke, 2006). This was felt to provide a useful point of reference as analysis continued to evolve, and was seen as a useful resource should further analysis of the data set be undertaken at a later date from an empirical ethics perspective.

Through this process the main overarching themes and sub-themes were identified through a clustering process whereby data is organised into sub-groups of themes that feed into higher order metathemes (Boyatzis, 1998, p. 134). These themes and sub-themes were then mapped onto the coding framework to organise codes under broad thematic categories. This process remained inclusive, for example including the theme “miscellaneous” for clustering sub-themes and codes that didn’t immediately fit into other themes (Braun and Clarke, 2006).

Coding the entire data set

Following broad organisation of the codes and themes into a coding framework, this was inserted into NVivo analysis software to assist with coding the entire data set. This commenced with inserting the hand-coded data into NVivo, and importing the transcripts (adapted to an appropriate format for NVivo, as discussed under Transcription above).

Following this the interviews from the first country were coded. After coding all interviews from the first country the coded data was explored by developing a summary table of the content of each code illustrated through ± 3 quotes; and some sub-themes were visually mapped. The processes of developing the summary table and visual mapping began to move analysis forward towards refining themes, for example identifying that the theme “justice / fairness” was linked to the overarching theme of “dissemination”, which prompted looking across the coding categories for areas of overlap. At this stage all cues for movement across the sub-set of data were drawn from links made by participants in interviews.

Following this the rest of the interviews were also coded to the coding framework. In this process the framework continued to be refined as coding categories were merged or added, and coding was reorganised. At the end of all coding there were a total of 26 overarching codes, containing 170 codes, 331 first level sub-codes, and additional fine-grained codes where needed.

During the coding process memos were made, understood as *“the theorizing write-up [of ideas about codes and their relationship] as they strike the analyst whilst coding”* (Glaser, 1978, p.83 quoted in Wengraf, 2001 – emphasis original). These were made as annotations in NVivo, which connects the notes to specific sections of interviews and to specific codes for review and retrieval.

Reviewing and refining themes

Up until this point the researcher was primarily immersed in the data itself, seeking to ensure themes identified were grounded in what participants had said. At the end of data coding the framework approach of charting, mapping, and interpreting was applied (Green and Thorogood, 2014), as data was re-mapped into thematic tables with a column for each country which contained key quotes illustrating each theme and sub-theme. Manual visualisation was used to explore the connections between the concepts and typologies identified in the data, facilitating comparison and contrasting across countries, as well as identifying links between data organised under different themes. Therefore, this stage involved both horizontal movement across case study countries, and vertical movement within case study countries (Green and Thorogood, 2014). This process led to the identification of key illustrating quotes for each theme and connections across the data set in relation to particular thematic issues such as procedural engagement with ethical review.

As themes were reviewed and refined the literature was revisited to inform the organisation of data (Braun and Clarke, 2006). For example, after identifying the broad theme of trust

underpinning participants' narratives about applying research ethics to practice, engagement with a broad literature around trust allowed analysis to move beyond the descriptive to begin to understand the signs, symbols, and operationalisation of trust at organisational and interpersonal levels. Equally exploring participants narratives of procedural engagement with ethical review revealed tensions in the presentation of official documentation and how fixed researchers' viewed the formal approved protocol. Exploring the tensions and signs in the data of something more going on through wider literature facilitated situating this finding within wider academic debates relating to research ethics, bringing additional analytic and theoretical lenses to bear on the data.

Throughout this process movement between coded sections of data and the original interview, as well as between specific themes and the entire data set continued. This movement sought to ensure that what was captured under themes and codes was accurate and concurred with the rest of the data set, or to identify deviant cases (Braun and Clarke, 2006; Green and Thorogood, 2014).

Refining and conceptualising thematic data organisation to produce research findings

By this stage data analysis had evolved to focus upon making choices about which aspects of findings in the empirical data to focus upon in the presentation of results. These included a broad understanding of all data that related to procedural ethics that was considered in light of the extensive literature on procedural research ethics that already exists; and an in-depth focus upon the latent theme of the role of trust as underpinning in-practice ethics.

For the procedural paper a first step was sharing key nuggets of data with a data analysis group comprised of colleagues and PhD researchers not involved in the study for feedback on what they "saw" in participant narratives. This led to a suggestion to map the data according to the journey that key procedural research ethics documentation follows when being developed and applied by organisations. This suggestion was pursued and found to provide an enhanced organisation of the data into a story that could be told about how organisations viewed, applied, and deviated from procedural research ethics. From this an interpretation of the data was made which sought to theorise about the relationship between the data and broader literature to understand the meaning and implications of the descriptions of the role of procedural research ethics in research practice (Braun and Clarke, 2006).

For the second paper focussing upon research ethics in-practice the latent theme of trust was identified early in the process of analysis as an important latent feature in participants'

narratives. Through input from the data analysis group it was agreed that the nature of trust relations required a focus upon longer descriptive extracts of data that could be unpacked for the features of trust that they drew upon. This approach was applied to the data, involving revising analysis by moving from targeted quotes back to the full interview to extract complete segments of interviews that discussed specific instances of trust or trusting relationships. This was achieved by undertaking text query searches for the word trust, and reviewing all coding under related thematic categories, such as the themes of “integrity”, “descriptions of research experiences”, and “mechanisms for verifying ethics”. This exploration of the raw data was complemented by attention to wider literature which explored trust from philosophical and organisational perspectives that were identified in the data as the key levels at which trust operates for participants. These wider frameworks became important in the final organisation and presentation of this data, as thematic categories were refined to speak to this wider contextual and theoretical understanding of trust.

Presenting and argument: writing up research findings

The results aimed to reflect the researchers’ presentation of “a deliberate and self-consciously artful creation...constructed to persuade the reader of the plausibility of an argument” (Foster and Parker, 1995, p. 204). For this consideration was given to the re-presentation of the data in each results paper. Consequently, the paper on procedural ethics provides shorter extracts of the data from across a large number of interviews that tie together into a description of the journey of procedural ethics documents; whilst the paper on in-practice ethics provides longer extracts from a small number of interviews which are unpacked for the features of trust that they illustrate. Each format was selected on the basis of how best to present the data to support the arguments being advanced (Braun and Clarke, 2006). This included revisiting coded data and entire interviews to ensure that findings remained grounded in the data and did not become distorted through the process of constructing written arguments and integrating these with wider literature and theoretical frameworks.

Therefore, both in the process of analysis and the presentation of the final results efforts were made to promote a rigorous process that fairly represented what participants said, whilst making contributions to an understanding of procedural and in-practice research ethics in post-conflict mental health research in the context of existing literature.

Respondent validation: sharing research findings with participants

Following analysis of data, dissemination visits were conducted in each country to share key research findings with research participants. These were conducted in October and November 2016, and involved a few days in each country. Due to difficulties contacting or the unavailability of some participants, as well as a cancelled trip to a regional site due to flight cancellations, dissemination visits did not reach all research participants. In such circumstances requests were made for internal transmission of key findings to researchers who continued to work for organisations, or for a research brief developed as a handout to be shared / posted to participants³⁰. In-person dissemination events were attended both by participants and wider members of organisations with an interest in the research findings. Each event was tailored to the available time and audience.

Dissemination events followed a presentation that detailed multiple components of the research. Prior to discussing the study, a brief historical overview of the emergence of research ethics from a biomedical, social sciences, and bioethical perspectives was provided following a request from research organisations for this background to build the knowledge of their researchers. Following this the study was described, covering: key literature review findings; the research aims; methodological considerations with a focus upon how the interpreter role was managed; data analysis procedures including the quality check process; and key research findings looking first at findings that related to procedural ethics, and secondly at those relating to in-practice ethics. The events were informal, with those in attendance encouraged to ask questions or offer critique of the study findings based upon their own experiences. The feedback received was supportive of the researchers' analysis of the data, with a particular emphasis upon the explicit recognition of the role of trust and comments that the presentation of data reflected well against their experiences of "doing" research ethics in their everyday research practice.

As a result of these dissemination events the researcher was invited to present findings at additional forums including to medical students. Furthermore, a request for adapting the dissemination brief for ethical review committees was made to share the results with the Ethical Review Committee of the World Health Organisation, with the potential for a follow-up presentation. These opportunities are being actively pursued.

³⁰ A copy of the dissemination handout is provided in Appendix 6

Strengths and limitations of the approach to data analysis

The data analysis followed moved through clear phases of analysis, with feedback loops and iterative movement across and between interviews and case studies embedded within the data set. This section discusses some ways in which data analysis sought to maintain rigor to enhance the research findings.

Making a conscious effort to remain embedded within the data during the early stages of analysis sought to provide an opportunity for the researcher to pay close attention to the explicit and implicit stories participants were telling in interviews. This approach facilitated “seeing” what was explicit in the data, which could then be analysed in the context of wider literature during latter stages of analysis (Braun and Clarke, 2006). Conducting thematic analysis following this process was important for ensuring compatibility with the phenomenological epistemology which seeks to understand the first order constructs embedded within participant’s narratives (Schutz, 1975). Engaging in an interpretive phenomenological analysis (Harper, 2012) involves treating participants talk as a window through which participants’ underpinning common-sense worldviews can be understood. The latter stages of analysis build upon these common-sense propositions of researchers to explore them as typologies of common experiences, and to consider them in light of wider schemas and theories about how a particular phenomenon arises and operates in the everyday social world (Schutz, 1975).

The process of data analysis was documented in an audit trail, providing a transparent account of what was done at what stage of analysis (Green and Thorogood, 2014). This document is important for demonstrating to others the process of analysis to make an assessment of its rigor. One limitation to the audit trail is the lack of clear documentation of *why* specific decisions were made during the analysis process, for example whilst discussions at data analysis groups are outlined, these offer multiple possibilities for how to proceed with analysis and no clear explanation is offered for why a given approach was pursued. It also doesn’t contain the process for engaging with wider theoretical literature through which data was subsequently analysed and presented in the results.

Although results inevitably do not represent the entire data set - as all analysis leads to the fracturing of participants’ narratives to tell only part of them (Miller and Glassner, 2011) - it is important to note that the entire data set was coded and subject to analysis, with those elements focussed upon for results subject to additional scrutiny. This included sharing data with the data analysis group and supervisors to ensure that interpretations of the data were

reflected in what participants said, guarding against researcher bias in “finding” preconceived ideas (Boyatzis, 1998; Green and Thorogood, 2014). Additionally, efforts were made to triangulate through comparing across the data within and between interviews and case study countries, including exploring deviant cases or disconfirming data to test results (Green and Thorogood, 2014). Another important aspect of rigor used in this study is respondent validation achieved through the presentation of research results to study participants in each country.

There are also some tools to enhance rigor of data analysis that I have not engaged with. Notably this includes the use of tabulations and reporting of frequencies (Byrne, 1998; Green and Thorogood, 2014). Instead, a sense of the frequency of reporting is suggested through language such as “the majority of” when reporting results, and explicit recognition of minority views. Another tool is triangulation which involves combining multiple methods (Byrne, 1998). However, as discussed above, two weaker forms of triangulation were included, namely that analysis flowed from earlier documentary analysis, and respondent and third party validation of data analysis and results. Finally, whilst extensive research diary notes were taken during data collection and data analysis, these were not fully integrated into the final analysis, which may have meant potential nuances or earlier interpretations of the data were not considered in the final presentation of results.

Reflections

As with most data analysis, the process was not as linear as it has been presented here, and involved some stages overlapping – notably early stages of analysis, interview transcription and development of a coding framework. A notable feature of analysis not fully appreciated before beginning was the time rigorous analysis requires. Equally, trusting in instincts was initially challenging, fighting against a concern to represent everything to think more analytically about the data. Another challenge was to ensure conscious orientation to the research questions and epistemology. This was aided through a reference sheet containing the key research questions and epistemological and methodological orientation that was prominently displayed and revisited throughout the analysis process to ensure the analysis retained focus.

Thinking analytically was challenging, therefore ways to enhance this were actively explored and pursued. These included engagement in data analysis sessions, attendance at methodological training sessions, discussions with supervisors, and informal discussions with colleagues. All of these allowed an opportunity to explore emerging analysis. Notably,

because research ethics is a ubiquitous feature of researcher's practice these discussions often led to others sharing their experiences of mostly procedural ethics processes such as ethical review. In doing so, the applicability of research findings to a range of studies and settings was suggested. Equally however some approaches were not pursued, such as an approach suggested during data analysis sessions to engage reflexively with my own experiences of procedural ethics processes, bringing this into the presentation of the results of the journey of procedural documentation.

Conclusion

This section has discussed the approach to data analysis, situating this in the context of the underpinning research epistemology and research questions, and the methods that flow from this. It has detailed the process of interview transcription, and the stages of thematic data analysis according to an interpretive phenomenological position. In the next chapters I will first present the results relating to procedural research ethics structures to introduce the formal quasi-policy environment in which researchers operate. This is followed by a second set of results which focus upon in-practice ethics, exploring the role of trust in the application of ethical procedures to practice, operating at organisational and individual levels. These results are drawn together in the discussion, which models their interaction to argue for a situated approach to research ethics that accounts for the realities of procedural and in-practice ethics when conducting mental health research in post-conflict settings.

References

- Bailey, J. (2008) 'First steps in qualitative data analysis: transcribing', *Family Practice*, 25(2), pp. 127-131.
- Bird, C. M. (2005) 'How I stopped dreading and learned to love transcription', *Qualitative Inquiry*, 11(2), pp. 226-248.
- Boyatzis, R. E. (1998) *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks: SAGE Publications, 1998.
- Bramberg, E. B. and Dahlberg, K. (2013) 'Interpreters in Cross-Cultural Interviews: A Three-Way Co-construction of Data', *Qualitative health research*, 23(2), pp. 241-247.
- Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77-101.

Byrne, B. (1998) 'Qualitative interviewing', in Seale, C. (ed.) *Researching society and culture*. London: SAGE Publications.

Chiumento, A., Machin, L., Rahman, A. and Frith, L. (2018) 'Online interviewing with interpreters in humanitarian contexts', *International Journal of Qualitative Studies in Health and Well-being*; 13(1), pp. 144487-144496

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online early view, pp. 1-19.

Dunn, M., Parker, M., Sheehan, M. and Hope, T. (2012) 'Toward methodological innovation in empirical ethics research', *Cambridge Quarterly of Healthcare Ethics*, 21(4), pp. 466-480.

Foster, J. and Parker, I. (1995) *Carrying out investigations in psychology: methods and statistics*. London: John Wiley and Sons Ltd.

Frith, H. and Gleeson, K. (2012) 'Qualitative data collection: asking the right questions', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester: John Wiley & Sons., pp. 55-68.

Green, J., Franquiz, M. and Dixon, C. (1997) 'The myth of the objective transcript: transcribing as a situated act', *TESOL Quarterly*, 31, pp. 172-176.

Green, J. and Thorogood, N. (2014) *Qualitative methods for health research*. 3rd edn. London: SAGE Publications.

Harper, D. (2012) 'Choosing a qualitative research method', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester: John Wiley & Sons, pp. 83-97.

Joffe, H. (2012) 'Thematic Analysis', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester John Wiley & Sons, pp. 209-233.

Kohrt, B. A., Upadhaya, N., Luitel, N. P., Maharjan, S. M., Kaiser, B. N., MacFarlane, E. K. and Khan, N. (2014) 'Authorship in Global Mental Health Research: Recommendations for Collaborative Approaches to Writing and Publishing', *Annals of global health*, 80(2), pp. 134-142.

- Lapadat, J. C. (1999) 'Transcription in Research and Practice: From Standardization of Technique to Interpretive Positionings', *Qualitative Inquiry*, 5(1), p. 64-86
- Mason, J. K. (1996) *Qualitative researching*. London: SAGE Publications.
- Miller, J. and Glassner, B. (2011) 'Qualitative research : issues of theory, method and practice', in Silverman, D. (ed.) *Qualitative research : issues of theory, method and practice*. London: SAGE Publications, pp. 131-148.
- Mishler, E. G. (1986) *Research interviewing : context and narrative*. Cambridge, Mass: Harvard University Press.
- Moran, D. and Mooney, T. (2002) *The phenomenology reader*. London: Routledge.
- Oliver, D. G., Serovich, J. M. and Mason, T. L. (2005) 'Constraints and Opportunities with Interview Transcription: Towards Reflection in Qualitative Research', *Social Forces*, 84(2), pp. 1273-1289.
- Palmer, R. E. (1971 [1927]) "'Phenomenology" Edmund Husserl's Article for the Encyclopaedia Britannica (1927): New complete translation', *Journal of the British Society for Phenomenology*, 2(2), pp. 77-90.
- Rapley, T. (2007) 'Interviews', in Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative research practice*. London: SAGE Publications, pp. 15-34.
- Ritchie, J. and Spencer, L. (1994) 'Analyzing qualitative data', in Bryman, A. and Burgess, R. G. (eds.) [electronic book]. London: Routledge, pp. 173-194.
- Schutz, A. (1944) 'The Stranger: An Essay in Social Psychology', *American Journal of Sociology*, 49(6), pp. 499-507.
- Schutz, A. (1975) *Alfred Schutz on phenomenology and social relations: selected writings*. 3rd edn. Edited by Wagner, H. Chicago: University of Chicago Press.
- Silverman, D. (1993) *Interpreting qualitative data: methods for analysing talk, text and interaction*. London: SAGE Publications.
- Silverman, D. (2013) *Doing qualitative research*. 4th edn. London: SAGE Publications.
- Simon, S. (1996) *Gender in Translation: Cultural identity and the politics of transmission*. London & New York: Routledge.

Smith, M. J. (1998) *Social science in question*. London: SAGE Publications in association with the Open University.

Temple, B. (2002) 'Crossed wires: Interpreters, translators, and bilingual workers in cross-language research', *Qualitative health research*, 12(6), pp. 844-854.

Van Manen, M. (1990) *Researching lived experience: human science for an action sensitive pedagogy*. Albany, N.Y.: State University of New York Press [electronic book].

Wengraf, T. (2001) *Qualitative research interviewing: biographic narrative and semi-structured methods*. London: SAGE Publications.

INTRODUCTION TO PROCEDURAL ETHICS RESULTS PAPER

This section briefly introduces the first results paper *Writing to template: researchers' perspectives of procedural ethics for mental health research in post-conflict settings* (Chiumento et al., in preparation) which focuses upon researchers' experiences of procedural research ethics. The introduction aims to briefly situate the paper by highlighting what it adds to existing knowledge, and identifying some potential implications of the research findings. These are further built upon in the discussion chapter.

This paper addresses the central aim of this research, namely to explore the tension between procedural and in-practice ethics. It focuses upon researchers' construction of procedural ethics documentation and engagement with procedural ethics processes. From this, it traces the impact these have upon the management of research ethics in-practice.

Specifically this paper explores researchers' definitions and understanding of research ethics, revealing that these are firmly placed within a principlist framework (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; Beauchamp, 2007; Beauchamp and Childress, 2013). It goes on to trace the development of procedural research ethics documentation such as the research protocol and informed consent form. In tracing these it is revealed that researchers adopt a standardised approach to writing procedural ethical documentation, suggesting that researchers act strategically in relation to procedural research ethics, underpinned by a desire to secure approval and move to the work of doing research. In adopting this approach the identification of situations stimulating ethical considerations is circumscribed to those required by principlism or identified by procedural templates or instruction provided by ethical review boards.

Descriptions of applying procedural documents to research practice highlight how the work of doing research can involve deviation from what is written in procedural documents. Exploring this, it is found that protocol deviations arise for two main reasons: firstly as a result of researchers' efforts to contort standardised ethical procedures to be applicable in diverse contexts, for example by inventing ways to document informed consent (Chiumento et al., in preparation); and secondly due to "active unknowing" (Hoeyer and Hogle, 2014) of contextual realities, facilitating a façade of unproblematic application of ethical principles to diverse socio-cultural contexts.

To illuminate researchers' engagement with procedural research ethics the framework of boundary objects is applied (Star and Griesemer, 1989). Through this framework the

competing uses and claims made upon procedural ethical documents such as research protocols and informed consent forms can be examined, situating the tensions arising in the context of shared documents that occupy different roles for different social actors – including ethical review boards, researchers, and funders. The multiple roles these documents play leads to competing claims to jurisdiction and moral authority over their content. These competing claims identify the limits inherent to anticipatory ethical regulation (Dixon-Woods *et al.*, 2007; Guta *et al.*, 2013), and foreground researcher assertions of a sphere of autonomy when translating procedural documents into practice in situated research contexts (Boulton and Parker, 2007; Hammersley and Traianou, 2012; Kingori, 2013).

This paper concludes with calls for attention to the need for a procedural ethical system that delivers consistency in its process, whilst also providing flexibility in its content to respond to specific research contexts. Researchers' descriptions underline that they routinely adopt a situated approach to operationalising ethical procedures in practice that responds to the context in which they are applied. This analysis therefore foregrounds the autonomy of researchers applying ethical principles and procedures in practice, highlighting the importance of their knowledge and skills for making situated day-to-day ethical judgements.

Consequently, this paper builds upon existing understandings of the role of procedural research ethics from the perspective of ethical review boards, drawing upon philosophical, empirical, and bioethical critiques of anticipatory ethical regulation upon the conduct of ethical research in practice (Strathern, 2000; Hammersley, 2006; 2009; Hedgecoe, 2012; Kingori *et al.*, 2013). It furthermore contributes to the empirical ethical literature, foregrounding the voice of the researcher responsible for practicing ethics (Kingori, 2013). Importantly, the approach taken here illuminates an understanding of how researchers approach to procedural research ethics impacts upon ethics-in-practice. In the second results paper this theme is extended as the gaze is turned to the role of trust in sustaining ethics-in-practice.

References

Beauchamp, T. L. (2007) 'The 'Four Principles' Approach to Healthcare Ethics', in Ashcroft, R. E., Dawson, A., Draper, H. and McMillan, J. R. (eds.) *Principles of health care ethics*. John Wiley [electronic book], pp. 3-10. Available at: <http://onlinelibrary.wiley.com/book/10.1002/9780470510544>.

Beauchamp, T. L. and Childress, J. F. (2013) *Principles of biomedical ethics*. 7th edn. New York: Oxford University Press.

Boulton, M. and Parker, M. (2007) 'Informed consent in a changing environment', *Social Science & Medicine*, 65(11), pp. 2187-2198.

Chiumento, A., Machin, L., Rahman, A. and Frith, L. (in preparation) 'Writing to template: researchers' perspectives of procedural ethics in mental health research in post-conflict settings', *unsubmitted*.

Dixon-Woods, M., Angell, E., Ashcroft, R. E. and Bryman, A. (2007) 'Written work: The social functions of Research Ethics Committee letters', *Social Science & Medicine*, 65(4), pp. 792-802.

Guta, A., Nixon, S. A. and Wilson, M. G. (2013) 'Resisting the seduction of "ethics creep": using Foucault to surface complexity and contradiction in research ethics review', *Social Science & Medicine*, 98, pp. 301-310.

Hammersley, M. (2006) 'Are ethics committees ethical?', *Qualitative Researcher*, 2, pp. 4-8.

Hammersley, M. (2009) 'Against the ethicists: On the evils of ethical regulation', *International Journal of Social Research Methodology*, 12(3), pp. 211-225.

Hammersley, M. and Traianou, A. (2012) *Ethics in qualitative research: controversies and contexts*. SAGE Publications [electronic book].

Hedgecoe, A. M. (2012) 'Trust and regulatory organisations: The role of local knowledge and facework in research ethics review', *Social Studies of Science*, 42(5), pp. 662-683.

Hoeyer, K. and Hogle, L. F. (2014) 'Informed Consent: The Politics of Intent and Practice in Medical Research Ethics', *Annual Review of Anthropology*, 43, pp. 347-362.

Kingori, P. (2013) 'Experiencing everyday ethics in context: Frontline data collectors perspectives and practices of bioethics', *Social Science & Medicine*, 98, pp. 361-370.

Kingori, P., de Vries, R. and Orfali, K. (2013) 'Special issue introduction: Bioethics in the field', *Social Science & Medicine*, 98, pp. 260-263.

Star, S. L. and Griesemer, J. R. (1989) 'Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39', *Social Studies of Science*, 19(3), pp. 387-420.

Strathern, M. (2000) 'Introduction: new accountabilities', in Strathern, M. (ed.) *Audit cultures: anthropological studies in accountability, ethics, and the academy*. Routledge [electronic book], pp. 1-18. Available at: <http://www.tandfebooks.com/isbn/9780203449721>.

The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research (1979) *Ethical Principles and Guidelines for the Protection of Human Subjects of Research (The Belmont Report)*. Department of Health and Human Services [Online]. Available at: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>. (Accessed: 12.02.2014).

WRITING TO TEMPLATE: RESEARCHERS' PERSPECTIVES OF PROCEDURAL ETHICS IN MENTAL HEALTH RESEARCH IN POST-CONFLICT SETTINGS

Abstract

This paper traces researchers' views of procedural research ethics through a qualitative multi-site case study conducted in South Asia with 35 researchers engaged in mental health research in post-conflict settings. Examining the perspectives of researchers foregrounds their everyday lived experience of procedural research ethics, acting as an entry point to explore the continuum between procedural and in-practice ethics. Focusing on this area allows examination of researchers' assessment of the additional ethical considerations the mental health topic and post-conflict context may entail.

To illuminate researchers' interactions with procedural research ethics, the analytic framework of boundary objects is drawn upon. Application of this framework identifies sites of cooperation between the social worlds of researchers and ethical review boards in the development and co-production of procedural ethics boundary objects such as the protocol, informed consent form and information sheet. It also exposes researchers' claims to autonomy when applying research procedures to practice. In this analysis researchers' perspectives are considered in comparison to the principalist approach to research ethics and its role in anticipatory procedural ethical regulation. Whilst researchers praise the standardisation and instruction provided by ethical review boards, they simultaneously critique these same features for failing to recognise the practice of researchers' ethical decision making in the field. This is emphasised by researchers' acknowledgement of the situated nature of moral judgements in research where the demands of ethics, methodology, and context are balanced to reach conclusions about the right course of action in specific situations. Compounding this is researchers' challenging the expertise required to assess the ethical acceptability of research, questioning the balance between the objectivity of procedural research ethics, and the subjectivity of researchers' ethical decision making in practice. It is therefore suggested that whilst appealing for its simplicity and amenability to governance structures, principlism in its procedural research ethics form may be undermining the moral aim of promoting ethical practice.

Throughout the paper are researchers' suggestions for strengthening procedural ethics. However, this paper adopts the position that the challenges of researchers experience are inherent to the bureaucratic needs of standardised regulatory processes. Therefore,

attention is drawn towards recognising the autonomy of researchers enacting ethical judgements in the field, calling attention to strengthening the knowledge and skills of researchers making situated day-to-day ethical decisions.

Introduction

The mental health and psychosocial impacts of conflict and humanitarian disasters, including reactions to stressors such as displacement, poverty, bereavement, and interpersonal conflict - are well recognised (Allden *et al.*, 2009; Roberts and Browne, 2011; O'Mathúna, 2014). To provide mental health and psychosocial support to those in need, research in emergencies is necessary, strengthening the evidence base to inform policy and practice (Zwi *et al.*, 2006; Tol *et al.*, 2011a; Tol *et al.*, 2011b). All research must adhere to ethical research guidelines and procedures (see e.g. The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; World Medical Association, 2013 [1964]; Curry *et al.*, 2014; Inter-Agency Standing Committee (IASC) Reference Group for Mental Health and Psychosocial support in Emergency Settings, 2014; Council for International Organisations of Medical Sciences (CIOMS), 2016) which aim to inform ethical practice in the field. This paper focuses upon procedural ethics understood to encompass the processes involved in applying for and securing research ethics approval such as developing research protocols, information sheets, informed consent forms, and other procedural documentation supporting research conduct. These processes are separate from, but interact with, ethics in practice which refers to day-to-day ethical issues often not anticipated or addressed when applying for ethical approval (Guillemin and Gillam, 2004).

Procedural ethics in health research

Biomedical and increasingly social science ethical research guidelines can be broadly characterised as following a principlist approach to ethics built around the four principles of respect for autonomy, nonmaleficence, beneficence, and justice (Beauchamp and Childress, 1989), most famously codified in what became known as the Belmont Report (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979). Principlism is founded upon a 'common morality' (Lacey, 1998; Beauchamp, 2003; Beauchamp and Childress, 2013; Hammersley, 2015) prioritising key ethical principles claimed to be universally applicable in achieving the objectives of morality (Beauchamp, 2007) and relevant across philosophical, theological, and social epistemologies (Emanuel *et al.*, 2004). It aims to provide a set of principles that can be easily understood and applied by diverse disciplines, stating that "the distilled morality found in principles gave

people a shared and serviceable group of general norms for analysing many types of moral problems” (Beauchamp, 2007, p. 3). Principlism is therefore packaged as a universal route to protecting the human subject in research (Hoeyer and Hogle, 2014).

There are many perceived advantages of principlism for procedural research ethics. Notably it offers simple and resource efficient ways to manage ethical problems in research (Widdows, 2007). Through claims to universal applicability across diverse settings and contexts (Petryna, 2005; 2009) the development of governance structures such as ethical guidelines and ethical review boards (ERBs³¹) have been facilitated. Governance seeks to offer accountability and auditable proof that ethics has been “done” through the production of ethical outputs, epitomised in the signed informed consent form (Strathern, 2000; Boulton and Parker, 2007; Jacob, 2007). Increasingly globally embedded, the formalisation and rationalisation of research ethics governance has been driven by the demands of structural and economic factors (Dixon-Woods *et al.*, 2007). These include that researchers comply with (often US) research ethics guidelines in order to receive funding (Boulton and Parker, 2007) and that ERBs participate in accreditation schemes seeking to professionalise ERBs in low and middle income countries (LMICs) (Douglas-Jones, 2015).

Despite perceived advantages and the practical applicability to governance structures, principlism is subject to critique. This includes the philosophical appraisal that it lacks a unifying moral theory (Clouser and Gert, 1990; Hammersley, 2015) and is therefore a poor guide to action (Levi, 1996). Relating to guiding actions, it is acknowledged that moral judgements are situated - for researchers balancing the demands of ethics, methodology, and context to collectively inform the right action in any particular instance (Fletcher, 1967; Hammersley, 2015). Specified principlism attempts to address this, taking broad principles and tailoring them to specific contexts (Levi, 1996). Whilst helpful for clarifying the meaning of principles and the grounds for particular ethical judgements, specified principlism challenges principlism’s general morality by integrating it with specific moral frameworks (i.e. cultural traditions, religious beliefs, individual ideals and attitudes) which challenges the “view from nowhere” central to principlism (Hammersley, 2015). A further critique of principlism in its regulatory form is that it is frequently transformed from abstract principles to prescriptions and proscriptions (Hammersley, 2006; 2009; Biehl and Petryna, 2013; Hammersley, 2015). This approach, instead of encouraging self-critical reflection or moral

³¹ This paper uses the term ethical review board (ERB) rather than the US term Institutional Review Board (IRB). For a discussion of the differences between the US and UK systems of research governance, please see Hedgecoe (2012)

reasoning, encourages rote application of prescribed or proscribed actions (Green, 1990), limiting the scope of what is identified and addressed as an ethical issue (Kingori, 2013).

Although appealing for its simplicity, principlism is open to the charge that it encourages rote application of prescriptions and proscriptions, rather than acting as a guide to moral decision-making. This is further compounded when principlism is applied in its regulatory and governance form, which may further undermine the moral aim of promoting ethical practice. It is important to note that for regulation and governance in general (i.e. regardless of its underpinning philosophical position), the assumption that governance can ensure ethical practice is heavily critiqued (Miller and Boulton, 2007). Here, tensions along the continuum between procedural ethics and ethics in practice comes to the fore (Guillemin and Gillam, 2004; Hammersley, 2015), turning the gaze from the abstract to the particular sites where research ethics is practiced (Kingori *et al.*, 2013; Hoeyer and Hogle, 2014).

Exploring researchers views of research ethics

This paper builds upon existing empirical ethics literature (Hedgecoe, 2012; Kingori, 2013; Douglas-Jones, 2015; Kingori, 2015) by exploring researchers' views of procedural research ethics. Examining the views of researchers enables tracing procedural ethics processes - such as writing research protocols and seeking ethical approval – for how these shape researchers' experiences of research ethics. Importantly this research extends existing literature through its focus upon a context (post-conflict) and a topic (mental health) often viewed to demand additional ethical oversight (Leaning, 2001; Allden *et al.*, 2009; Jesus and Michael, 2009).

The analytic framework of boundary objects (Star and Griesemer, 1989) is drawn upon to illuminate researchers' interactions with procedural research ethics, extending previous work where this framework has been applied to informed consent (Hoeyer and Hogle, 2014). In this study, the views of researchers situated within research organisations are privileged, taking as the point of departure their lived experience of procedural research ethics in everyday practice. The concept of boundary objects recognises that in procedural research ethics the interests of multiple social worlds combine, namely: researchers, funders, ERBs, research participants, bioethicists, the general public, and professional bodies. Importantly, each social world has its own bodies of knowledge / practice, and its own professional / lay orientation towards the boundary objects which include the research 'objects' i.e. protocols, informed consent forms, and other standardized procedural ethics documents. Using boundary objects as an analytical framework privileges these multiple social worlds and

standardised forms from the perspective of researchers, foregrounding their interactions with procedural research ethics to reveal inherent tensions.

As defined by Star and Griesemer (1989), boundary objects:

“both inhabit several intersecting worlds....*and* satisfy the informational requirements of each of them... They are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identify across sites. They are weakly structured in common use, and become strongly structured in individual-site use” (p.393, italics original).

Key features of boundary objects are that they are simultaneously concrete and abstract; specific and general; conventional and customised, emerging organically through cooperation and operating as bridges or anchors across social worlds (Star and Griesemer, 1989; Star, 2010). They develop through multiple social worlds shared engagement to create representations of a thing, in this case the design of a research study. Problems of conflicting world views that arise when developing boundary objects are managed by representing the lowest common denominator and ensuring that boundary objects remain reconfigurable, allowing each social world to adapt them to local purposes whilst retaining recognisable form that serves the purposes of all social worlds (Star and Griesemer, 1989; Star, 2010). Procedural research ethics standardised forms such as research protocols and informed consent forms are considered to contain these boundary object key features, being a generalized shared referent between researchers, ERBs, funders, and research participants which are actualised in practice through the actions of researchers interacting with research participants. Researchers are central to this process, engaging with procedural ethics boundary objects at the common level with ERBs and funders, and at the level of individual site use where they are tailored and applied to local practice. A specific interest in this paper is the “backstage” work of researchers who both develop and apply the boundary objects to practice, considering the invisible work that surrounds the formal “front stage” of procedural research ethics (Goffman, 1959; Star, 2010).

Examining researchers’ experiences of procedural research ethics through the lens of boundary objects focuses attention on procedural research ethics as a social phenomenon, and can illuminate tensions along the continuum between procedural ethics and practical judgements of researchers in the field (Guillemin and Gillam, 2004; Hammersley, 2015). Gaining the perspectives of the *who* of ethics – in this case researchers - brings to the fore views of those responsible for *practicing* ethics (Kingori, 2013). Consequently, this analysis

aids understanding of how the development and specification of procedural research ethics boundary objects can enhance or constrain a researcher's ability to respond to everyday ethical issues that arise in the field.

Methods

This study explores procedural research ethics from the perspective of researchers engaged in mental health research in post-conflict settings. The main focus is to examine the interactions between procedural ethics and ethics-in-practice (Guillemin and Gillam, 2004), seeking to understand how procedural ethics is approached from the perspectives of researchers.

Research setting

This research employed a multi-site case study design (Yin, 2009), conducted in three countries in South Asia. Anonymity of organisations prevent identifying the countries; however a broad overview of the research settings is provided to situate results.

All three countries have experienced conflict within the last decade, currently host refugee and / or internally displaced populations, and continue to experience political instability and natural disasters. Each country is culturally diverse, with a multiplicity of ethnic, religious, and language groups. Two countries are classified by the World Bank as lower middle income, and the third as a low income country (World Bank, 2017). Literacy rates in all three countries continue to improve, particularly for younger generations, although in two countries older generations have literacy rates of around 40% (United Nations Educational Scientific and Cultural Organization (UNESCO), 2015). Populations in all three countries use multiple biomedical and religious / traditional healthcare systems (World Health Organisation, 2001). Mental health is recognised as a Government priority in all three countries, with two countries having recently passed Mental Health Acts and the third frequently mentioning mental health in policy frameworks. However, in all three countries mental health stigma, often founded upon religious or traditionally-informed understanding of the causes of mental ill-health, remains a significant barrier to treatment (Thornicroft, 2006; Patel, 2007).

This paper assumes sufficient similarity in procedural ethics structures across all three countries to draw comparisons. All settings have centralised or devolved requirements that biomedical research follow international guidelines and be subject to ethical review, and all participate in national and regional forums such as accreditation schemes (e.g. FERCAP: see <http://www.fercap-sidcer.org/index.php>). Furthermore, all three organisations were in

receipt of international funding that requires participation in multiple levels of international and national ethical review. Therefore similarity in procedural ethical systems is assumed. Whilst also accepting that each country will have its own distinct approach to ethics as local norms impact upon the prioritisation of ethical principles. As this paper seeks to explore researchers' experiences of procedural ethics processes it is considered that there is sufficient similarity across the country systems for a multi-site case study approach.

In-depth interviews

Research was conducted between September 2014 and February 2015, involving 35 individual in-depth interviews conducted with researchers across the three countries. Research questions sought to explore procedural and in-practice ethics, and to unpack interactions between the two. This included discussing how researchers understood and defined research ethics; researcher engagement with governance processes such as ethical review; how ethical issues are identified; what guides researchers' responses to ethical issues that arise in the field; and understanding approaches to research ethics training and staff development. By taking procedural research ethics boundary objects as the focus of analysis, the impact of multiple social worlds cooperating to develop procedural research documents upon researchers understanding and approach to procedural and in-practice research ethics is placed centre-stage. This allows exploration of how the interaction across multiple social worlds shape research ethics in specific ways, with implications for ethics-in-practice when the boundary objects are applied by researchers.

Table 14 summarises the interviews conducted in each country, identifying categories of researchers involved and six interviews conducted online in the third country due to the security situation preventing in-person travel. Interpreters were involved in 24 interviews to facilitate the full engagement of participants. They were hired at each research site and trained for the purpose of this study as co-interviewers alongside the researcher. For full discussion of the methodological approaches to interviewing with interpreters and online interviewing please see (Chiumento *et al.*, 2017b, 2018). All interviews were digitally recorded, with the English conversation transcribed and anonymised for analysis. Anonymity procedures include the use of pseudonyms and fictional place names denoted by the use of { } brackets. In the presentation of quotes, those in italics represent what was conveyed by

interpreters on behalf of participants, whilst those in normal text are participants speaking in English. To ensure readability quotes have been tidied up³².

Table 14: Interview overview

	Country 1: {Florin} September 2014		Country 2: {Bialya} December 2014		Country 3: {Markovia} January-February 2015	
Number of interviews	17		9		9	
Interview location						
UK	-		2		1	
In-country (no. of sites visited)	17 (3)		7 (2)		8 (1)	
Conducted online in-country	-		-		6	
Interpreter involvement	Without interpreter	With interpreter	Without interpreter	With interpreter	Without interpreter	With interpreter
All interviews	4	13	5	4	2	7
<i>Primary Investigators</i>	2	-	2	-	1	-
<i>Research / field coordinators</i>	2	1	2	-	1	1
<i>Data collectors</i>	-	12	1	4	-	6

Ethics

This study received ethical approval from the University of Liverpool and ethical review boards in all three countries. All participants provided written voluntary informed consent. Interpreters signed confidentiality agreements, were paid at a local rate, and were provided with references attesting to their role in this study to support their career development.

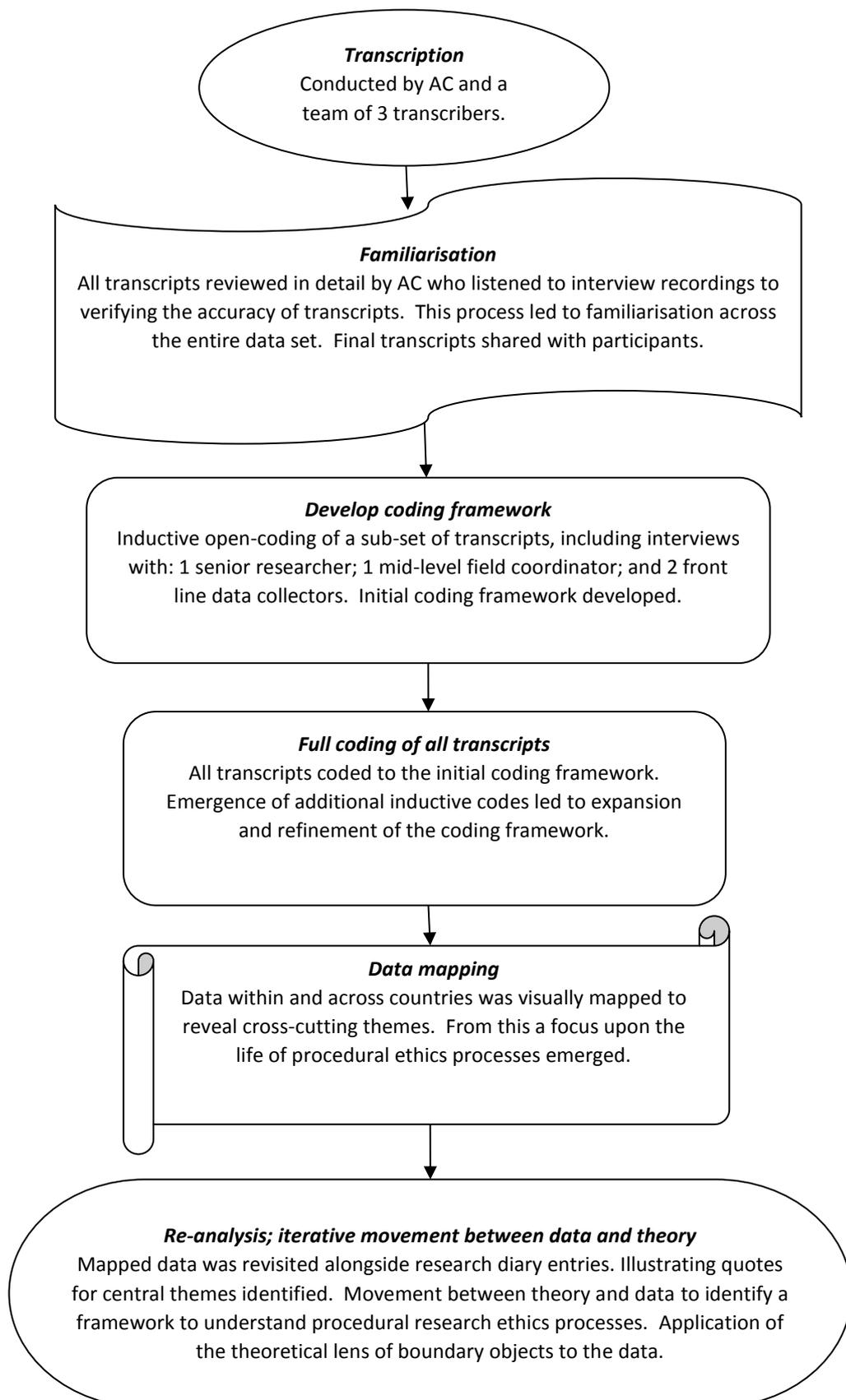
Analysis

Thematic analysis was driven by an underlying phenomenological epistemology (Schutz, 1944; 1945; 1967). The analysis process involved open coding a sub-set of transcripts to inductively develop a coding framework that continued to be refined as subsequent transcripts were analysed (Boyatzis, 1998; Green and Thorogood, 2014). Following initial coding of all transcripts, the coded data was revisited and re-analysed to map procedural research ethics processes by following participants' narratives about the development and management of documents such as the research protocol and informed consent forms; and engagement in ethical review. Therefore, the approach to analysis was to look *at* rather than *through* procedural ethical documents to reveal the functions and roles they occupy. This

³² All interview extracts are identified by a pseudonym and the country number (C1, C2 or C3). In all extracts words that have been anonymised (people's names, place names, and titles of research projects) are identified by the use of { } brackets. The use of bracketed dots e.g. (...) indicates the removal of one or more sentences, whereas ... indicates the removal of up to a few words, and () indicated inaudible segments of interviews that could not be transcribed. The removal of some words and sentences has been undertaken to enhance the readability of the extracts.

focus led to the identification of boundary objects as a productive theoretical lens to aid understanding of the social functions of procedural research ethics. The analysis process is outlined in figure 6.

Figure 6: Data analysis process



Results

Developing procedural ethics boundary objects was described by researchers through three stages: (1) researchers developing procedural documentation (protocol, informed consent form, etc); (2) co-production of these documents between researchers and ERBs through the ethical review process; and (3) spheres of researcher autonomy when applying procedural objects in practice. Throughout researchers narratives key tensions arise, including the jurisdiction of researchers and ERBs over the boundary objects, and where the demarcation of autonomous action upon these objects lies. Inherent to these tensions are claims to moral authority - understood as the authority to make decisions about what is or is not ethical when conducting research. All of these claims are situated in the specific context of post-conflict mental health research, often premised upon the expertise required to give rise to jurisdiction over ethical research conduct.

Creating procedural research ethics boundary objects

Descriptions of developing procedural documentation emphasised standardisation: “a lot of ethics forms are almost written to template now” (Kari, PI: C2, I9). In this process researchers adopt a strategic approach to form filling (Israel and Hay, 2006), explicitly responding to standardised templates and reiterating established responses and procedures:

“research that we do has...ethical procedures in place that we generally always do, and that the {SKAXIS} approves.” (Hubert, PI: C1, I1)

“looking for...a fairly standard information sheet.” (Kari, PI: C2, I9)

In this process the boundary object’s generalised nature is reinforced, facilitating communication across social worlds through shared templates with instruction from ERBs that aim to aid researchers’ identification of ethical issues inherent to a study. The recycling of procedures used previously appeals to researchers’ knowledge-in-practice accumulated through lived experiences of research and finding methods or tools that facilitate their role (Carlile, 2002), and have been approved in the past. This reveals a tension between the generalised/standardised and localised/particular roles that procedural ethics documentation occupy. This tension is negotiated by researchers who satisfy the demands of the generalised and standardised procedural documentation templates, whilst inserting their own agency by embedding localised and particular strategies to ethical research.

Some researchers felt the standardised nature of procedural documentation limited their adaptability: “Do we tailor make our ethical processes enough to the population? Er, the short answer is probably not.” (Hubert, PI: C1, I1). One researcher described where he

viewed the demarcation between localised practice and standardised approaches to fall in procedural documents:

“part of the whole ethical approval, processes is to perceive,...pre-empt, or identify...ethical challenges...I think the process has become...a matter of giving answers that people think would be taken or accepted. ...trying to provide the answer the examiner is looking for” (Orville, Supervisor: C2, I6).

In drawing an analogy with examiners the relationship between researchers and ERBs is characterised as one where the ERB has control over an application outcome, with the researcher required to meet certain competencies to pass and move to research conduct.

For mental health research in post-conflict settings researchers emphasised the importance of contextual understanding for its impact upon ethical conduct. This includes the extent to which mental health is stigmatised, and being perceptive about the different socio-demographic statuses of groups and individuals that research may engage with:

“[Populations exposed to emergencies] are very physically, psychologically, socially, emotionally vulnerable. And that affects their decision-making capacity. (.2) ...and if you tag research in too, could be (.4) undue inducement for participation.” (Spiro, PI: C2, I8)

“mental health field is more sensitive than other researches. And if the information shared by respondents aren't kept confidential then there is a high risk...the respondent would have to cope with stigma and some other problems in the community.” (Graham, Supervisor: C1, I10)

Ultimately, researchers recognised that the application of ethics, “changes with the, er, context, culture, and the, you know, relationship between you and respondent” (Silvia, RA: C1, I14), foregrounding the range of considerations made by those on the front line applying ethics in their everyday research practice.

Researchers described internal organisational systems of checking documents prior to submission to ERB's to ensure they contain the necessary information expressed in ways required to facilitate approval (Jacobs: 2007):

“where there's an instrument that has been developed...the research design has been done...I shall also have to review...the documents...to check whether the, the basic [ethical] elements [are] ...reflected.” (Brendon, PI: C1, I17)

“my job, is often around, getting that into as lay language as possible. ...ethics committees definitely scrutinise, for lay language and making sure it's not full of jargon.” (Kari, PI: C2, I9)

As these researchers' make explicit, the aim of this process is to verify that documents reflect key ethical principles and are written in ways defined by ERBs – emphasising the use of non-technical lay language which support generalised boundary objects by appealing to the lowest common denominator across the social worlds that engage with them (Star and Griesemer, 1989).

Highlighting the role of language reinforces that these boundary objects are representations of knowledge (Carlile, 2002). Facilitating these representations is the shared semantic and knowledge frame of principlism, as one participant put it: “the basic...ethics..., rules are er autonomy, non-maleficence and beneficence, justice” (Mercurius, RA: C2, I5). For some researchers additional emphasis was placed upon confidentiality of data and maintaining participant anonymity; that research employs a sound study design likely to generate useful information - ascribing to the evidence-based medicine model (Adams, 2013); and that researchers are held accountable for their use of funding and other resources. Although some researchers made reference to wider underpinning moral theories, most frequently founded upon religious beliefs, the majority defined research ethics exclusively in line with principlism. This suggests that the principlist framework was viewed as sufficient for managing the ethical issues inherent to mental health research conducted in post-conflict settings, albeit with additional emphasis upon the mental health impacts of conflict exposure:

“broadly speaking ethical principles in research, are fairly generic...I’m struggling to think of something specific in mental health that, takes it beyond any other study um. ...I’m just not convinced that (.2) the information gathered in mental health is, is nearly as sensitive in [research participants] eyes themselves as some people imply” (Kari PI: C2, I9).

“research...in trauma affected areas...we can do anything where there the ... situation is normal but in (post-trauma, post-conflict areas, we have to be very careful)” (Tanika, Supervisor, C3, I8).

Researchers' narratives also reveal a tension between adherence to principlism in its procedural form, and perceptions about acting morally in research practice: *“ethics is the soul of research, any research...ethics is not just about following the, all the procedures, but also about maintaining morality”* (Tamati, RA: C1, I11). The interaction between procedures and acting morally arises when procedural ethics boundary objects are specified into practice through the actions of researchers. This therefore becomes a pivotal point with upstream

implications for jurisdiction over the content of boundary objects; and downstream consequences for researchers specifying them to particular settings.

Researcher and ERB coproduction of procedural research ethics boundary objects

Coproduction of procedural research ethics boundary objects occurs through the ethical review process. For all researchers the outcome of ethical review was implied as inevitable, always moving towards the end goal of approval:

“we submitted...Then {Skaxis} provide the feedback: please, er, revise this section. This is not clear. The consent form is not right. Please include these things. Then we incorporate their feedback and again submit and they provide the approval. ...if er, we think, you know, er based on the {Skaxis} feedback, if er you are not agreed with this then you justify.” (Milenko, Supervisor: C1, I16)

Ethical review is therefore typified as a bureaucratically functional process, a view echoed by a researcher who sits on an ERB highlighting their responsibility to deliver efficiency in the ethical review process:

“as a reviewer...you read the research proposal thoroughly. ...based on your knowledge and your preconceived ideas...decide...this is ethical or this is, you know, unethical...then it depends on the body...on the final committee...if we have similar concern. Then we say yeah, okay, it has to be changed. ...We will, you know, re-review quickly, and then, you know, we will give the approval.” (Shahashi, Supervisor: C1, I3)

These descriptions suggest the nature of “backstage” work (Goffman, 1959) where ERBs review of protocols involves negotiation and reconciliation within the committee before being shared with researchers through letters of approval or revision/ammendment. These negotiations are written-out and presented to researchers through a lens of bureaucratic functionality, appealing to the efficiency of defined social processes that serve to legitimate the ERB’s authority by setting expectations about each actor’s role in the review process (Dixon-Woods *et al.*, 2007).

The bureaucratic functioning of ethical oversight was seen to promote an ethical research culture:

“the good thing is that there is a culture that,...research has, ethics, you know, the research purposes should be reviewed by a group of people, and at least that, that they agree. Even if they agree crap, but they agree, it went through the process. ...I am not criticising in low and middle income countries, this is a new concept, so, you

know, review would just be a formality also. ...but it's a...first important step actually, in ethical research." (Shahsahi, Supervisor: C1, I3)

This quote emphasises that ethical review in LMIC settings is under development, suggesting that current practice is a "formality" in the performance of due process. The notion of an evolving process reinforces how the boundary objects are malleable to new practices and knowledge, reflected by one researcher in relation to consent: "You know er, the same [informed consent] things... That we are using now, and 20 years later it's not er, different. ...issues are raised by the current situations. You know socio-cultural changes, perspectives of the people, knowledge of the peoples" (Milenko, Supervisor: C1, I5). Here the informed consent boundary object is typified as static and unchanging, as the social world interacts with them in different ways (Miller and Boulton, 2007), reinforcing that the coproduction and application of research ethics boundary objects is both facilitated and constrained by their generalised and standardised form.

Expertise to conduct ethical review

Recognising competing knowledge claims is an essential feature of the coproduction of boundary objects that facilitate cooperative work processes (Star and Griesemer, 1989; Star, 2010). In the second and third countries researchers expressed concern that ERBs conducting reviews were not equipped with relevant contextual expertise - both of conducting research in conflict-affected settings, and technical mental health and research methods expertise. This lack of contextual and technical expertise was seen to challenge the authority of ERBs to make decisions that were better than those researchers could reach (Hammersley, 2009).

Researchers in the second country critiqued the make-up of ERBs, citing a biomedical bias which impacted upon effective lay member representation:

"every committee has a lay person, but what the hell does that mean you know? ...in our part of the world, this lay person...he just sits there. ...Because he is dominated by, you know the, the clinicians" (Orville, Supervisor: C2, I6).

The potential for enforced participation in ERBs by those with neither the experience nor the desire to be involved was raised: "the concept of ethics committees is just starting to take,...things are improving. ...[but] they're just there for the for the sake of being there...not of their choice..., but because, you know somebody has to do it" (Orville, Supervisor: C2, I6). These critiques strike at the heart of the authority of ERBs to provide effective research governance and oversight, contesting the required moral and technical expertise to fulfil this

role. Whilst it was acknowledged in relation to expert ERB members that “[i]t’s difficult to find...an expert in bioethics, and who has already done fieldwork.” (Mercurius, RA: C2, I5) - placing emphasis upon combined training and experience in the ethics of emergency mental health research specifically - the perceived failure of ERB’s to be comprised of members with the required credentials was present across all three countries.

Therefore, all researchers emphasised the need for knowledge about research context to effectively assess the ethical issues inherent to a proposed study:

“occasionally come across ethics committees where...you have to reassure them that actually these mental health questions have been asked of tens of thousands of people in community studies all around the world, different cultures everything else um. And if there was a sort of general, sensitivity around those questions or it was felt that they were kind of uncomfortable questions I think we’d know about it.”

(Kari, PI: C2, I9)

Here, researchers appeal to their lived experience of mental health researchers as a collective (“we’d know about it”) as providing the moral authority for researchers to make decisions about what it is or is not ethical in a given setting.

Review process: external control vs. internal moral compass

Coproduction of boundary objects is an inherently interactional process engaged in by researchers, ERBs, and at times funders. Therefore, researchers’ typification of this interaction can illuminate the spheres of jurisdiction and responsibility in relation to ethical research.

ERB’s were described as a “guardian”, “protector”, and “gatekeeper”, with responsibility for “safeguarding” rights and ethical duties, highlighting the ERBs role of externally imposed anticipatory regulation to prevent unethical research (Hammersley, 2006; 2009; Simpson *et al.*, 2015). The ERB acting *on behalf* of potential research participants is also raised, requiring that ERB’s assess documents from not only an ethical perspective, but also the perspective of potential research participants (Simpson *et al.*, 2015). As above, researchers conceptualised the scope of research ethics in line with principlism. Beyond this, some researchers considered the ERB’s role to entail protecting *researchers* from harm, particularly in emergency contexts:

“researchers themselves, don’t get into harm’s way in the process of collecting the data, especially in...dangerous zones in the world... Where there are infectious diseases, where there are conflicts going on.” (Mercurius, RA: C2, I5)

Researchers felt that participant protection is achieved by an independent body reviewing and approving procedural boundary objects, firmly locating jurisdiction over approval for study conduct with ERB's: "I think all projects do need ethical review and I would certainly defend that to the hilt. Someone independent needs to have seen what you're going to do and approved it" (Kari, PI: C2, I5). One researcher suggested that self-regulation would be insufficient and that external regulation was necessary to prevent researcher excess, appealing to historical precedent for procedural research ethics (Beecher, 1966; Shuster, 1997):

"fundamental purpose of an ethical committee is...to stop people from er, you know, exploiting. ...without that obviously people would not...have any control any regulations over what they do" (Orville, Supervisor: C2, I6).

Considering control and the prevention of excess, researchers called for proportionality in ethical review, restating the tension over the ERB's sphere of legitimate and illegitimate jurisdiction over the coproduction of boundary objects: "It should be facilitatory (...) it should not be punitive (...) I see ethics intervention like any other intervention (...) it has to be appropriate (...) it should be doing more good than harm" (Pedro, PI: C3, I9). Appealing to the principle of beneficence suggests that the ERBs sphere of legitimate jurisdiction is derived from their moral authority as protectors of potential research participants. This authority is threatened by ethical review seen to overstep the ERB remit to become a process of control over researchers:

"the whole concept of the ethical approval can be...an exercise in applying control...it's become a process of policing. ...some call it rigmarole...because otherwise they won't be able to do anything" (Orville, Supervisor: C2, I6).

These descriptions emphasise researchers' submissive role inherent to "submitting" to ethical review, where the researcher must demonstrate docility and deference to a higher authority (Dixon-Woods *et al.*, 2007, p. 800). Therefore, in contrast to all social worlds having partial jurisdiction over boundary objects, the balance is tipped in favour of ERB's who can impose their view.

In the second country punitive review was explored, asking who protects researchers against the power of ERBs? Responses invoked the notion vulnerability:

"like the research participants become vulnerable in the face of a researcher, (...) people who go into ethics committees and submit proposals [are in] a way vulnerable to the ethics committee review" (Spiro, PI: C2, I8).

Invoking vulnerability suggests that the researcher or the research project itself could be at risk of harm – such as harm to individual or study reputation, or harmed through enforced changes in study designs. Examples of these and other harms were shared in C2 and included arbitrary denial of ethical approval, and requirements to remove perceived sensitive questionnaires from a research design, viewed by the researchers as weakening the study.

Extending ethics review as control, quasi-legal interpretations of the ERB's role were common, summed up by one researcher using a banknote watermark analogy:

“committee that really guards against...possible, er malpractice. ...holding it against the light...like you check er, er, er, money, for a water mark er is it, is it real, is it good, is it solid? ...there's a neutral body that does that. ...reviewing that it has the safeguards in place...against...ethical malpractice.” (Hubert, PI: C1, I1)

The focus here remains the anticipatory prevention of “ethical malpractice” achieved by holding a banknote against the light to reveal an engrained watermark, suggesting that ethical considerations are embedded within the fabric of a project but may not be immediately evident and require specific actions by the ERB to reveal them. This analogy extends the tension over the respective responsibilities of researchers and ERBs to make explicit or “see” the ethical issues inherent to a project. The form-driven nature of this process is critiqued for leading researchers to adopt practices that facilitate approval rather than serve the ethical interest of a given project (Hammersley, 2006; Jacob, 2007; Hammersley, 2009): “us trying to make [the reviewers] happy and they are looking for those,...answers that make them happy” (Orville, Supervisor: C2, I6).

Conversely, writing research protocols according to established research ethics principles was felt to provide researchers with an internal moral compass or “self-ERB”:

“first ERB is you yourself...[as a researcher]...and then you know respondent...would you be willing to, you know, give this answer...self-reflection is needed [to] actually see the situation of the, you know, respondent. ...self-ethics” (Shahashi, Supervisor: C1, I3).

This emphasises the importance of *researchers* assessing study protocols from the perspective of potential research participants (Simpson *et al.*, 2015). In this process, the role of “fear psychology” was described:

“Because we are human, we are bound to what we agree. And we also have fear,...if I don't follow what, what I have submitted to the ethics board, and I would have consequences to myself and to my institution. So, this is positive fear... [it] helps you

to be serious in operationalising the ethical values and principles.” (Shahashi, Supervisor: C1, I3)

Here the protocol as a boundary object operating across multiple social worlds becomes a strength, acting to encourage each social world to appreciate the perspectives of others. It furthermore serves to bridge the procedural ethics / ethics-in-practice continuum with organisational or procedural concerns interacting with autonomous application of these to research practice: “these two are actually working very well together to actually produce, to operationalise the ethical, er principles” (Shahashi, Supervisor: C1, I3).

Similarly being embedded in the local community was seen to facilitate researchers gaining a “deep understanding” of the population that supports applying ethical principles to research:

“if you’re already there in the population,...already embedded,...the principles remain the same, you only need to understand..., their application, and their application can only come from the deep understanding of the of the population. ... Working with them, knowing their priorities, knowing their culture, knowing...what is important to them. ... You’re part of the situation.” (Pedro, PI: C3, I9)

This “deep understanding” was emphasised as of especial importance for understanding cultural attitudes towards mental health and perceptions of research - particularly where conflict may have disrupted previous socio-cultural norms.

Multiple levels of ethical review

Researchers referred to multiple levels of review of research conducted internationally (Douglas-Jones, 2015) - generally requiring both in-country and sponsor country review - as routine practice: “standard routes of getting ethics approval both here...and in {Bialya}” (Kari, PI: C2, I9). Review in LMIC’s was recognised to mirror the operating styles of ERBs in high income countries, for example through increased instruction: “Simplified,...more instructions on..., what is expected and how to fill...this is what we expect. ...it’s becoming better” (Orville, Supervisor: C2, I6). These views suggest the impact of the globalisation upon ethical review systems (Douglas-Jones, 2015), with a formalised structure aiding the coalescence of social worlds in the coproduction of boundary objects.

Commenting on bioethical capacity as opposed to procedural functioning of LMIC ERBs, researchers continued to question their ability to provide ethical scrutiny:

“they're doing it - to the best of their capacity” (Hubert, PI: C1, I1);

“very low...kind of mechanism that...need to be strengthened” (Brendon, PI: C1, I17)

Low levels of capacity were emphasised by comparisons to review systems in other LMICs: “partner organisations...review process they, go through, it's just there's more, questions asked and more information needed than that is asked in {Florin}” (Hubert, PI: C1, I1). Also noted was the lack of technical expertise in LMIC's that researchers argued may mean ERB's should defer aspects of review to those with these expertise and resources:

“In theory committees are there to also, know that the research is appropriate and everything but it's harder for committees to judge that...it's certainly easier on a committee when a study... [has] external funding.” (Kari, PI: C2, I9)

This critique moves away from review-as-process to focus upon the content which is recognised to require technical research methods knowledge. The involvement of funding agencies who scrutinise research from a scientific perspective is thus seen as a way to address the limitations of LMIC ERB's, identifying the benefits of the protocol as a boundary object that is acted upon by multiple social worlds.

Researchers felt that international ERB's physical and cultural distance from local research settings could lead to raising issues inappropriate to the local setting:

“ethics review at [international] level, I'm not sure what is their er structure, how much the members on the committee, they know the local setting...I didn't think that all the questions, all the concerns they were raised were very appropriate” (Pedro, PI: C3, I9).

Knowledge of the local setting was emphasised as essential when assessing the ethicality of a project, knowledge that is rarely available due to the distance between ERBs and the settings where research is conducted. Reliance upon generalised boundary objects limits the opportunity to gain contextual knowledge that researchers' feel is relevant to the operationalisation of ethical principles in specific settings (Hammersley, 2006; Ryan, 2007; Hammersley, 2009; Lê *et al.*, 2013). In contrast to the potential strengths of multiple social worlds coproducing boundary objects, this quote reinforces the disproportionate jurisdiction given to ERBs in determining their content, and arguably in the case of Western committees reviewing LMIC research, the imposition of individualistic operationalisation of ethical principles (Emerson *et al.*, 1995; Swift, 2006; Ryan, 2007) that may not be locally applicable.

Another researcher's experience of multi-level ethical review raised these concerns:

“my experience is that sometimes...people sitting in that tries to go beyond their mandate, and questions certain things that they don't understand...I've had some ridiculous questions coming from, the Western committee that approve my study,

because they simply didn't ask er, didn't understand the context, right? The cultural context of what I'm doing and what, who these people are and who I am and who my you know, my team is...the same way I've had input from the local committee that, that questioned the scientific rigor of my study which has, um, undergone, I don't know three or four international reviews, won grants (). It's just ridiculous...it's a miss-match." (Orville, Supervisor: C2, I6)

This researcher critiques both the local and international ERBs for lacking specific expertise: contextual expertise in the case of international ERBs assessing research conducted in LMICs, and local ERBs for lacking technical research expertise. Therefore, researchers' are left in a position of trying to balance the distance – both geographical and cultural - between the pronouncements of different ERBs, reconciling these to ensure research remains scientifically valid and cultural appropriate.

Therefore, beyond the procedural limits of the form, the ethical challenges in post-conflict mental health research could be being made more intractable (Heimer, 2013) due to a combination of ERBs lacking the required expertise to assess the ethical issues of particular projects, whilst retaining sole jurisdiction to certify research for conduct. This suggests that the intrinsic feature of boundary objects appealing to the lowest common denominator shared between all social worlds can be a challenge, especially where researchers as one social world feel the generalised nature of these objects come at the expense of more detailed representations required to fully convey the ethical issues inherent to a given project (Carlile, 2002; Hammersley and Traianou, 2012).

Researcher autonomy: applying procedural research ethics to practice

At the intersection between procedural documents and research practice particular tensions arise, both around the generalised nature of boundary objects, and between researcher and ERB claims to jurisdiction over their content.

Creating artefacts: adapting research procedures to context

A feature of creating procedural research ethics boundary objects was the adaptation of procedures – notably informed consent - to ensure they met the standards required to secure ethical approval, whilst being socio-culturally appropriate for the setting where they were to be applied. These adaptations emphasise the shared use of boundary objects, taking a form that enables them to operate across diverse social worlds. This process involved inventing ways for illiterate participants to demonstrate written consent required for ethical audit trails, whilst addressing research participants' fear of signing documents:

“Almost 95% or 100% who are illiterate, they, they are afraid even to provide er, thumb, thumb print. ...Because they can’t read. They say sometimes why you need? I don’t know whether you have written..., er, about my house, my land. How can I, I do this?” (Masood, Supervisor: C1, I12).

All three countries recognised that the historical context of population exploitation by signing documents that could not be read had contributed to a generalised fear of signing forms, particularly amongst the illiterate. In response, researchers drew upon precedent from other settings, using procedures such as consent witnessed by an independent person not connected to the research, researchers documenting verbal consent, and the use of a line or mark:

“explore what other,...organisation are doing, and what is international practice. ... if the respondent is illiterate and not ready to give you a thumb print? [They] say oh no we get, just requested to them to mark. [Now] We are just requesting them to make, er, line or something like that. ...whatever you want to mark.” (Masood, Supervisor: C1, I12)

The practice of inventing procedures to comply with ERB requirements was depicted as common practice across LMIC settings, reinforcing the universalised and standardised nature of informed consent which facilitates sharing approaches. In this context the generalised boundary object is again recognised as a strength, enabling transferability of approaches across geographical settings, extending the evidence-based medical model approach of generalisability and transferability (Adams, 2013) to ethical procedures (Biehl and Petryna, 2013). Ascribing to the ERB mandate emphasises researcher docility in their “submission” to the ERBs authority (Dixon-Woods *et al.*, 2007). In these responses to the challenges procedural documents present to research-in-practice, researchers both accept and contest the jurisdictional authority of ERBs over these boundary objects – asserting researcher autonomy and implicitly critiquing the generalised and universal approaches by inserting socio-culturally embedded representations of these boundary objects, whilst retaining their overarching form and content.

Researchers expressed their autonomy when identifying what is important to inform the ERB about when adapting boundary objects for application in the local setting:

“minor changes, for example the words, the language. In such situation it's not necessary to resubmit the consent form to the {Skaxis}. ...if we change the methodology for example, ...after er, receiving the {Skaxis} approval, if we change

the er study districts...sample size...we inform the {Skaxis}.” (Milenko, Supervisor: C1, I16)

This captures the autonomy researchers claim to specify boundary objects to a particular setting, suggesting that their sphere of jurisdiction primarily arises once the documents have been approved for site-use by ERBs. It also challenges the ERBs’ authority by not submitting back for approval procedural objects adapted for site-use. This may be both a pragmatic response that recognises the bureaucratic burden this may place on ERBs and the need for researchers to “do” the research, as well as a response that reasserts researchers’ jurisdiction to specify the boundary objects for use in research practice.

Interactions between procedural ethics and ethics-in-practice

The value of ethical approval extended beyond the procedural to research practice, for example by offering proof that research follows established ethical norms:

“without making protocol, like it's really hard to function at every level. ...while going to any organisation or going to field, they ask what, what guidance, what code of conduct they have been following. What protocol they have.” (Ranjit, RA: C1, I6)

“people’s in the community who has some knowledge about the research, they say that..., ‘Do you have some ethical approval from the {Skaxis}?’ They ask...especially from the District health facilities,...so the ethical approval is also essential” (Milenko, Supervisor: C1, I16).

These descriptions call attention to the role of ethical approval in facilitating research practice, including the ways gatekeepers such as health authorities place demands upon them, for example to access research sites. Beyond research conduct, ethical approval was also identified as necessary for research publication: “if you want to publish, you have to have a, you know, ethics clearance.” (Shahashi, Supervisor: C1, I3). Consequently, written ethical approval becomes a boundary object generated through the ethical review process that attests to the research having been approved by the recognised authority.

Researchers identified as an inherent limitation of procedural ethics being restricted to reviewing written documentation: “they can look at the materials and they can approve the materials, and that’s all...look at the proposal and look at what the investigators say they’re going to do” (Kari, PI: C2, I9). The anticipatory nature of ethical review - what investigators say they are going to do - and engagement with generalised boundary objects was felt to create a disjunction between procedural and in-practice ethics:

“sit in ah, table and discuss all these things, but the issues actually come when you go into the field. ...most of the things we experience in the field are not written in

books, you don't find them in guidelines. So you just have to go with your gut feeling and stick to is this right or wrong?" (Mercurius, RA: C2, I5)

Emphasising the differences between field realities and the boundary objects used by the ERB disputes the authority of the ERB over the ethics of research-in-practice, as researchers balance the competing demands of methods, context, population, and research ethics to make situated field-based judgements. This was echoed by a researcher who recognised that "it is impossible to anticipate every single way that a person would react" (Orville, Supervisor: C2, I6), suggesting that when confronted with field realities researchers must respond to what they face, which may be beyond the scope of what was anticipated at the ethical review stage (Guillemin and Gillam, 2004; Heimer, 2013). It has been observed that researchers blindly following the proscriptions and prescriptions of procedural boundary objects coproduced during the ethical review process could lead to the abdication of responsibility for the ethicality of their actions to ERBs (Hammersley, 2009). However, findings from this study suggest that researchers rather than feeling a moral duty to comply with the letter of approved procedural boundary objects, actually find their moral duty compels them to respond to the context in which these objects are operationalised. This carries implications for the purpose of ethical review which becomes symbolic and instrumental in legitimating research conduct that may not adhere to what has been written in procedural documentation.

With regards governance of research-in-practice, a researcher who sits on an ERB recognised that current approaches of monitoring ethical documentation is inherently limited: "if they are managing the, you know, documentation, at least they are doing something" (Shahashi, Supervisor: C1, I3). Other researchers recognised the limits to ERB ongoing ethical auditing through presentations to ERBs about research conduct and announced site monitoring visits. This monitoring system was viewed as extending the problems inherent to ethical review, namely that it involves auditing what can be measured (Power, 1997; Strathern, 2000) and is based upon pre-emptive self-reporting or announced visits that permit reporting what ought to be rather than what is:

"send the e-mail, ...research update,...come to present your er research findings. ...Because the {Skaxis} provide the ethical approval...in the powerpoint presentation...we just mentioned there that we provided the some refreshment costs, for lodging, but...in the real practice we are not able to provide the food. Instead of the food we provide the money... But er, in the report we mention that we provide some...refreshment costs." (Milenko, Supervisor: C1, I16)

This example could be considered “unethical” practice as researchers adjust their practice in response to the contextual realities confronting them, rather than following what was anticipated in the research protocol. Regardless of the ethicality of these actions however, it is clear that researchers feel compelled to report back to the ERB according to what was written in the original protocol, undermining the role of auditing compliance to ethical regulation.

Similarly, another researcher reiterated the gap between adherence to procedures and acting morally in research practice:

“rubber stamp...you hide behind these legal documents. ...you cover the small print legally, but, where’s the moral, morality? So, the way you communicate, and the information you give, and the process of engagement [with participants]. That’s what actually (.2) think about the big picture, talk about the big picture not about the small print” (Spiro, PI: C2, I8).

This quote constructs procedural ethical review as focused upon the “small print”, which involves checking research has in place procedures and documentation to evidence that ethics is being done, at the expense of the “big picture” - the human interactions when implementing procedures in practice, and therefore merely presents an ethical facade. To counteract this, the onus is placed upon the researcher to ensure the “big picture” is conveyed: “I strongly believe the person who takes the proposal into the ethics committee has the responsibility to try and tease out, in advance, the ethical issues” (Spiro, PI: C2, I8). However, findings suggest that the generalised and abstracted format of procedural ethics boundary objects, coupled with researchers explicitly seeking to provide the correct responses mandated by ERBs, prevents engagement with potential ethical issues inherent to research.

Conversely, whilst ethical applications could make more explicit the operationalisation of ethical principles, one researcher questioned: “If that would translate in more ethical research, I wonder” (Hubert, PI: C1, I1). This emphasises the gap between generalised boundary objects and the autonomy of researchers in the field, recognising the challenges to comprehensively anticipate and operationalise ethical principles on paper to fully reflect their application in practice. To address this gap a role for reflection was identified:

“When you design something...when you start actually collecting it...it’s the mismatch...It’s something to put on paper based on scientific principles,...one thing to go and you know get get information based on that. So how do you bridge these two

things? Pffff...I think it's a continuous sort of process of reflection and learning...changing or improving...you need...scientific rigor, and you also need the ethical rigor, you need, you also need the information, you also need to face the ground reality. ...But then to a specific population, you need to adapt" (Orville, Supervisor: C2, I6)

The lived experience of this researcher reinforces the autonomy of researchers in the field and the ongoing process of reflecting and adapting to the situational context in which research is conducted. Being able to adapt therefore draws attention to the skills of individual researchers in ensuring ethical research conduct, rather than the content of boundary objects developed to meet the procedural requirements of a bureaucratic process rather than the realities of the field.

Suggestions to enhance ethical review processes

Despite the opportunities for ethical review to promote engagement with ethical, methodological, and practice challenges that may arise during the conduct of the research, researchers' descriptions focus upon obeying the form. This was the case even when it was recognised to frustrate what researchers identified as an improved ERB process where contextual information is provided to reviewers. Suggestions to enhance procedural ethics include reconceptualising ethical review to be more consensual, for example by incorporating in-person interactions:

"a more sort of, interactive manner, rather than taking a very top down, closed decision. ...come into more consensual decision, rather than you know say "oh yeah, we don't think this is appropriate so you have to change this in the form and resubmit." ...bring a, a representative or the PI or whatever from the team. And then you know, have a discussion. Try and understand what's going on before you start to pass a judgment" (Orville, Supervisor: C2, I6).

Here again the format of the boundary objects are critiqued for being predefined and abstracted from research practice which requires an understanding of research setting, population, and researchers. The suggestion of in-person interactions emphasises that the opportunity for ERBs to interact with researchers is important for making judgements about how ethical research will be managed in practice, rather than doing this via the form as a proxy (Hedgecoe, 2012).

Suggestions for enhancing procedural ethics processes relate to repositioning ethical review as a capacity building opportunity. To achieve this would require a shift from the current

view of ERBs as “policing”, to bodies that supported an ethical research culture, recognising the expertise of all social worlds that engage with the boundary objects and resisting the ERB’s increasingly hegemonic jurisdiction:

“researchers to come, and share their ethical practices. And learn from each other..., there has to be no penalty for such, you know, mistake. ...orientation of the...review boards should be not as punitive but as a capacity building. ...improving the research culture...if that is the orientation then it is completely possible. ...But if you are, you know, asking them to,...get punished, then it is impossible ((laughs)).” (Shahashi, Supervisor: C1, I3)

“learn from different settings. How different studies are done in different contexts... Especially in humanitarian crisis...the voice of the participant...the research assistants may be involved...more input from them.” (Orville, Supervisor: C2, I6).

These recognise the value of cross-learning between researchers which is facilitated by boundary objects that are universally recognised - as described in the informal sharing of best practice in the adaptation of informed consent procedures; and participatory approaches to learning from the community involved in research.

It was also suggested that ERB’s could promote ethical reflection:

“if,...they clearly suggested please mention the ethical guidelines, and what types of ethical problem er, arise...during your study period, and how could you handle? ...If they asked such types of questions, then, er, we, we are also need to mention these things” (Milenko, Supervisor: C1, I16).

Therefore, ERB’s were seen as being in a position to promote active reflection upon the application of ethical procedures to practice (Eckenwiler *et al.*, 2015). These suggested approaches are at odds to characterisations of procedural research ethics governance that follow prescription and proscriptions. Equally, such approaches may encroach upon the current autonomy afforded researchers when engaged in research practice, potentially opening up research practice to similar levels of bureaucratic scrutiny as procedural ethics that may exacerbate the problems inherent to procedural research ethics.

A number of researchers suggested ERBs should have increased lay representation from local communities, or involve researchers applying boundary objects on the ground:

“It looks ethical from our point of view, but what about the point of view of the participants? ...Somebody who can represent the community.” (Mercurius, RA: C2, I5)

“should be more locally led... How many people are actually you know, on the ground, who are researcher, are involved?” (Pedro, PI: C3, I9)

The perspectives here call for a rebalancing of the jurisdiction between ERBs, researchers, and the community, recognising the fundamentally social nature of operationalising ethical principles with specific communities that the boundary objects needed to fully capture so that procedural research ethics is connected to research-in-practice.

Discussion

Applying the analytical framework of boundary objects to researchers’ experiences of procedural research ethics suggests that whilst operating across multiple social worlds, researchers challenge the ERBs claim to authoritative jurisdiction over the boundary objects and ultimately procedural research ethics. These claims are not static but shift as the boundary objects move through the procedural research ethics processes of development, co-production in ethical review, and field application; with areas where the ERB jurisdiction is submitted to, and those where it is contested. Underlying contested jurisdiction are claims to who has the moral authority to make decisions about ethical research design and conduct, questioning whether these should be abstract or situated judgements. These tensions recognise that “ethics review determines what is possible in the production of knowledge: what can be done, what can be asked, by whom, and for what purpose” (Guta *et al.*, 2013, p. 307) and is therefore central to researcher’s everyday lived experiences of ethics.

Adopting the boundary objects analytic framework aids identification of sites of cooperation and autonomous action upon procedural ethics documents, exposing the management of tensions that arise due to the multiple roles procedural research ethics boundary objects occupy. The standardised and routinised format of ERB and researcher interactions, and the universalised normative framework of principlism, provide a stable structure and shared knowledge framework for procedural research ethics, with ethical approval valued as a stable commodity that gives research external legitimacy. However, researchers also describe subverting the moral aim of anticipatory regulation that defines in advance how ethical issues are to be managed in the field, articulating spheres of autonomy to act with the procedural boundary objects in practice - for example through adapting instruments and the wording of information leaflets for informed consent. Consequently, in research practice the stability imposed upon the boundary objects during procedural research ethics processes is disrupted through application to the social world, as ethical judgements move from the abstract to the situated. Whilst these spheres of autonomous action are accommodated

within a boundary objects framework, from a research ethics perspective for researchers to act autonomously beyond pre-approved documents frustrates the moral and regulatory aims of procedural research ethics, and therefore requires examining.

Researchers demonstrate an expansive understanding of the remit of “ethics”, whilst viewing ethics through its accompanying procedures, rather than as a philosophical or moral concern. This stance reflects a pragmatic approach to complying with a proliferation of research governance and auditing structures (Strathern, 2000; O'Neill, 2002; Boulton and Parker, 2007). Notably, results show that researchers felt the arguably complex context of post-conflict mental health research did not require specific ethical principles, or demand additional ethical oversight. This reflects a recent literature review which found consensus regarding the applicability of ethical research principles to mental health research conducted in emergencies, but identified debates concerning their application to research practice (Chiumento *et al.*, 2017a). A tension between the universal and the situated was present throughout researchers’ philosophical critique of principlism, recognising the challenges to the normative framework that principlism offers arise in the application of abstract principles to specific situations. For example, whereas researchers recognised the concept of vulnerability, this was viewed as contextual and localised, resisting reductionist universal epistemic frameworks that invoke a blanket notion of vulnerability (Rosenstein, 2004; Mackenzie *et al.*, 2007; Jesus and Michael, 2009; Luna, 2009; 2017) that fails to recognise the inherently individualised nature of the risk of harm that must be evaluated in context (Levine, 2004). Here the continuum between procedural ethics and ethics-in-practice is foregrounded, as attention is focussed on the way researchers operationalise ethical principles for application when confronted with contextual social realities.

Therefore, researchers critique procedural ethics for promoting a view from nowhere, abstracting the social relationships upon which research depends in favour of and “highly ritualised and culturally normative” audit processes that seek stability in settings where social, economic, political, and cultural contexts are rapidly changing (Adams, 2013, p. 76), with such changes often more rapid following emergencies. In praising clear articulation of what procedural documentation should contain, researchers commend the ritualised and culturally normative nature of these boundary objects developed according to each ERB’s defined scope of what is and is not ethically permissible, reflected in ERBs reduction of principlism to prescriptions and proscriptions. Underpinning this is an epistemological stance that prioritises generalisability through reductionist and mechanistic approaches to procedural research ethics that can be uncritically deployed in globalised settings, whilst

remaining stable in the production of intended ethical outcomes such as ethical approval and auditable ethical practice through the signed consent form (Hogle, 1995; Strathern, 2000; Miller and Boulton, 2007; Biehl and Petryna, 2013). Prioritising approaches to secure ethical approval shifts from a moral discourse to one of regulation (Ashcroft, 2003), as research ethics as a procedural concern becomes divorced from philosophical bioethics (Douglas-Jones, 2015) and a pre-eminent feature becomes researchers obtaining or receiving ethical approval (Dixon-Woods *et al.*, 2007). Here, the check-box nature of ethical review is emphasised, potentially linked to concerns about institutional risk management which foster a compliance culture, and increasing bureaucratisation of ERB's as a result of funding agencies and accreditation schemes (Allen, 2008; Guta *et al.*, 2013; Douglas-Jones, 2015).

The co-production of procedural research ethics is facilitated by standardised forms and routinised practice focussed upon the goal of approval for research. On the one hand stability is afforded through bureaucratic processes that emphasise what is visible and auditable (Heimer, 2013) and that set researcher and ERB expectations about their respective roles. Standardised forms encourage researchers to package information to fit regulatory structures, emphasising skills in respecting the document templates down to the level of language and presentation (Jacob, 2007). As researchers identify, one reason for writing to template is the efficiency this offers for gaining approval: “[t]he researcher’s creativity thus contains built-in bureaucratic design and, in turn, the bureaucrat’s pre-established forms are bound to anticipate researchers’ idiosyncratic knowledge. Each mode of thinking necessarily has to trade off, give in, and submit itself to the other’s knowledge” (Jacob, 2007, p. 255). In this trade-off researchers in this study praise procedural research ethics increased bureaucratisation and standardisation for *more* instructions on what is expected, seeking predictability in a system in which all outcomes are intended (Suchman, 2006). Consequently, as currently structured procedural ethics encourages researcher’s to engage in a ““compliance culture” where what is ethical is defined by conforming to the prescriptions and proscriptions” of ERB’s (Hammersley, 2015, pp. 444-445).

Researchers suggest that multiple social worlds are encouraged to actively un-know the situational realities in which ethical principles will be operationalised as procedural ethics becomes a “matter of pretence” (Hammersley, 2006, p. 6) in which both researchers and ERBs engage. Engaging in this pretence involves researchers uncritically reflecting or developing procedures that meet ERB requirements, despite potential challenges that may arise when enacting these procedures in-practice - such as gaining signatures on informed

consent forms in settings where this is viewed with suspicion (Lê *et al.*, 2013; Chiumento *et al.*, 2016). In taking this approach researchers are operating in the moral domain of what *ought* to be through instilling morally sanctioned intentions (Hoeyer and Hogle, 2014), evident when researchers describe seeking to respond to what “the examiner” looks for by uncritically responding to ERB instruction. In adopting this attitude it is possible that informed consent becomes “at best a polite fiction” (Chambliss, 1993, p. 651) as the ethical review process encourages researchers to “become more cynical, or adopt a proceduralist mentality, simply complying in order to get agreement from ethics committees, worrying little about any discrepancy between what they say they are going to do and what they actually do” (Hammersley, 2009, p. 219). As with the participant reimbursement in C2, this study has uncovered examples of such discrepancies, and revealed where researchers view the limits to ERBs jurisdiction when applying ethical principles to practice. Therefore, when engaging with procedural ethics researchers and ERBs operate in the domain of what ought to be which “produces a form of active “unknowing” [and] shapes a remit of ignorance” (Hoeyer and Hogle, 2014, p. 352) about the social reality encountered when applying procedures to practice. However, it is this shared “remit of ignorance” that allows researchers to retain the autonomy to adapt procedures and enact their own moral values in practice (Kingori, 2013).

Researchers’ experience of ethics-in-practice was frequently invoked when critiquing ERBs lack of mental health and/or technical research methods expertise to assess the ethicality of a given project. These challenge the notion of “expertise” and speak to a fundamental tension in both philosophical and regulatory debates surrounding procedural ethics over who has the expertise, experience, and therefore authority to make pronouncements about what is and is not permissible (Hammersley, 2006; 2009; Biehl and Petryna, 2013; Hammersley, 2015). The distance between Western ERBs and research conducted in LMICs is further highlighted by Emerson *et al.* (1995): “the ‘is’ of those living in the developing world is not the same as the ‘is’ of those living in industrialised nations, and this is morally significant” (p.102). Researchers emphasise that due to a suppression of context and a mismatch of expertise, ERBs “may be constitutionally incapable of consistently reaching sound judgements about what is and is not ethically acceptable for a researcher to do in a particular project” (Hammersley, 2006, p. 6), leading to researchers viewing ERB decisions as inappropriate or unjustified. That ERBs differentially interpret guidelines when appraising the same project has been documented (Ramcharan and Cutcliffe, 2001), foregrounding that

the morally justifiable action cannot be unproblematically derived from general principles (Levi, 1996; Hammersley, 2009).

Equally however, researchers emphasise the importance of an “independent” and “neutral” body to verify the ideas of researchers, embodied in the ERB. Therefore, researchers on the one hand accept the purpose of ethical regulation based upon a role for ERBs “to determine what is and is not, would be and would not be, ethical in any particular research project, and to make *better* judgements about this than the researcher(s) involved” (Hammersley, 2009, p. 212). Almost in the same breath however, researchers make claims to embeddedness and that a “deep understanding” of the research context and population are essential to assessing the ethicality of actions, both features that ERBs are constitutionally unable to access. Consequently, fundamental tensions over the scope of the ERB role and what expertise is deemed authoritative for making decisions about how to operationalise ethical principles remain. Though researchers suggest ways to manage this tension, for example by having face-to-face contact between researchers and ERBs and increasing the level of contextual detail in applications, there remains an underlying tension between objectivity or abstraction and subjectivity or specification in ethical assessments of research. Equally the impact of the increasing bureaucratisation of ERB procedures is noted, as ethical review is increasingly mediated via electronic forms with word limits, in turn further restricting opportunities for ethical dialogue between ERB members and researchers (Guta *et al.*, 2013).

A key finding from this study is that researchers respond to this challenge by autonomously exercising their own moral judgement when applying ethics in practice. This is undertaken both with ERB sanctioning, for example through the invention of procedures such as ways to document informed consent; and in subversion of ERB approvals, such as providing direct monetary compensation rather than gifts. In the invention of procedures researchers demonstrate efforts to balance adherence to a deductive principlism which view the prescriptions and proscriptions of guidelines as injunctions, whilst recognising the need for procedures to respond to the cultural context in which they are to be applied. Here experiences of fieldwork practice lead to the creation of new organisational approaches to rule making, as localised practices interact with standardised global imperatives to generate new knowledge (Hogle, 1995). In this researchers recognise the multiple audiences that engage with the informed consent form, maintaining a facade of ethical universalism that assumes ethical homogeneity that ERB’s are searching for (Riessman, 2005); but that in practice are open to reinterpretation and accommodation when operationalised with research participants in ways that avoid causing harm. By adopting such approaches,

researchers accept the moralism that has become inherent to research ethics by seeking to realise the extrinsic value of the principle of autonomy through the prescribed route of obtaining written informed consent (Hammersley and Traianou, 2012), whilst resisting the standardisation of how this is to be achieved in practice.

The result of researchers approaching ethical research protocols as an “exam” and seeking to contort principlist prescriptions and proscriptions to fit the context of research could be to increase the potential for mismanagement of ethical issues that may arise in the field: “researchers may become more irresponsible: they may treat ethics committees as having taken over responsibility for the ethics of what they are doing, so that they will engage in practices that (...) are actually unethical in the particular context” (Hammersley, 2009, p. 219). This suggests that researchers prioritise meeting quasi-legal rather than moral standards (Benatar, 2002). However, findings from this study challenge this, suggesting that researchers continue to prioritise ethical research conduct through the insertion of their own moral agency to ensure procedures remain ethical in specific settings. This re-emphasises the limitations inherent to anticipatory procedural research ethics, and the continuum between ethical procedures and research in practice. Proposals for adjusting research ethics procedures, such as to embrace “real-time responsiveness” (Eckenwiler *et al.*, 2015) which views ethical review as cyclical, ongoing, and iterative throughout research conduct, and is seen as a way to invite genuine co-production of ethical norms in response to in-practice ethical issues that arise in the field. Ultimately, however, the promotion of ethical practice is achieved by equipping front-line data collectors with ethical literacy through training, focussing attention on the “misfit between complex and fluid social worlds and increasingly standardised and regulated ethics procedures” (Miller and Boulton, 2007, p. 2208) at the centre of the tensions in this study. This includes shifting from a proceduralist and governance approach to research ethics, towards an approach that prioritises the positive moral obligations of researchers.

Study strengths and limitations

Empirically investigating researchers’ experiences of procedural research ethics in three settings across South Asia fills a gap in existing knowledge, complementing existing empirical and bioethical research on how ERBs approach procedural ethics (Dixon-Woods *et al.*, 2007; Miller and Boulton, 2007; Hedgecoe, 2012; Douglas-Jones, 2015). Recognising that procedural research ethics follows the same format globally, and having explored the complex setting of post-conflict mental health research, suggests that findings from this study could have relevance to procedural research ethics in other contexts. However, it is

possible that this context also foregrounds a setting and study topic for which ERBs are ill-equipped, thereby exaggerating the challenges of procedural ethics overall. Furthermore, important methodological limitations remain, chiefly the potential for researcher's to have displayed social desirability in their responses to being asked about procedural ethics due to fear of organisational or personal reputational harm (Chiumento *et al.*, 2017b). Whilst the researcher did not feel this was the case, and examples of what could be viewed as unethical practice suggest open discussion, this cannot be ruled out.

Conclusion

This qualitative study has shown that researchers are searching for a procedural research ethics system that delivers consistency of process that is also capable of recognising flexibility in content: "what is and is not ethically acceptable as regards any particular research project depends upon the *context* in which it is to be carried out" (Hammersley, 2009, pp. 214 - emphasis original). An important finding is the balance researchers strike between adherence to the standardised prescriptions and proscriptions of procedural research ethics, alongside retention of their own moral agency when implementing procedures in the field. This approach is generalised across the three settings in this study, and reflected in bioethical literature regarding the inherent limitations to procedural research ethics in all settings (Hammersley, 2009; Hedgecoe, 2012; Heimer, 2013; Douglas-Jones, 2015). Due to occupying a governance role that requires independence from a given study, ERBs as the guardian of procedural research ethics are constitutionally comprised in a way that means they do not have access to contextual knowledge about a particular setting. Furthermore, from a moral perspective even if the constitution of ERBs and information provided to them were changed, the nature of ethical judgements is such that even if agreement over abstract principles was achieved, there would likely to continue to be differences of opinion regarding the specific application of principles in particular contexts (Hammersley, 2006).

Therefore, ethical research conduct is shown to be dependent not upon anticipatory regulation and auditing, but upon the sphere of researcher autonomy when conducting research-in-practice. As Hammersley (2009) notes: "guidelines can only be guidelines, not rules that *govern* behaviour" (p.215). This is emphasised in researchers' explicit and implicit acknowledgement of the situated nature of moral judgements in research, in which the demands of ethics, methodology, and context are balanced to reach conclusions regarding the right course of action in any situation. Therefore, this paper makes a case for rebalancing the locus of control over procedural research ethics away from standardised regulatory practices to recognise the autonomy of researchers enacting ethical judgements in the field

(Boulton and Parker, 2007; Hammersley and Traianou, 2012; Chiumento *et al.*, 2016), calling attention to the knowledge and skills of researchers making situated ethical decisions (Hunt, 2008; Kingori, 2013; Curry *et al.*, 2014). This is not to suggest that the locus of control shifts from ERBs to researchers, but that procedural ethical processes should be a result of genuine co-production between researchers carrying out the study, and those charged with promoting ethical research conduct.

References

Adams, V. (2013) 'Evidence-based global public health: subjects, profits, erasures', in Biehl, J. G. and Petryna, A. (eds.) *When people come first: critical studies in global health*. Princeton University Press [electronic book], pp.54-90.

Allden, K., Jones, L., Weissbecker, I., Wessells, M., Bolton, P., Betancourt, T. S., Hijazi, Z., Galappatti, A., Yamout, R., Patel, P. and Sumathipala, A. (2009) 'Mental health and psychosocial support in crisis and conflict: report of the Mental Health Working Group', *Prehospital and Disaster Medicine*, 24(Suppl 2), pp. s217-s227.

Allen, G. (2008) 'Getting Beyond Form Filling: The Role of Institutional Governance in Human Research Ethics', *Journal of Academic Ethics*, 6(2), pp. 105-116.

Ashcroft, R. E. (2003) 'The ethics and governance of medical research: what does regulation have to do with morality?', *New Review Of Bioethics*, 1(1), pp. 41-58.

Beauchamp, T. L. (2003) 'A Defense of the Common Morality', *Kennedy Institute of Ethics Journal*, 13(3), pp. 259-274.

Beauchamp, T. L. (2007) 'The 'Four Principles' Approach to Healthcare Ethics', in Ashcroft, R. E., Dawson, A., Draper, H. and McMillan, J. R. (eds.) *Principles of health care ethics*. John Wiley [electronic book], pp. 3-10. Available at: <http://onlinelibrary.wiley.com/book/10.1002/9780470510544>.

Beauchamp, T. L. and Childress, J. F. (1989) *Principles of biomedical ethics*. 3rd edn. New York: Oxford University Press.

Beauchamp, T. L. and Childress, J. F. (2013) *Principles of biomedical ethics*. 7th edn. New York: Oxford University Press.

Beecher, H. K. (1966) 'Ethics and clinical research', *New England Journal of Medicine*, 274(24), pp. 1354-1360.

Benatar, S. R. (2002) 'Reflections and recommendations on research ethics in developing countries', *Social Science and Medicine.*, 54(7), pp. 1131-1141.

Biehl, J. G. and Petryna, A. (2013) 'Critical global health', in Biehl, J. G. and Petryna, A. (eds.) *When people come first: critical studies in global health*. Princeton University Press [electronic book], pp.1-20.

Boulton, M. and Parker, M. (2007) 'Informed consent in a changing environment', *Social Science & Medicine*, 65(11), pp. 2187-2198.

Boyatzis, R. E. (1998) *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks, CA: SAGE Publications.

Carlile, P. R. (2002) 'A Pragmatic View of Knowledge and Boundaries: Boundary Objects in New Product Development', *Organization Science*, 13(4), pp. 442-455.

Chambliss, D. F. (1993) 'Is Bioethics Irrelevant?', *Contemporary Sociology*, 25(5), pp. 649-652.

Chiumento, A., Khan, M. N., Frith, L. and Rahman, A. (2016) 'Managing ethical challenges to mental health research in post-conflict settings.', *Developing World Bioethics*, 16(1), pp. 15-28.

Chiumento, A., Rahman, A., Frith, L., Snider, L. and Tol, W. A. (2017a) 'Ethical standards for mental health and psychosocial support research in emergencies: review of literature and current debates', *Globalization And Health*, 13(1), pp. 8-26.

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017b) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online pre-print, available at: <http://journals.sagepub.com/doi/abs/10.1177/1468794117730121>.

Clouser, K. D. and Gert, B. (1990) 'A Critique of Principlism', *Journal of Medicine and Philosophy*, 15(2), pp. 219-236.

Council for International Organisations of Medical Sciences (CIOMS) (2016) *International ethical guidelines for health-related research involving humans*. Geneva: CIOMS. [Online]. Available at: <https://cioms.ch/new-cioms-ethical-guidelines-for-health-related-research-involving-humans/>. (Accessed: 12.02.2014).

Curry, D., Waldman, R. and Caplan, A. (2014) *An Ethical Framework for the development and review of health research proposals involving humanitarian contexts*. [Online]. Available at:

http://www.elrha.org/wp-content/uploads/2015/01/FINAL-R2HC-Ethical-Framework_Final-Report_24-January-2014_0.pdf (Accessed: 03.02.2014).

Dixon-Woods, M., Angell, E., Ashcroft, R. E. and Bryman, A. (2007) 'Written work: The social functions of Research Ethics Committee letters', *Social Science & Medicine*, 65(4), pp. 792-802.

Douglas-Jones, R. (2015) 'A 'good' ethical review: Audit and professionalism in research ethics', *Social Anthropology / Anthropologie Sociale*, 23(1), pp. 53-67.

Eckenwiler, L., Pringle, J., Boulanger, R. and Hunt, M. (2015) 'Real-time Responsiveness for Ethics Oversight During Disaster Research', *Bioethics*, 29(9), pp. 653-661.

Emanuel, E. J., Wendler, D., Killen, J. and Grady, C. (2004) 'What makes clinical research in developing countries ethical? The benchmarks of ethical research', *Journal of Infectious Diseases*, 189(5), pp. 930-937.

Emerson, R. M., Fretz, R. I. and Shaw, L. L. (1995) *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press.

Fletcher, J. (1967) *Moral responsibility: situation ethics at work*. London: SCM Press.

Goffman, E. (1959) *The presentation of self in everyday life*. London: Penguin.

Green, J. and Thorogood, N. (2014) *Qualitative methods for health research*. 3rd edn. London SAGE Publications.

Green, R. M. (1990) 'Method in Bioethics: A Troubled Assessment', *Journal of Medicine & Philosophy*, 15(2), pp. 179-197.

Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.

Guta, A., Nixon, S. A. and Wilson, M. G. (2013) 'Resisting the seduction of "ethics creep": using Foucault to surface complexity and contradiction in research ethics review', *Social Science & Medicine*, 98, pp. 301-310.

Hammersley, M. (2006) 'Are ethics committees ethical?', *Qualitative Researcher*, 2, pp. 4-8.

Hammersley, M. (2009) 'Against the ethicists: On the evils of ethical regulation', *International Journal of Social Research Methodology*, 12(3), pp. 211-225.

- Hammersley, M. (2015) 'On ethical principles for social research', *International Journal of Social Research Methodology*, 18(4), pp. 433-449.
- Hammersley, M. and Traianou, A. (2012) *Ethics in qualitative research: controversies and contexts*. SAGE Publications [electronic book].
- Hedgecoe, A. M. (2012) 'Trust and regulatory organisations: The role of local knowledge and facework in research ethics review', *Social Studies of Science*, 42(5), pp. 662-683.
- Heimer, C. A. (2013) "'Wicked' ethics: Compliance work and the practice of ethics in HIV research", *Social Science & Medicine*, 98, pp. 371-378.
- Hoeyer, K. and Hogle, L. F. (2014) 'Informed Consent: The Politics of Intent and Practice in Medical Research Ethics', *Annual Review of Anthropology*, 43, pp. 347-362.
- Hogle, L. F. (1995) 'Standardization across Non-Standard Domains: The Case of Organ Procurement', *Science, Technology, & Human Values*, 20(4), pp. 482-500.
- Hunt, M. R. (2008) 'Ethics beyond borders: How health professionals experience ethics in humanitarian assistance and development work', *Developing World Bioethics*, 8(2), pp. 59-69.
- Inter-Agency Standing Committee (IASC) Reference Group for Mental Health and Psychosocial support in Emergency Settings (2014) *Recommendations for Conducting Ethical Mental Health and Psychosocial Research in Emergency Settings* IASC. Available at: https://interagencystandingcommittee.org/system/files/1._iasc_recommendations_for_ethical_mhpsr_research_in_emergency_settings_0.pdf. (Accessed: 03.03.2017).
- Israel, M. and Hay, I. (2006) *Research ethics for social scientists: between ethical conduct and regulatory compliance*. SAGE [electronic book]. Available at: <http://srmo.sagepub.com/view/research-ethics-for-social-scientists/SAGE.xml>.
- Jacob, M.-A. (2007) 'Form-Made Persons: Consent Forms as Consent's Blind Spot', *PoLAR: Political & Legal Anthropology Review*, 30(2), pp. 249-268.
- Jesus, J. E. and Michael, G. E. (2009) 'Ethical considerations of research in disaster-stricken populations', *Prehospital and Disaster Medicine*, 24(2), pp. 109-114.
- Kingori, P. (2013) 'Experiencing everyday ethics in context: Frontline data collectors perspectives and practices of bioethics', *Social Science & Medicine*, 98, pp. 361-370.

Kingori, P. (2015) 'The 'empty choice': A sociological examination of choosing medical research participation in resource-limited Sub-Saharan Africa', *Current Sociology*, 63(5), pp. 763-778.

Kingori, P., de Vries, R. and Orfali, K. (2013) 'Special issue introduction: Bioethics in the field', *Social Science & Medicine*, 98, pp. 260-263.

Lacey, E. A. (1998) 'Social and medical research ethics: is there a difference', *Social Sciences in Health*, 4(4), pp. 211-217.

Lê, Q., Hguyen, H. B., Le, T. and Ogden, K. (2013) 'Ethical issues in intercultural health research', in Le, T. and Lê, Q. (eds.) *Conducting research in a changing and challenging world*. New York: Nova Publishers., pp. 291-300.

Leaning, J. (2001) 'Ethics of research in refugee populations', *Lancet*, 357(9266), pp. 1432-3.

Levi, B. H. (1996) 'Four approaches to doing ethics', *The Journal Of Medicine And Philosophy*, 21(1), pp. 7-39.

Levine, C. (2004) 'The concept of vulnerability in disaster research', *Journal of Traumatic Stress*, 17(5), pp. 395-402.

Luna, F. (2009) 'Elucidating the concept of vulnerability: layers not labels', *International Journal of Feminist Approaches to Bioethics*, 2(1), pp. 121-139.

Luna, F. (2017) 'A way forward with layers: the two step process', *Oxford Global Health and Bioethics International Conference*. Oxford, 18.07.2017.

Mackenzie, C., McDowell, C. and Pittaway, E. (2007) 'Beyond 'do no harm': The challenge of constructing ethical relationships in refugee research', *Journal of Refugee Studies*, 20(2), pp. 299-319.

Miller, T. and Boulton, M. (2007) 'Changing constructions of informed consent: Qualitative research and complex social worlds', *Social Science & Medicine*, 65(11), pp. 2199-2211.

O'Neill, O. (2002) *Autonomy and trust in bioethics*. Cambridge University Press [electronic book]. Available at: <http://ebookcentral.proquest.com/lib/liverpool/detail.action?docID=202188>.

O'Mathúna, D. P. (2014) 'Disasters', in ten Have, H. A. M. J. and Gordijn, B. (eds.) *Handbook of Global Bioethics*. Springer [electronic book], pp. 619-639. Available at:

<http://search.ebscohost.com/login.aspx?direct=true&db=edselc&AN=edselc.2-52.0-84925312624&site=eds-live&scope=site>.

Patel, V. (2007) 'Mental health in low- and middle-income countries', *British Medical Bulletin*, 82-81(1), pp. 81-96.

Petryna, A. (2005) 'Ethical Variability: Drug Development and Globalizing Clinical Trials', *American Ethnologist*, 32(2), pp. 183-197.

Petryna, A. (2009) *When experiments travel: clinical trials and the global search for human subjects*. Princeton: Princeton University Press.

Power, M. (1997) *The audit society: rituals of verification*. Oxford: Oxford University Press.

Ramcharan, P. and Cutcliffe, J. R. (2001) 'Judging the ethics of qualitative research: considering the 'ethics as process' model', *Health & Social Care in the Community*, 9(6), pp. 358-366.

Riessman, C. K. (2005) 'Exporting ethics: A narrative about narrative research in South India', *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 9(4), pp. 473-490.

Roberts, B. and Browne, J. (2011) 'A systematic review of factors influencing the psychological health of conflict-affected populations in low- and middle-income countries', *Global Public Health*, 6(8), pp. 814-829.

Rosenstein, D. L. (2004) 'Decision-Making Capacity and Disaster Research', *Journal of Traumatic Stress*, 17(5), pp. 373-381.

Ryan, A. (2007) 'Ethical Issues', in Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative research practice*. SAGE [electronic book], pp. 218-35 Available at: <http://ebookcentral.proquest.com/lib/liverpool/detail.action?docID=1138447>.

Schutz, A. (1944) 'The Stranger: An Essay in Social Psychology', *American Journal of Sociology*, 49(6), pp. 499-507.

Schutz, A. (1945) 'On multiple realities', *Philosophy and Phenomenological Research*, 5, pp. 533-576.

Schutz, A. (1967) *The phenomenology of the social world*. Evanston: Northwestern University Press.

Shuster, E. (1997) 'Fifty years later: the significance of the Nuremberg Code', *New England Journal of Medicine*, 337(20), pp. 1436-1440.

Simpson, B., Khatri, R., Ravindran, D. and Udalagama, T. (2015) 'Pharmaceuticalisation and ethical review in South Asia: Issues of scope and authority for practitioners and policy makers', *Social Science & Medicine*, 131, pp. 247-254.

Star, S. L. (2010) 'This is not a boundary object: reflections on the origin of a concept', *Science, Technology, & Human Values*, 35(5), pp. 601-617.

Star, S. L. and Griesemer, J. R. (1989) 'Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39', *Social Studies of Science*, 19(3), pp. 387-420.

Strathern, M. (2000) 'Introduction: new accountabilities', in Strathern, M. (ed.) *Audit cultures: anthropological studies in accountability, ethics, and the academy*. Routledge [electronic book], pp. 1-18. Available at: <http://www.tandfebooks.com/isbn/9780203449721>.

Suchman, A. L. (2006) 'Control and relation: Two foundational values and their consequences', *Journal of Interprofessional Care*, 20(1), pp. 3-11.

Swift, A. (2006) *Political philosophy: a beginners' guide for students and politicians*. 2nd rev. and expanded edn. Cambridge: Polity.

The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research (1979) *Ethical Principles and Guidelines for the Protection of Human Subjects of Research (The Belmont Report)*. Department of Health and Human Services. [Online]. Available at: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>. (Accessed: 12.02.2014).

Thornicroft, G. (2006) *Shunned: discrimination against people with mental illness*. Oxford: Oxford University Press.

Tol, W. A., Barbui, C., Galappatti, A., Silove, D., Betancourt, T. S., Souza, R., Golaz, A. and van Ommeren, M. (2011a) 'Mental health and psychosocial support in humanitarian settings: linking practice and research', *Lancet*, 378, pp. 1581-1591.

Tol, W. A., Patel, V., Tomlinson, M., Baingana, F., Galappatti, A., Panter-Brick, C., Silove, D., Sondorp, E., Wessells, M. and Ommeren, M. v. (2011b) 'Research Priorities for Mental Health and Psychosocial Support in Humanitarian Settings', *PLoS Medicine*, 8(9), p. e1001096.

United Nations Educational Scientific and Cultural Organization (UNESCO) (2015) *eAtlas of Literacy*. Available at: <http://www.uis.unesco.org/data/atlas-literacy/en> (Accessed: 04.07.2017).

Widdows, H. (2007) 'Is global ethics moral neo-colonialism? An investigation of the issue in the context of bioethics', *Bioethics*, 21(6), pp. 305-315.

World Bank (2017) *World Bank Country and Lending Groups*. Available at: <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups> (Accessed: 04.07.2017).

World Health Organisation (2001) *Legal Status of Traditional Medicine and Complementary/Alternative Medicine: A Worldwide Review*. New York. [Online]. Available at: <http://apps.who.int/medicinedocs/en/d/Jh2943e/> (Accessed: 04.07.2017).

World Medical Association (2013 [1964]) *WMA Declaration of Helsinki: ethical principles for medical research involving human subjects*. Available at: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/> (Accessed: 26.02.2016).

Yin, R. K. (2009) *Case study research: design and methods*. 4th edn. Los Angeles, California: SAGE Publications.

Zwi, A. B., Grove, N. J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D. and Tarantola, D. (2006) 'Placing ethics in the centre: negotiating new spaces for ethical research in conflict situations', *Global Public Health*, 1(3), pp. 264-277.

LINKING THE PROCEDURAL ETHICAL RESULTS PAPER WITH THE IN-PRACTICE ETHICS RESULTS PAPER

This section connects the previous paper exploration of procedural research ethics, with the second results paper *Trust in ethical research practice: manifestations, methods, and implications* (Chiumento *et al.*, in preparation), which explores ethics in-practice. It will briefly outline the key aims and findings of the in-practice ethics paper, and link the two papers through the role trust plays in promoting and sustaining ethical research.

The in-practice paper addresses the research aim of exploring ethical research procedures in-practice, as experienced by researchers engaged in day-to-day research conduct. It builds upon the first results paper by foregrounding researchers' autonomous application of ethical principles and procedures to practice, focusing upon the central ethical procedure of voluntary informed consent. By focussing upon the informed consent process, opportunities for exploring the connections between an overt research procedure and the everyday realities of ethics-in-practice are provided.

By exploring the informed consent process as practiced by researchers, the role of trust as an underpinning feature of ethical research conduct is foregrounded and unpacked. The approach to data analysis in this paper recognises that "trust by itself constitutes nothing" (Hardin, 1993, p. 512), calling attention to the situated operationalisation of trust. To trace this data analysis retains a focus upon a small number of extended interview extracts that explore the manifestations, methods, and implications of the role trust plays in ethical research. Similarly to the first results paper, the approach here is to look at rather than through ethical research procedures, using the processes that surround informed consent to stimulate analysis – such as the role of gatekeepers, the importance of minimising interpersonal trust whilst promoting professional trust (Buchanan, 2000), and the way that training and supervision seek to instil and verify trust. Alongside this, the natural antithesis to trust, that of control, is explored for its role in undermining trust (Pettit, 1995; Das and Teng, 2001).

The findings presented in this paper challenge the assumption that trust necessarily has a positive influence upon research, identifying situations where there is either *too much* trust which impacts upon voluntary decision-making; or where trust is *diminished*, evidenced in the impulse to verify or audit researchers' trustworthiness to enact research procedures in the field, suggesting supervisor *distrust*. As such, findings demonstrate the tensions and conflicts inherent in interpretations of trust, and the role trust plays in different contexts to

either promote, sustain, or destroy trust and undermine ethical research. These are discussed in the context of research practice, making recommendations for rebalancing the relationship between trust and control to promote ethical research practice.

In the final discussion chapter the papers that comprise this thesis are brought together via three overarching meta-themes of trust, control, and voice. The discussion aims to place research findings in their broader social and epistemological context, identifying research limitations, and assessing research recommendations for their feasibility and the likelihood of their uptake at this time. Finally, some concluding comments are offered.

References

Buchanan, A. (2000) 'Trust in Managed Care Organizations', *Kennedy Institute of Ethics Journal*, 10(3), pp. 189-212.

Chiumento, A., Machin, L., Rahman, A. and Frith, L. (in preparation) 'Trust in ethical research practice: manifestations, methods, and implications', *Unsubmitted*.

Das, T. K. and Teng, B.-S. (2001) 'Trust, Control, and Risk in Strategic Alliances: An Integrated Framework', *Organization Studies*, 22(2), pp. 251-283.

Hardin, R. (1993) 'The street-level epistemology of trust', *Politics & Society*, 21(4), pp. 505-529.

Pettit, P. (1995) 'The Cunning of Trust', *Philosophy & Public Affairs*, 24(3), pp. 202-225.

TRUST IN ETHICAL RESEARCH PRACTICE: MANIFESTATIONS, METHODS, AND IMPLICATIONS

Abstract

Recognising that procedural systems of research ethics oversight lack formal enforcement mechanisms, the question of what underpins ethical research practice is an important one. Through a multi-site case study involving 35 qualitative interviews conducted in three countries in South Asia, this research explores views and experiences of ethics from the perspective of researchers active in mental health research in post-conflict settings. Research findings explore an in-depth analysis of trust relations surrounding the enacting of informed consent in research practice, highlighting the manifestations of trust at societal, organisational, and interpersonal levels. In the narratives of researchers, trust is seen as a critical resource, both instrumentally to facilitate research conduct, and normatively as demonstrating researcher integrity and adherence to ethical research standards. Importantly, in participants' narratives trust often appears alongside its natural antithesis: that of control. This is particularly evident in descriptions of efforts to monitor and verify the trustworthiness of researchers; autonomous practice in the field. The discussion explores the balance between trust and control in researchers' everyday practice, and their connections to procedural and in-practice ethics. The paper concludes by suggesting some approaches to effectively integrate and rebalance trust and control relations to promote ethical research practice that responds to the socially embedded situational context in which ethical research procedures are operationalised.

Introduction

Research ethics guidelines render explicit morally acceptable research conduct, encompassing interactions with research participants, and protection of the professional status of research³³ (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; Beauchamp and Childress, 2013; World Medical Association, 2013 [1964]; Curry *et al.*, 2014; Council for International Organisations of Medical Sciences (CIOMS), 2015; Miltra and Sethi, 2016). These can be viewed as public statements of how researchers should behave, whilst simultaneously disciplining the research profession in line with accepted norms of conduct (Pels, 2000). Increasingly globally

³³ Research ethics guidelines encompass: norms of behaviour in relation to research participants; in respect of those who fund the research; and as overarching statements about the responsibility of researchers towards the general public.

embedded in international guidelines and procedural systems of research oversight, research ethics guidelines cover all research from biomedical (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; World Medical Association, 2013 [1964]; Council for International Organisations of Medical Sciences (CIOMS), 2015) to social science studies (American Anthropological Association, 2012; Economic and Social Research Council, 2015; Research Councils UK, 2015 [2013]), with adherence to the principles and procedural mechanisms they contain increasingly mandated by research funders (Siriwardhana *et al.*, 2017; Research for health in humanitarian crises and ELRAH, n.d.).

With weak formal enforcement measures, adherence to research ethics guidelines relies upon complex and multi-layered relationships of trust which operate concurrently as an individual, organisational, and societal-level phenomenon. Relating to research ethics this spans procedural systems of ethical review and other formal mechanisms of research oversight; and in-practice research ethics involving the implementation of ethical procedures to research practice with participants or other stakeholders. Ethics in practice encompasses the day-to-day ethical issues that arise during research conduct, and that are often not anticipated at the ethical approval stage (Guillemin and Gillam, 2004). As a result of not being anticipated, that researchers will respond in line with the ethical norms of a given project relies upon trust.

Exploring the nature and role of trust in the everyday practice of researchers has recently been the focus of empirical investigation. These studies move away from a focus upon trust within a procedural ethics framework - for example how trust affects ethical review boards' (ERBs) decision-making (Hedgecoe, 2012; Stark, 2013) - to explore researchers and research participants' perspectives of the nature and role of trust in research, focussing attention upon situated decision-making in specific contexts (Kass *et al.*, 1996; Kingori, 2013; Johnsson *et al.*, 2014; Guillemin *et al.*, 2016; Kerasidou, 2017).

This paper builds upon this empirical literature, taking the ethical principle of informed consent as the point of departure, recognising its centrality in ethical research procedures and practice. The study involved qualitative interviews exploring research ethics with researchers from three post-conflict countries in South Asia engaged in mental health research. By tracing the narratives of research, webs of trust and trusting relationships are identified to underpin research conduct. These consider the role of gatekeeper trust for community access and in shaping the interpersonal researcher-participant interaction; and

extend to trust between research assistants and their supervisors. Here the supervisor's impulse to seek verification of the trustworthiness of the autonomous actions of research assistants in the field points to the antithesis of trust: that of control. Attention is also drawn to societal trust in research that shapes the environment in which researchers work.

This exploration of trust is located within the *practice* of research ethics, recognising that "trust by itself constitutes nothing" (Hardin, 1993, p. 512), only coming into view in situated contexts. Through attention to the sites of research practice, we examine the role of trust in facilitating and sustaining ethical research practice, whilst problematizing the abstract nature of normative research ethics guidelines and procedures through analysis of specific instances of situated decision-making. This paper does not seek to reconcile these tensions, but to call attention to the realities of socially-embedded research practice which frequently fail to conform to the idealised scenarios presented in procedural ethical documentation. The paper concludes by considering the potential implications of research findings for approaches to research assistant training and monitoring, foregrounding the complementary roles that trust and control can play in promoting ethical research practice.

Trust

Trust as a theoretical concept has been conceptualised from philosophical, organisational, and social science perspectives. Recognising that trust operates as a basic fact of social life (Luhmann, 1979), this paper adopts a common-sense morality framework (Eyal, 2014a) which bears "not only on what conduct is proper...[but] also on what makes it proper, and on what should motivate proper conduct, and what to believe and feel about it" (p.477). A common-sense morality refers to codes of conduct put forward by individuals as a guide to their own behaviour, identified in descriptions of morally desirable traits and independent of appeals to any underpinning normative theoretical positions. Analysis of researchers' descriptions of what guides their behaviour identifies the underpinning role played by various forms of trust.

Approaching morality descriptively also facilitates problematizing the universalising logic of the research ethics framework of principlism (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; Beauchamp, 2007; Beauchamp and Childress, 2013; Council for International Organisations of Medical Sciences (CIOMS), 2015) which was the research ethics framework most frequently appealed to by participants in this study (Chiumento *et al.*, in preparation). A critique of principlism is that it lacks a unifying underpinning moral theory (Clouser and Gert, 1990; Hammersley, 2015),

drawing upon consequentialist or utilitarian ethics (Mill, 1998) alongside deontological or duty based ethics (Kant, 2012 [1785]). Given this mixed normative underpinning it is appropriate to approach investigation of researchers' everyday practice of research ethics descriptively through a common-sense morality. Furthermore, given this study involved qualitative interviews with researchers from a mix of cultural, ethnic, and religious backgrounds based in three countries in South Asia, it is expected participants will have a range of influences underpinning their personal moralities. In summary, this paper explores what researchers identify as proper (i.e. morally correct) ethical research conduct to identify and unpack the role of trust underpinning researchers' narratives.

As a concept and an action trust remains difficult to pin down. Accounts of trust place as central that "tis impossible to separate the chance of good from the risk of ill" (Baier, 1985, p. 219 citing Hume (1978), p.497), as actors choose to place confidence in their expectations of the actions of another (Luhmann, 1979). There is broad agreement that trust is difficult to get started, easier to maintain, and never hard to destroy (Baier, 1986; Hardin, 1993). Insights from existing theoretical literature on trust and trustworthiness draw attention to its features at societal and organisational levels; as well as in interpersonal relationships by considering the beliefs and attitudes of those entering into trusting relationships. All of these are relevant to understanding the role of trust in mental health intervention research explored in this study. A brief overview of key aspects of this literature is provided to frame subsequent results and discussion.

At the societal level it is emphasised that trust relations are always embedded within social structures (Luhmann, 1979; Giddens, 1994; Bachmann and Zaheer, 2006), with trust seen as a social good (Bok, 1978; Giddens, 1994). Many explorations of trust are founded upon a phenomenological understanding of the everyday lifeworld in which actors have a shared understanding of the world in common, including building typologies of persons and actions, using this familiarity as a key source of information when entering trusting relationships (Schutz, 1944; 1945; Mollering, 2006). Hessels *et al.* (2009) use the notion of a tacit contract between science and society as a heuristic device to explore societal support for research. Drawing on the credibility cycle (Latour and Woolgar, 1986), they bring attention to elements important for establishing research and researcher credibility, including the professional status of research, the self-regulation of research and researchers, and the role of the institutional and policy environment in shaping the autonomy of researchers (see also Bachmann, 2006). Similarly Luhmann (1979) emphasises controls in-built within the system of knowledge generation which enable the public to trust in the truth generated by science.

Here control by external organisations, such as procedural ethics bodies setting acceptable rules of behaviour, can become a key source of trust (Bachmann, 2006), reinforcing the role of research ethics guidelines as a public statement of research conduct and disciplining the profession, both of which shape the social context in which researchers operate.

Trust extends beyond the individual researcher to encompass the researcher as a representative of a profession or organisation. Buchanan's (2000) analysis is relevant here, introducing concepts of "status trust" which attach trust to members of a social group or profession simply by virtue of being a member of that social group or profession, giving rise to a presumption of trustworthiness (p.190); and merit trust which is gained because of the individual's "perceived merit, where merit is based on the individual's capacities and behaviour" (p.191). Both concepts are relevant in a biomedical research context, and are reflected in discussions of research integrity which emphasise adherence to professional standards (Steneck, 2006). Organisational and individual trust can be seen as multi-directional: where researchers draw upon organisational reputation to enhance their trustworthiness whilst simultaneously their actions shape organisational reputation (Kerasidou, 2017); whilst concurrently the behaviour and skills of individual researchers must be understood in an organisational context which shapes such behaviour (Buchanan, 2000).

The concept of goodwill is identified across accounts of trust, encompassing "good faith" (Pettit, 1995), good intentions, and integrity (Das and Teng, 2001). A number of authors distinguish trust from other similar concepts such as reliance (Baier, 1986; Pettit, 1995) or confidence (Luhmann: 1979). For Baier (1986) reliance is dependence upon habits, whereas trust is motivated by goodwill which involves knowledge by both parties of having entered into a trusting relationship in which the trustee makes themselves vulnerable to the trusted acting in their interests. In line with Baier, Pettit (1995) distinguishes reliance from trust, viewing reliance as demonstrating that one will be bound by constraints to behave as required. In contrast, to trust another is to contribute to their good opinion, which in turn offers reasons for the trusted to act in ways the trustee relies upon him to act. Similarly Luhmann (1979) identifies confidence as a latent expectation not to be disappointed, whereas trust requires actively engaged expectations in situations where the trustee is presupposed to be at risk should expectations be disappointed. These positions shift the focus to the beliefs and attitudes of those who enter into trusting relationships.

Hardin (1993) understands trust as an unmoralised notion, viewing it as a rational choice that involves giving some discretionary power to another to affect one's interests. His analysis

focuses upon the individual believer, rather than the belief itself, as he seeks to provide a theory of trust that encompasses individual, organisational, and societal trust. For Hardin the capacity for trust is a learned behaviour as previous encounters shape present and future trust decisions. Pettit (1995) similarly views trust as a rational strategy, introducing the concept of “trust responsiveness” understood as the desire to prove reliable when trusted by another (p.216). Trust responsiveness is distinguished from trustworthiness which is seen as a desirable trait, whereas trust responsiveness is associated with the desire to be well thought of and thus a trait few would acknowledge desiring. However, it is a trait potentially relevant to the research profession, with scientists acknowledging they are motivated by reputation and recognition (Whitley (2000) in Hessels *et al.*, 2009).

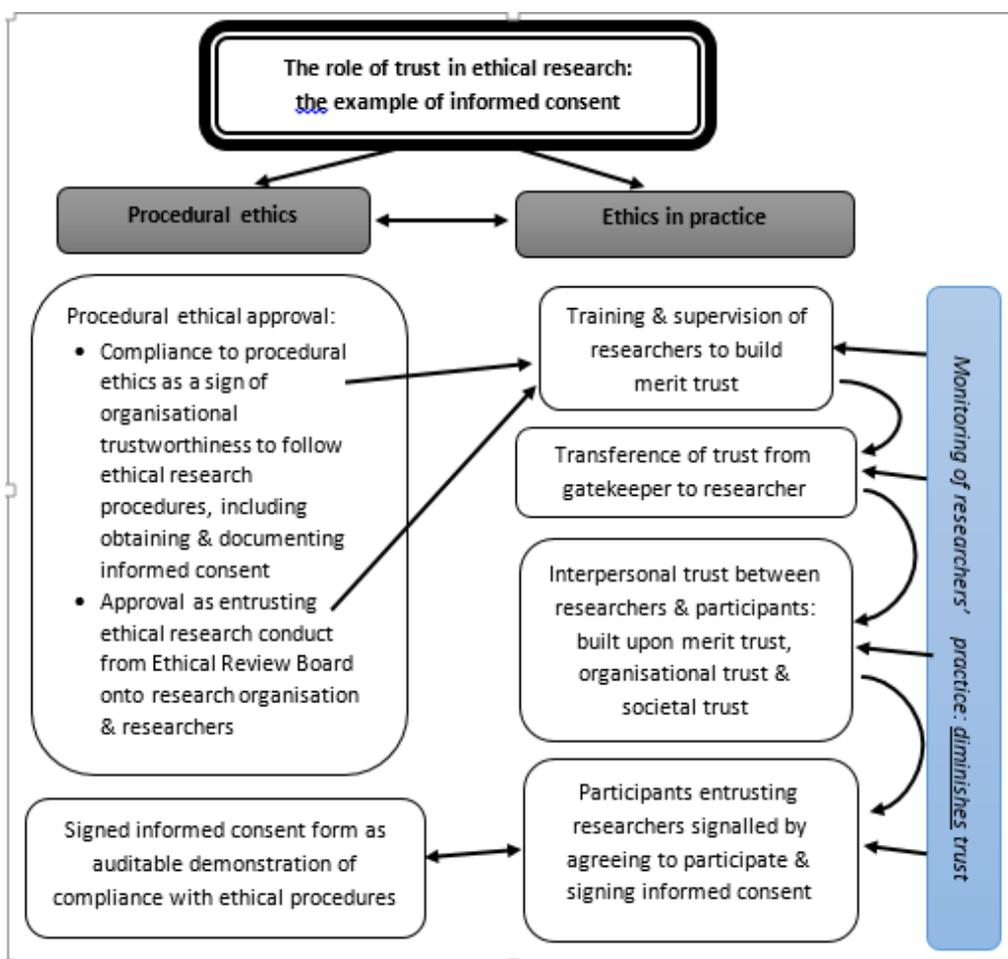
Insights from a bioethical perspective emphasise that “trust is a confident belief in and reliance upon the moral character and competence of another person” (Beauchamp & Childress: 2001, p.34). This focuses upon the character of the trusted, that they will act with appropriate motives and in accordance with shared norms to achieve the desired outcome of trusting relationships, without reference to the motivations for this conduct or the environmental constraints in which the trusted operates. For Baier (1986) this relationship is understood as entrusting, the formal handing over of the care of something, in the biomedical context the health of the patient, and is distinguished from trusting which often has no clear point of initiation, instead growing slowly and imperceptibly. In both medical and research relationships, adherence to rules of veracity are emphasised as essential to the development of trust and to demonstrate respect for the participant (Beauchamp & Childress: 2001). In a research ethics context this relationship is epitomised in the principle of informed consent whose role in building individual and societal trust in research is emphasised in theoretical and empirical literature (Bok, 1978; 1995; 2014; Eyal, 2014b; Kerasidou, 2017).

The relationship between trust and control is also important to consider (Das and Teng, 2001; Gargiulo and Ertug, 2006; Long and Sitkin, 2006). Pettit (1995) argues that systems of verification intended to monitor work outputs are opportunities for manifesting that trusting relations have been lost. Here, monitoring structures intended to promote transparency and enhance trust have the opposite impact by acting as displays of distrust. Instead of the act of trusting, the reliability of another’s work becomes a product of constrictions and monitoring meaning trust relations are unable to flourish because trust-responsiveness cannot occur (Pettit, 1995). Similarly, when engaged in surveillance and information gathering the incentives to engage cooperatively are reduced (Gambetta, 1988), thereby

reducing the opportunities for trust to take root. These insights carry implications for the monitoring of researchers' practice, both through established procedural ethics systems of audit (Power, 1997; O'Neill, 2002; Chiumento *et al.*, in preparation), as well as through informal organisational approaches to monitoring workers. Importantly Gambetta (1988) highlights that to engage "as if" trusting is likely to generate more trust, and that to monitor for distrust can be self-fulfilling. In the context of calls to extend ethical auditing (Siriwardhana *et al.*, 2013; Siriwardhana, 2015; Sumathipala & Siribaddana, 2004) it is important to consider the impact this may have upon trust relations that could be promoting ethical research practice.

These theoretical insights into trust are useful for examining the role and nature of trust in research, which in this paper focusses upon applying informed consent to research practice. As a public-facing performance of ethical research that sits at the intersection between procedural and in-practice research ethics, informed consent offers an appropriate entry-point for exploring trust relations. As figure 7 illustrates, trust operates as a bridge between procedural and in-practice research ethics, as well as a promotor of ethical research practice.

Figure 7: Trust in ethical research practice: the example of informed consent



Trust is encapsulated in the procedural ethical approval as an outward expression of ethical review boards entrusting researchers with the ethical conduct of research. Drawing upon this approval acts to reinforce organisational trustworthiness in line with societal expectations of the procedural mechanisms research organisations should adhere to. Trust embedded within the ethical approval is further entrusted to research assistants through training and supervision in ethical research conduct, translating procedures into practice and building merit trust in an ability to carry out the researcher role in accordance with approved ethical procedures and norms of conduct. The skills imparted through training and supervision equip researchers to build interpersonal trust with participants, drawing upon both status trust participants have in gatekeepers, and merit trust in researchers' training and skills. As a result, participants enact a display of entrusting through agreement to research participation, often epitomised in the auditable signed informed consent form, which leads to a procedural ethics trust feedback loop. However, potentially disrupting trust is the monitoring of researchers' practice which as a form of control suggests a potential distrust of researchers' autonomous actions in the field.

Methodology

Research employed a multi-site case study design (Yin, 2009), conducted across three countries in South Asia. An underpinning phenomenological epistemology (Schutz, 1944; 1945; 1967) drew attention to researchers' lived-through experience of research ethics in their everyday research practice. Ethics was understood broadly, as interviews sought to explore the interaction between procedural and in-practice ethics as experienced by researchers (Guillemin and Gillam, 2004).

Research setting

Confidentiality agreements with study organisations prevent identification of the specific countries and sites of research. However, recognising the importance of context to situate research findings, a broad overview of the South Asian research settings is provided. Where pertinent, additional description is offered alongside the results to contextualise participants' narratives.

Research was conducted in three South Asian countries with recent histories of conflict. Each country continues to experience political instability and natural disasters, and hosts refugee and/or internally displaced persons. The countries are classified by the World Bank as lower-middle and lower income (World Bank, 2017). All three countries contain a multiplicity of ethnic, religious, and language groups; and have mixed biomedical and traditional healthcare

systems (World Health Organisation, 2001), including free-to-access healthcare facilities, as well as private healthcare systems (World Health Organisation, 2017). Mental health has been recognised as a policy priority in all three countries, either in Mental Healthcare Acts and/or making frequent mention of mental health in policy frameworks. However, mental health stigma remains a significant barrier to treatment, founded upon religious or traditionally-informed understandings of the causes of mental ill-health (Thorncroft, 2006; Patel, 2007).

At the time of study all participating organisations were engaged in or had recently been conducting research with conflict-affected populations. The organisations include: a dedicated psychosocial and research NGO (Country 1); a research and training NGO (Country 2); and a tertiary hospital (Country 3). In the first and second countries the organisations operate country-wide with multiple projects operating concurrently, and offer support to national governments with the mental health aspects of disaster response when required. In the third country the research explored in this study was the only community-based research the organisation was conducting. In all three countries research assistants were employed, trained and supervised as short-term hires for the duration of a specified project, with opportunities for transferring to other projects or for research career progression in countries one and two in particular.

All three settings have formalised procedural ethics structures including requirements to obtain ethical approval prior to conducting research. Additionally, all three organisations were in receipt of international funding which further mandated adherence to ethical review mechanisms and ongoing ethical oversight of research, either via in-country procedures or through additional funder or organisation-specified requirements. All organisations had developed their own programmes of research assistant training which included key principles of research ethics, conceptualised according to principlism (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; Beauchamp, 2007; Beauchamp and Childress, 2013), and with an additional emphasis upon the practice of implementing research methods - centrally interviewing skills that recognised the sensitivity of discussing mental health. Researchers' approaches to and experiences of ethics-in-practice, ethical governance mechanisms, and organisational approaches to training in ethics are considered sufficiently similar for multi-site analysis.

The study

Qualitative in-depth interviews were conducted between September 2014 and February 2015 with researchers of all levels – including primary investigators/technical advisors, field coordinators/supervisors, and field research assistants. A total of 35 interviews were conducted, each lasting on average 90 minutes. Due to language barriers interpreters were available to facilitate interviews. Interpreters were hired after a selection interview, and were trained and supervised by the lead researcher (AC) in their role as co-interviewer (Chiumento *et al.*, 2017).

Interviews were broadly structured around a topic guide, with attention paid to emerging lines of enquiry and to iterative evolution of interview topics (Rapley, 2007). The topic guide contained broad focal points, including researchers' definitions of research ethics; their understanding and experiences of procedural research ethics such as writing protocols for ethical review and experiences of the ethical review process; and in-practice ethics, identifying research experiences that were felt to entail ethical issues and discussing how these would be managed in-practice. All interviews were digitally recorded and the English conversation transcribed for analysis. Interview transcripts have been fully anonymised through the use of pseudonyms and fictional place names, denoted by { } brackets.

Ethics

Ethical approval was obtained from the University of Liverpool and in each case study country. All participants provided voluntary written informed consent prior to interviews. Interpreters signed confidentiality agreements, were provided a salary in-line with the local rate, and had all travel and accommodation expenses covered if fieldwork required travel. At the end of the study all interpreters participated in an exit interview and were given a written reference letter attesting to their role in this study.

Analysis

Analysis was driven by a phenomenological epistemology (Schutz, 1944; 1945; 1967), with trust coming to the fore when attention was paid to what was underpinning researchers' descriptions of ethical research practice. Data analysis involved first open coding a sub-set of transcripts to develop an inductive coding framework that was then applied, extended, and refined through analysis of subsequent transcripts (Boyatzis, 1998; Green and Thorogood, 2014). Once coded, the data set was reviewed for researchers' experiences of in-practice ethics which revealed the centrality of trust in the web of relationships at the societal level of public trust in research; the organisational level between research assistants

and supervisors, and at the interpersonal level between research assistant and participants. Trust as a mechanism is both explicitly stated, and implicitly signposted in researchers' narratives, coming into view in the situated context of specific examples of research practice. Therefore, analysis retains a focus upon the specific sites where trust operates, recognising that it is only in situated practice and relationships that trust acquires meaning (Hardin, 1993).

To fully explore the nuances in narratives this paper presents extended extracts from five interviews, allowing narratives to be dissected for the signs, symbols, and manifestations of trust. Analysis focusses on lived-through experiences of the informed consent process, using this central feature of research ethics as a heuristic device that allows the trust relations that surround it to be explored. It is important to note that the themes and ideas expressed in these extracts are reflected across the data set, and are considered to typify the experiences of researchers in this study. Where illustrative, quotes from other participants are presented to reinforce, expand upon, or challenge the selected extracts. All extended interview extracts are taken from interviews conducted in English, therefore attention to the meaning embedded within participant narratives is appropriate.

Results

Five interview extracts are presented from two research assistants, a mid-level researcher, and two senior primary investigators (PIs)/technical advisors. These extracts trace the web of trust relations present when enacting informed consent in research practice, expanding upon the elements identified in figure 7. Results attend to participants' narratives, with the discussion building upon and extending findings in light of wider literature.

Informed consent: the importance of who is doing the asking

This extract is from an interview with a research assistant (hereafter RA) in the third country. In this country a generalised distrust of researchers at the societal level was described (Chiumento *et al.*, 2016). This was seen to result from biomedical data being collected under the guise of research that were actually for national security and anti-terrorist operations and did not have any research purpose. The impact of this deceptive "research" has been to erode public trust, affecting researcher-participant interactions and public trust in the health profession who colluded in the deception (Bok, 1978; 2014; Chiumento *et al.*, 2016). This deception took place in the region where participants in this study were based, and form a critical aspect of the situated research setting. Here the RA explores the role of gatekeepers in establishing the trustworthiness of researchers:

it's helpful if someone...their local counsellor or their doctor. If they tell them about this study and we are along with them I think that would be much easier for them to understand and er even to trust to that, to you.

Okay so so maybe if somebody else was introducing the study and then the research assistant then did consent afterwards, you think that that would help people er accepting really the research?

Yes, yes, because. I mean for example in {Reagan} the people who regularly visit there, the families or everything, if the {Reagan} people the doctor who is er in contact with these people all the time, if he introduces us to them and says these are...carrying out this study, and basically this is what they are doing and, and it's for people's benefit and nothing...harmful or anything. So just if they can er give a brief introduction, I think that that's very encouraging for them and that develops the trust which is the basic thing which we are looking for.

...if he assures that there's, there's nothing wrong in this or, I think it would develop more trust. ...(.2) And it happens in our communities most of the time if the local leader or person or whoever is representing them in some way or other, if he says something people sometimes (.2) I think they would understand but sometimes they just follow him they, they trust him because they know him for years, for twenty thirty years so they just follow him. They, they say that he, uh whatever he does it's in our interest.

Okay. So do you think this could potentially er have an impact upon people making their own informed decision to take part [in research]?

...In some ways it can affect, they might not want to read the whole informed consent although we will be doing the same process like for, explain it again to every individual. But sometimes in our community these things happen where they, if the local community leader agrees.... Sometimes because of that blind trust they just agrees with everything. But still I think we would be following our own er, [informed consent] procedure.

(Shaheen, Supervisor: C3,16)³⁴

³⁴ All interviews are identified by a pseudonym and the country number (C1, C2 or C3). In interview extracts the text in bold is the interviewer, and in normal font is the participant. The use of bracketed dots e.g. (...) indicates the removal of one or more sentences, whereas the ... indicates the removal of up to a few words, and () indicated missing data due to inaudibility. The removal of words and sentences has been done to enhance the readability of the extracts. As explained in the

In this extract the participant explores the researcher being introduced by a gatekeeper - someone within the community who is known to the participant and whom they trust, identified here as a doctor or local leader – with trust transferred onto the RA as a result of their association.

The emphasis upon the gatekeeper assuring that the research is not harmful and is being conducted in participants' interest is important in the situated country setting where deceptive research has led to public questioning of the veracity of statements about the purpose and use of research data. This suggests that in a climate of generalised public distrust, assurances of the trustworthiness of the research and researchers is important. It is interesting to note that in the RAs assessment despite the collusion of doctors in deceptive research that led to the breakdown of public trust in research, they are still viewed as an appropriate party to vouch for the trustworthiness of researchers. Here trust has an instrumental value as it is drawn upon to facilitate the next steps in participant recruitment, despite recognition that this may be based upon “blind trust” rather than actively chosen, and therefore may not adhere to the normative foundations of informed consent (Council for International Organisations of Medical Sciences (CIOMS), 2015).

Once potential distrust has been overcome through the gatekeeper's introduction, the RA is afforded an opportunity to prove their trustworthiness, at which point the RA appeals to the informed consent procedure. This implies that the informed consent process alone is sufficient to embed a trusting relationship upon which the normative features of informed consent can operate - encompassing being fully informed, the veracity of the information, and the participant making an autonomous and voluntary decision about research participation. When critically considering the pathways to trust that have led to the participant engaging in the informed consent process against the normative elements of the informed consent principle, it is possible that these assumptions may not be justified. This is because the role of the gatekeeper as described by the RA acts *in place of* the informed consent process, usurping the procedural and normative foundations of informed consent, rendering informed consent “at best a polite fiction” (Chambliss, 1993, p. 651).

section on anonymity, the use of { } brackets indicates replacement of an identifiable word such as place name or religious group with a pseudonym or non-identifiable replacement term.

Informed consent: a complex web of trust

The second extract illustrates the management of potential challenges identified in the first, namely to prevent “blind trust” from overriding the normative foundations of research ethics. This is achieved through supervisors’ trust in RAs knowledge and skills in ethical research practice, established via training. Training in ethical research conduct is seen as an effective way to establish merit trust and mitigate status trust arising from pre-existing interpersonal trust relationships participants may have with RAs, addressing the *why* of research conduct alongside the practicalities of *how* (Eisen and Berry, 2002).

This interview is with a mid-level researcher overseeing data collection for his PhD in the second country. His role involved all aspects of the study including research design; recruiting, training and supervising RAs; data analysis; and disseminating research findings. The extract explores the training and supervision of RAs, with a focus upon building trust in research assistants’ knowledge and skills in ethical research conduct, focussing upon informed consent:

I noticed in certain [research assistants]...obviously some of them, they knew the community. They would sort of, especially the {Wpylin} er RAs, they (), they're not from the same community but they had grown up, they had gone to school with some people. And so there was a sense of familiarity and people..., you know accepting them when they come and say right we want to ask you questions they would just accept. So again the consent, and giving information and all that would be you know easily bypassed. So that obviously had to be instilled and said right, you know, just because you know them or they respect you and stuff...doesn't mean that you don't get consent, you do need to explain everything, you really do need to get consent, provide a copy of consent form to them, bla bla bla. So not cutting corners. So I think that was the er biggest sort of lesson, er, message that...the consent process has to be, strictly followed

Okay and your confident that was?

I think, I cannot be, I cannot say. ...You know...we spent a long time establishing connections and rapport with, not with only the participants but with their leaders and with community and all that. So we didn't go in as medics we went with, you know even, we went and talked with the {Alerassa} first and then the camp leaders and then went with them, but then obviously the problem of, the camp officers coming and saying “right you know, this is

a research project you need to support” obviously he wants to hang around, and then we had to you know, take him out of the picture. And there is a lot of sort of those sorts of challenges but I think...given the context, given the situation, given the the the er background, we were successful in not coercing people to participate but, you know genuinely getting people to agree.

(Orville, Supervisor: C2, I6)

This extract explores multiple-layers of trust operating concurrently, illustrating some mechanisms through which trust is signalled and established, and the paradoxical challenge of minimising pre-existing interpersonal trust to build professional trust founded upon administration of ethical procedures. Explicit recognition of the RAs’ prior relationship with members of the community leading to “*familiarity*” and “*acceptance*” between the participant and RAs is drawn upon in a number of ways. The language of “*acceptance*” and “*familiarity*” suggest unconscious trust (Baier, 1986), where the familiarity of RAs impacts upon the development of a trusting relationship (Luhmann, 1988). Whilst the RAs were not hired from the community being researched, there is a clear sense that they were community insiders (Hynes, 2003). In stating that the participants “would just accept” the level of familiarity is identified as a factor that may lead RAs to circumvent the informed consent process and thereby act in ways that do not confirm to the trust supervisors have placed in them to conduct research in accordance with ethical research procedures.

The role of professional trust is explored later in the extract, described as establishing “*connections and rapport*” with community gatekeepers and potential research participants, contrasting it to the pre-existing trust between RAs and the community. Building this trust is identified as a discrete procedural step when approaching participants, occurring prior to approaching individual participants. Interestingly, establishing community trust in this way is identified as an important foundation for the conduct of informed consent, but is differentiated from prior relationships RAs may have with participants. Specifically building trust in researchers for the research itself is differentiated from the familiarity of interpersonal trust between RAs and local communities. This suggests that the deliberate and professionalised approach to building trust relationships with community gatekeepers establishes a different trusting foundation that is more acceptable for research because it is built upon professional roles, responsibilities, and norms of conduct. Similarly, the extract explores efforts to mitigate the influence of camp officers whose intervention could affect the voluntariness of decisions to participate in research. Conceptualisation of the role of

gatekeepers in establishing researcher trustworthiness is seen as more limited than in the first extract, displayed in the statement *“obviously he wants to hang around, and then we had to you know, take him out of the picture”*. This emphasises the importance of situated country dynamics and an understanding of contextual factors that shape approaches to research practice.

When approaching the community, conscious rejection of being positioned as a “*medic*” is emphasised, drawing attention to the presentation of self (Goffman, 1959). Efforts to mitigate the status afforded to medical professionals in country two are described by another participant:

...when you say you're a doctor ... they're given a high status in er {Bialya}. So we didn't want to do that so we dressed, we didn't wear a tie, so we just dressed decently..., if we wore tie and things like that and went in people would feel that they had to participate because it's some big person has come... So we didn't try to look too dominating, I guess. That would be the word. We didn't want to look too dominating. That way people are more comfortable with you.

(Mercurius, RA: C2, I5)

Thus, in this country researchers explicitly recognised that their status as medical professionals brought a dominating power dynamic that they sought to avoid, associating the status trust in medical professionals as leading to *too much* trust. In contrast to professionalism to establish trust, here the power of the medical profession is identified as potentially overriding it. Interestingly, here the medics make efforts to look familiar rather than “*dominating*” by adopting dress makes the community to feel “*comfortable*”. This suggests that the supervisors recognise the value of some degree of familiarity for facilitating contact with communities, upon which professionally-grounded trust relations can then build.

Recognising the contextual factors, stress is placed upon the biggest lesson for RAs: to *“explain everything, you really do need to get consent, provide a copy of the consent form to them”*. The emphasis upon not “*cutting corners*” implies that failure to follow the step-by-step informed consent procedure would be to circumvent its ethical basis. This suggests that through the application of procedural ethics such as informed consent the influence of contextual factors such as prior relationships and “*blind trust*” can be mitigated. This conclusion echoes the first extract, and suggests that researchers themselves may have their

own “blind trust” in the ability of research procedures to ensure the ethicality of research, independent of the human interactions that go into enacting procedures with participants in the real world.

Trust in researchers: reliance upon signs and signals

The third extract continues to explore trust built through RA training and supervision, connecting this with researcher integrity and ethical research practice. The interview is with a senior PI in the first country who occupies a technical advisory role which involves providing input from study conceptualisation, through study conduct, and reporting. This includes a role in training and supervising the locally-based research supervisors. The PI was not based in the country setting, but made frequent extended visits to conduct supervision with the research team, as well as providing ad-hoc guidance from a distance (via e-mail / skype). The extract explores how integrity connects with ethical research practice and notions of trust:

...if you can unpack that idea of...the role that researcher integrity plays?

...I think it's...understanding the sensitivities and the vulnerability of the respondent. And again so that means, being able to take a position beyond the direct goal of the research, so the direct goal of the research is to get answers on this, there is information that I need. Right?

Yep.

And I think,... (.02) er a research assistant with a not so high level of integrity will just get their, er, their sheets filled up and, and, and make sure that there's no values and that's important. Erm, er, somebody with a, the higher you go on, on a scale of integrity I think the more, somebody's able to have an empathetic, and I think empathy is a key word for me, is er, have an empathic stance towards a respondent as a person ((laughs)) rather than a, as a respondent. Erm, so that means, you know, taking, being able to take that position at a more, meta-level, on the research and, and the vulnerabilities and the sensitivities related to that. Er, I think that's what it means. In practice it also means er, er, (.02) yeah again and again if I'm looking...critically...for example the issue of confidentiality, for example there's overlap on, er, therapeutic and, and research integrity and and one of them is confidentiality.

Mmhum.

...I went to a home visit yesterday of one of the patients and I came back and er, I just happened to be sitting with er (.02) with...the team and, you know, I

said, I'd gone to a home visit and they said "oh where?" and I said in this village and then they said "oh with who?" and everybody knew the person so, and you know, this is bound to happen because it's a small team and da-da. But I mean everybody knew the name and it was, clearly not er, so, I have total trust in the team that they keep that within them, but I [don't know.

[Yeah, yeah.

...it's, erm, (.03) yeah, hoping that their integrity is high enough that that indeed stays within the team and I think these are, these are the operationalisations of your integrity. ...Are people confidential, are (.02) ha, do they have interviewing skills that are...matching the vulnerabilities and sensitivity erm, rather than again focusing on, erm, and I hope, I really hope that our longer term training again, we are a psychosocial organisation, so we have quite a bit of emphasis on that I mean the, the communication skills er, er and sensitive, sensitive interviewing skills. That get translated back in, in erm, in, in practice but again, that's something that you should check.

...At the moment it's all hope? ((laughs))

No, it's. Yes and no I mean when you talk to them you get a sense of that, I mean and again this is this ongoing monitoring and I, I, I get the impression that that... we do video-taped role plays you know,...we definitely have a sense of their skills, once we send them out, but indeed, once they are out, er, we're not, checking that.

Mmhum.

But during the, the case sharing, or the sharing and the monitoring missions...I don't get the impression that we have like a, a team of bullies out there that is just erm, information hungry.

(Hubert, PI: C1, I1)

The extract opens and concludes with reflections upon the purpose of the research enterprise: to generate knowledge to benefit humans. It highlights the importance of integrity that goes “beyond the direct goal of the research” and being “information hungry” to encompass an empathetic stance towards research participants that recognises the vulnerability and sensitivities inherent to mental health research. The emphasis upon an “empathetic stance” concur with theoretical assessments of the role of goodwill as a key facilitator underpinning trust. A mid-level researcher in the second country conceptualised integrity as integrating professional norms alongside moral or ethical norms:

“researcher integrity...just maintaining and adhering to ethical guidelines, to ethical principles...and a professionalism” (Mercurius, RA: C2, I5).

The idea of the integrity of the research process as well as the research outputs is emphasised in this extract: that researchers must move beyond the “direct goal of the research” (to obtain knowledge) to appreciate broader structural and social context that shape the vulnerabilities and sensitivities of individual participants (Farmer and Campos, 2004; Farmer *et al.*, 2006, Luna, 2009, 2017). This captures a concern for public trust in institutions and the research enterprise, identified in the PI’s concern to be seen to be practicing as the public would expect of a psychosocial organisation. It is worth noting here that in all three countries public perceptions of organisations was something researchers at all levels were cognisant of, seeking to ensure public trust in the organisations conducting research that would facilitate future research interactions and safeguard the integrity of the research enterprise. Linking integrity as instrumental in building and maintaining both public and individual participant trust suggests that integrity is conceptualised as the expression of a moral disposition of truthfulness, reliability, and adherence to professional standards of conduct that are essential to establishing and maintaining trust.

When considering what integrity looks like when operationalised, the example of confidentiality within the research team is offered, identifying “*total trust*” that the team will maintain confidentiality. The extract ends with a discussion about the signs of RA integrity that supervisors look for – demonstrated in skills such as an empathetic stance when interviewing, maintaining confidentiality, and demonstrating communication skills that match the potential vulnerabilities of participants. These skills are instilled during RA training and assessed via role plays and ongoing monitoring, which in this country involved daily and weekly team supervision where research progress and challenges faced are discussed. This assessment and surveillance of research process includes seeking to verify the operationalisation of ethical principles and researcher integrity outside of the field, with evidence from simulated practice or through open discussion considered sufficient to warrant trusting that this is how the RAs operate at all times. The intangible nature of reliance upon signs and signals that trust is warranted is reinforced when the PI states later in the interview that integrity is “*not a thing on a check-list*”, but is gained through a “*sense of their skills*” and “*impression*” of how RAs will practice when acting autonomously in the field.

Researchers' experiences of trust

This extract is from an interview with an RA in the first country discussing their understanding of research integrity. It is important to note that in this interview integrity was a term the RA recognised, but was unable to fully define. Therefore, for the purpose of further discussion integrity was defined as “reliability, truthfulness, honesty”:

Truthfulness, true at heart no? True at heart. We'll go there um, and er we'll interview with certain people. The datas, the informations that she or he had given to us will be true confidential no? Ah and er, and we also don't break that confidentiality when we are in office...We'll record it, we'll assign the code numbers so that their name can be blanked out. Yes we maintain the privacy and in that case we also think that we are honest no?

Yeah.

Because we have not broken their trust. Second thing we have not lied that they would be the benefited from this research in a long run, yes we have not cheated them. According to the interventions designed, it will be done in the ah, in that appropriate area...Generally speaking of me I feel that I, that I had...such ah, researcher integrity or reliability, something like that.

....is it always written or is some of ethics unwritten, part of...the way you practice?

Yes,...many...are written also but some of the ethics, ethics means, yes when you feel ah that you should not do or this is not do if you feel er, what should I say? ((laughs)) Yes er. No I understand your point, I understand your point but I'm feeling myself. Ethics, when you feel something that is good or bad..., some of the ethics are also not written some you have to ahh realize deep inside of yourself also.

(Alexandre, RA: C1, I4)

There are clear connections being drawn in this extract between truthfulness, honesty, and trust, all of which act as signs of researcher integrity and reliability. The signals identified to demonstrate these features are familiar to systems of audit such as selecting the right people to interview, assigning code numbers to protect participants' identities, and ensuring that interventions are delivered where participants live so they are able to receive the benefit of

service access³⁵. Beyond audit mechanisms the RA identifies ethics and integrity as being “*true at heart*”, realised “*deep inside of yourself*”. These suggest that the practice of researchers – including their trustworthiness to practice ethically and with integrity, as well as their ability to build trust with participants and communities – is a product of more than following guidelines and rules. Instead RAs need to have an internal commitment to, and active implementation of, norms underpinning ethical research practice. Furthermore, in expressing these views the RA echoes the perspectives of the PI in the previous extract from the same country suggesting that organisational behavioural and normative expectations have been internalised by RAs.

Similar conceptualisations of integrity were expressed by researchers at all levels, for example, one senior PI in the second country stated:

“integrity you have within yourself (.2) that’s the most powerful and strongest um force....integrity is very much to do with ethics...it’s what you believe, and what you deliver...trust is earned (.2) through work....(.4) That’s I think integrity....That is the most important one, if you lose integrity, you lose everything.” (Spiro, PI: C2, I8)

This participant emphasises the duality of outward demonstration of credentials of practising ethically (which encompasses integrity), achieved “*through work*” delivered; alongside the internal “*beliefs*” as a force “*within yourself*”. These extracts emphasise the intangibility of ethical research practice and integrity, whilst underlining the critical importance the role of trust plays in underpinning both.

Trust in researchers: the impulse to verify

The final extract considers the ways that supervisors verify the trustworthiness of researchers to practice ethically and with integrity. This extract is drawn from an interview with a senior PI and technical advisor based in the second country, and explores organisational approaches to verifying researchers’ informed consent practice:

...in all our projects, we train the people who take informed consent

Yep.

We (.3) see whether that’s done.

Mmhum.

³⁵ For an interesting discussion of whether access to services is an appropriate benefit to prioritise, please see Hasting Centre (2004) *Moral standards for research in developing countries: from “reasonable availability” to “fair benefits”* The Hastings Centre Report; 34(3):17-27.

Sometimes we ring the participants, to make sure that, you know, these people came, whether they signed the form, whether they received erm, their, money. What do you call, compensation for participation. And we have sacked people who didn't do things, we try to, I mean then we, get them, try to rectify them if, things are repeated. I mean, you know, we don't reprimand people straight away.

No, yeah, yeah.

And quite interestingly...we have had dummy participants, you understand? ...So where...research assistants go and interview... They think, you know, they are interviewing a real participant.

Yeah.

But then, we get the feedback from [the dummy participant], so that is there. But I'm still not saying everything is perfect, so.

Mmhum.

There have been instances when people have not got informed consent, or done the data collection completely, by themselves not interviewing the participant, I mean we have caught them, sacked them.

Yeah.

Not paying the money, so we, we do our best...I mean you have to be mindful, otherwise you know, you may end up with a data set which (was cooked), and you've really had it.

Do you know, it's really interesting because that has been reported to me in all countries I've spoken to.

Yeah. Yeah. I mean that's...very much happens... But I don't compromise on that. It's not distrust. Making sure, that, as a supervisor my responsibility is to defend.

(Spiro, PI: C2, I8)

This extract details the lengths that organisations go to when seeking to verify the practice of their RAs. It also highlights responses to practice that does not meet the required standards, namely through additional training to “rectify” their practice, or as a last resort, termination of employment. In the other two countries other similar approaches to verification of RA skills and attitudes were described, involving covert and overt observation of informed consent with participants, and an examination to test the ethical knowledge of RAs before they were sent into the field (country 1 only). Furthermore all countries used role plays in

training and ongoing supervision of RAs as an essential feature of building supervisor trust that ethical research skills are being implemented correctly.

In the extract the impulse to verify is explicitly stated not to amount to distrust. Instead, the PI identifies his actions as motivated by a “*responsibility...to defend*”. This responsibility can be understood as the PI being accountable – in research including accountability to participants, funders, and the general public - for RAs’ behaviour meeting the moral/professional standards expected of them. This accountability gives rise to a moral duty that the PI do all within his power to ensure the moral/professional standards are maintained through monitoring and taking steps to address practice that fails to meet required standards, including additional training or termination of employment. In appealing to “*defend*” a number of considerations are raised. Defending can be used in two senses, the first is to resist an attack or protect from harm (Oxford English Dictionary, 2017). This raises the question of who or what is being protected from harm: individual participants who are harmed through unethical practice such as not being compensated for their time; to protect from harm the reputation of the organisation conducting research (Buchanan, 2000; Hessels *et al.*, 2009); and lastly to protect public opinion of the research enterprise from harm (Bok, 1978; 2014). These levels at which the PI may be seeking to defend overlap with the levels at which trust operates: individual, organisational, and societal. The second use of the term defend is to use in defence of, for example defending the actions of someone in a lawsuit (Oxford English Dictionary, 2017). This second usage is also relevant here, defending RA skills by addressing deficiencies in the case of a genuine mistake rectified through additional training and awareness; as well as in self-defence of the organisational reputation which may be harmed by instances of unethical practice that could be scrutinised by professional or ethical audit mechanisms. Whilst all of these efforts are understandable, they ultimately operate as features of control rather than foundations for trust. Given this, and recognising the impossibility of monitoring all practice of all RAs acting autonomously in the field, the need to strike a balance between control and trust is foregrounded.

Discussion

The discussion considers the forms of trust, entrusting, and trustworthiness embedded within participants’ narratives against theoretical typologies to indicate the role of trust underpinning ethical research practice (Schutz, 1944; 1967; Mollering, 2006). From here the discussion explores the role of control operating alongside trust, focussing upon how these two concepts interact to promote or stifle trust and how they are reconciled in researchers’ everyday practice. Following this, suggestions are made for how trust and control can be

balanced in the situated context of mental health research in post-conflict environments, with specific implications for researcher training and organisational approaches to monitoring. The discussion concludes by reflecting upon the mechanisms of control and trust inherent to procedural ethical mechanisms and research in practice.

All theoretical accounts of trust identify risk as a factor critical to the presence of trust. Participants' narratives stress a range of risks when conducting mental health research: at the societal level the risk of deceptive research or "cooked" data sets for trust in the veracity of the research enterprise (Bok, 1978; Hessels *et al.*, 2009; Bok, 2014). At the societal and organisational levels the reputational risks of not adhering to professional norms and standards - including failing to follow the informed consent procedure (Eyal, 2014b; Kerasidou, 2017). These norms and standards act as a key source of trust (Bachmann, 2006) through their functional authority as mechanisms that control the production of expert knowledge which enables a latent form of societal trust to emerge (Luhmann, 1979). Finally, at the interpersonal level the risk of participant exploitation is recognised, for example through circumventing the informed consent process, failure to provide participant compensation, or coercion via gatekeeper presence (Yamout and Jabbour, 2010), all of which entail feedback loops to organisational and societal trust. To manage risk in each of these contexts, trust amounts to a state of positive expectations when entrusting the conduct of research into the care of another (Baier, 1986), trusting in the behavioural consequences of trust (Das and Teng, 2001) – in this study focussed upon trust in RAs' autonomous actions in the field. Therefore, it is clear that at all levels trust operates to render manageable perceived risks to research at the societal, organisational, and individual levels.

Throughout participants' narratives a mix of competence and goodwill trust is evident. Competence trust involves expectations of technically competent role performance (Luhmann, 1979) which increases confidence in successfully meeting goals (Das and Teng, 2001), and is akin to merit trust "that attaches to an individual because of his or her perceived merit...based on the individual's capacities and behaviour" (Buchanan, 2000, p.191). Merit trust is further separated into primary merit trust founded upon beliefs and perceptions about the competence and commitment of individuals (Buchanan, 2000, p.194); and derivative merit trust which follows from a "belief or perception about the quality of the *organization*" (p. 191) in which an individual practices or works. Therefore, merit trust is evident at the individual level of RA competence and skills, and in organisational reputation; and is distinct from status trust that results from association with specific social groups or professions.

Considering these typologies against researchers' descriptions of gatekeeper and researcher trust suggests that the form of trust also shifts. Gatekeeper trust can be considered a form of status trust, an often unconscious trust premised upon the belief that the trusted person will act in the best interests of the truster. However, as has been demonstrated in medicine trusting in "best interests" doesn't always hold as patient presumptions that doctors act in their best interests (Kass *et al.*, 1996) ignores structural conditions of resource scarcity meaning doctors are unable to maximise the best interests of all patients at all times (Buchanan, 2000). This assessment can be extended to mental health which is poorly resourced worldwide (World Health Organisation, 2013) leading to trade-offs in best interest decisions. Trade-offs are arguably augmented under the structural realities of healthcare access in LMICs where research participation becomes a rational route to healthcare (Kingori, 2015). The decisions of gatekeepers may therefore involve seeing research participation as a critical route to accessing mental healthcare independent of any rational assessment of research risks and benefits for participants.

In participants' descriptions a notable suggestion is that status trust in gatekeepers – community representatives such as village elders or camp officials - is sufficient for participants to engage with researchers, conferring status trust onto researchers through their association. However, at this point it is proposed that researchers establish and maintain both primary and derivative merit trust through adherence to the informed consent process. Similarly, when seeking to mitigate status trust in the medical profession appeals are made to establishing merit trust. Therefore, there is a clear sense that status trust is rejected as grounds for agreeing to research participation - a finding echoed elsewhere (Kass *et al.*, 1996; Kerasidou, 2017) - whereas merit trust is acceptable, conceptualised as trust grounded in professional competence and expertise coupled with the active and voluntary decision of participants to join research after consideration of all pertinent information. It is important to note that senior researchers' descriptions either explicitly or implicitly recognised the role of RAs' local embeddedness, therefore suggesting that some level of status trust or at minimum familiarity remains acceptable – for example RAs and research participants sharing gender, religious, or ethnic group affiliation. Equally, when identifying dress codes for medics that seek to promote "comfort" and are not too "dominating" there is a sense of reverting to standards that are familiar to the community being accessed. These recognise that some level of familiarity is important for trust to evolve (Good, 1988; Gargiulo and Ertug, 2006), especially in settings that have recently experienced conflict and where outsiders or those in positions of authority may be distrusted (Hynes, 2003).

The informed consent process is therefore invoked as a way to protect against “blind trust”. This concept is worth unpacking for its impact upon the procedural requirements of informed consent: namely that consent be (a) fully informed, (b) that a rational assessment of research information is conducted to ensure its full comprehension; and (c) is entered into voluntarily, free of any undue influence or coercion in the decision to participate in research (Council for International Organisations of Medical Sciences (CIOMS), 2015). Baier (1986) suggests that blind trust occurs only with those who are maximally vulnerable (p. 240), emphasising dependency between those unequal in power inherent to trust relations as the trusters make themselves vulnerable to the trusted. Therefore, blind trust can be seen to devolve into a paternalistic relation involving excessive and irrational trust resulting in the therapeutic fallacy that research aims primarily to benefit the individual participant (Eyal, 2014b). Recognising paternalistic power relations, and alongside researchers’ emphasis of the “vulnerabilities” and “sensitivities” of potential research participants, it is suggested that researchers’ faith in the informed consent procedure fails to recognise the potential for blind trust mechanisms to be underpinning the informed consent process. In suggesting that informed consent is the point at which trust is *established* is to consciously un-see the structural and power relations surrounding the RA and participant encounter.

It is interesting to consider the form of trust researchers are aiming at in place of status or blind trust. Descriptions suggest that researchers view trust built through informed consent as an active trust “which has to be won, rather than coming from the tenure of pre-established social positions or gender rules. Active trust presumes autonomy rather than standing counter to it...compliance is freely given rather than enforced by traditional constraints” (Giddens, 1994, p. 14). This form of trust is explicitly situational, contingent upon active establishment and maintenance that contrasts it from forms of trust that arise from tradition or status. In participants’ narratives the active foundation emphasised is professionalism and adherence to the informed consent procedure. This form of active trust is therefore fragile in contrast to status trust, as a conscious effort is required to continually demonstrate such trust. Empirical evidence has found that participants engage in complex assessments when deciding upon research participation. Kass *et al.* (1996) document the complex interplay of trust in professionals as a result of status, beliefs about acting in the best interests of those under their care, and as merit trust founded upon professionals’ perceived topic expertise; and trust in institutional reputation and the research enterprise overall. Alongside these are other motivations such as viewing research participation as a civic responsibility. In this complex web of motivations and trust relations participants report

that their decisions regarding research participation are made *before* informed consent began. As a result, Kass *et al.* (1996) promote attention to sensitivity to the role of trust in research. In light of this empirical evidence, and the assessment of the role of gatekeepers and other forms of trust that may be present as described by participants in this study, to assume an operationalisation of active trust in professionalism and adherence to ethical research procedures seems naive at best.

In many extracts the concept of goodwill trust is evident, referring to the expectation of moral obligations and responsibilities to demonstrate a special concern for others' interests above their own. This encompasses for example gatekeepers' good faith in organisations conducting research consistent with stated aims and approved protocols; and supervisors' good faith in the intentions and integrity of RAs in the field (Pettit, 1995; Das and Teng, 2001), epitomised in RAs taking an "empathetic" stance towards research participants. From the perspective of the RA as the trusted party both goodwill and competence trust are appealed to. For example goodwill trust is invoked in descriptions of being "true at heart" and ethics being realised "deep inside of yourself", suggesting internalising of professional and organisational norms. Whilst competence trust is identified in adherence to procedural standards, for example of maintaining confidentiality and following anonymity and informed consent procedures, all of which demonstrate familiarity with the technical competencies of the RA role (Hammersley and Traianou, 2012).

Trustworthiness is also invoked in researchers' narratives. Theoretically trustworthiness is understood to entail three elements, that an individual: (a) acts in conformity with certain rules and this has little or nothing to do with moral conviction; (b) has a moral abhorrence of abusing trust; and (c) is a person who ought to be trusted (Horsburgh, 1960, p. 349). In the first sense trustworthiness does not affect the moral character of the person, and is more akin to a form of reliance or confidence; whereas in the second and third senses trustworthiness can produce moral goodness or goodwill, understood to presuppose "a belief in the possibility of stirring someone's conscious to an extent sufficient to affect his conduct" (Horsburgh, 1960, p. 346). Consequently, trust and trustworthiness as ways to affect conduct can be viewed as a form of social control which involves the development of shared values, beliefs, and goals so that appropriate behaviours are reinforced and rewarded (Ouchi (1979) in Das and Teng, 2001). In light of the shared discourse evident in the accounts of all levels of researchers citing the centrality of the informed consent procedure, and appeals to moral traits or characteristics such as honesty and truthfulness, it is suggested that organisations in this study practice this aspect of social control. One limitation to this

assertion is that the potential for a social desirability bias in participants' accounts of their views and experiences of research ethics cannot be excluded.

Recognising that trust and control are likely interrelated, it is recommended to consider them concurrently (Long and Sitkin, 2006), whilst seeking to retain clarity over their distinctness. Control is demonstrated through processes of regulation and monitoring to make elements of a system more predictable in pursuit of an objective organisational goal (Das and Teng, 2001). Like trust, control comes in many forms, including behavioural controls involving measures to verify a process, and output controls which rely upon reliable assessment of performance (Ouchi and Maguire, 1975). The choice of control mechanisms depends upon the degree to which the transformation process is well defined and understood, and the ability to objectively and reliably measure outputs (Eisenhardt, 1985). Participants' narratives refer to all forms of control: in monitoring informed consent such as dummy participants and phoning to check on the informed consent process behavioural controls are evidenced, and in auditable signed informed consent forms output controls are deployed. Finally, in regular case sharing or supervision meetings social and behavioural controls act to reinforce competence and goodwill trust and social control through the development of shared values, norms, and procedures or processes for collecting data.

Mechanisms of behaviour control and goodwill trust are also important to consider for their impact upon the social context of an organisation as they become institutionalised (Mollering, 2006). For behaviour control these include policies and procedures, reporting structures, and staffing and training (Sydow, 2006). Policies and procedures encompass contracts – such as role descriptions and employment contracts - which specify rules of conduct as well as rewards for pre-specified behaviour, and can become an object of learning and means to increase mutual understanding. Reporting structures refer to role specifications to identify organisational hierarchies and structures of monitoring and supervision. Finally, staffing and training are important for regulating and standardising behaviour. Goodwill trust can similarly be built through institutional bases of trust, such as appeals to professional associations and regulations – which could include ethical guidelines and regulation by ethical review boards. Appeals to external standards can be seen to increase transparency and establish an organisation in reference to disciplinary or field properties (Sydow, 2006), seen as part of the external regulation of researchers which therefore promote trust. Additionally, the routinisation of procedures and corresponding expectations can become typified and objectified as part of an organisation's identity, therefore acting as a mechanism of social control (Das and Teng, 2001; Mollering, 2006)

through the reproduction of organisational norms, procedures, and systems of reward and discipline which shape an organisations social context (Sydow, 2006). In the context of research this social control can include elements of goodwill trust, as organisations define themselves in relation to the epistemic values central to the pursuit of knowledge (Hammersley and Traianou, 2012) to improve the lives of others, irrespective of personal gain, as expressed in some researchers' narratives in this study.

Das and Teng (2001) highlight the inherently contextual nature of the influence of control mechanisms upon trust. For example, through strict process controls RAs can provide little evidence of their own competency as they must adhere to pre-established research procedures. Conversely however, through adherence to pre-established procedures a positive track record can be established (Goold and Campbell (1987) in Das and Teng, 2001), potentially engendering competence or merit trust through demonstration of reliability. It is often contended that output controls in particular can be detrimental to trust as they manifest a distrusting attitude (Pettit, 1995) and can be self-fulfilling (Gambetta, 1988). This is especially relevant to the pervasive monitoring of RAs which can lead to a myopic focus upon specific procedures and outputs, to the detriment of the development and demonstration of wider competencies and goodwill, that could act to deepen trust and enhance the development of individual researchers that practice with integrity and in accordance to norms of behaviour rather than proscribed actions (Hammersley, 2009). Furthermore, in the socially embedded research environment, an important consideration is whether process and output controls are accurate measures of RA practice, and thus trustworthiness. If not, the contention that monitoring in this context could amount to nothing more than a display of distrust seems more credible.

An important question to consider is why supervisors experience an impulse to monitor and control RAs, and what this can tell us about the role of trust and control in the context of global mental health research? This question is largely addressed by the final respondent's identification of the "responsibility to defend", as the monitoring and verification of RAs practice through process and output controls are seen as mechanisms that protect individual participants, organisational reputation, and therefore the status of the research enterprise. This responsibility can be understood in the context of wanting to promote trust in research outputs, as is suggested by an earlier respondent, the research enterprise rests upon societal support for its purpose: the generation of knowledge to benefit humans (Steneck, 2003). The societal purpose of research is only achieved through the effective operation of its constitutive parts, hence the strategic importance of the reputation of individual

organisations (Dollinger *et al.*, 1997). It is also important to note that empirical research has found that individual and organisational-level trust, whilst distinct, are highly correlated (Zaheer *et al.*, 1998). This recognises that research participants can trust in RA personal characteristics such as their sex, age, or membership of a particular ethnic or religious group; or system characteristics such as an organisational reputation (Sydow, 2006). Hence the focus of senior researchers upon the conduct of individual RAs can be understood as a concern to ensure organisational reputation is maintained through every interpersonal contact with research participants.

Here, the conscious reassertion of the basis for active trust could explain the impulse to verify the practice of RAs in the field, as to compromise this foundation could threaten the conduct of research as distrust could take root. In light of the pervasive distrust of researchers in Country 1 as a result of one study which abused participant trust, this concern is understandable. Equally, recognising that RAs are often short-term hires employed for the duration of a specific project and with little prior experience of the researcher's role, an approach that favours control over trust may reflect the reality of having little time to instil integrity and build both competence and behaviour trust in individual RAs. This challenge was emphasised by a respondent from the second country who described a study in which funders mandated research timelines, meaning RA training was curtailed, and in which an RA hired to join the team for the project falsified data. Data falsification was only considered possible due to the lack of opportunities for supervisors to observe the signs and symbols of trust through training and initial supervision where the qualities of individuals – both technical competencies and displays of goodwill – can be observed, and subsequently entrusted to conduct research ethically. It is arguable that in the context of mental health research in post-conflict environments where participants may be vulnerable due to a range of social, environmental, or individual factors (Luna, 2009; Luna and Vanderpoel, 2013; Luna, 2017), the importance of supervisors developing trust in the conduct of their RAs cannot be underemphasised.

Despite rationales for the impulse to control, theoretical and empirical literature suggest the optimal situation is a balance between control and trust (Luhmann, 1979; Das and Teng, 2001). Findings from this study suggest that the balance favours control mechanisms over those of trust, particularly in the domain of RAs' autonomous actions in the field. Recognising a trend towards increased process and outcome control via procedural ethical mechanisms, and calls to extend ethical auditing (Siriwardhana *et al.*, 2013; Siriwardhana, 2015; Sumathipala and Siribaddana, 2004), it seems important to carefully consider the

impact these may have upon situated research practice and the development of researchers who have internalised principles of ethics and integrity rather than rote application of procedures alone (Hammersley, 2006; 2009).

Considering the primary risk identified by participants, that of falsification of data and exploitation of participants, empirical literature highlights that the incidence of actions which amount to research misconduct is relatively rare (Steneck, 2006). However, the incidence of actions that fall short of misconduct but that fail to attain expected professional standards – termed questionable research practices – is more common (Steneck, 2006). Whilst Steneck (2003; 2006) does not equate integrity with research ethics as participants in this study do, his observations on responsible research conduct are relevant: “integrity in research is the product of individual behaviour, but it can also be significantly shaped or influenced by the environment in which research is undertaken.....environmental factors that encourage or discourage researchers from following best practices” (Steneck, 2003, p. s242). Therefore, the importance of trust and control mechanisms in shaping the organisational context in which individual researchers operate remain important considerations for researcher integrity, research quality, and ultimately research ethics.

In this final section we consider the implications of findings to consider how trust and control can be integrated into the everyday practice of research organisations including RA training and the promotion and monitoring of RAs’ role performance. From this, we explore how the connections between procedural and in-practice ethics can be strengthened. Findings suggest that RA training and supervision should seek to instil a moral disposition towards research ethics and researcher integrity as foundations upon which social control and competence or merit trust rely. These are further reinforced through behaviour control in clear articulation of researcher role descriptions, and the relative roles across an organisational system, including systems of monitoring and supervision. These include reference to external standards and norms such as appeals to research ethics principles and procedures, moral disposition in researcher integrity, and the professional role of a researcher.

When considering training and supervision, there is support for the approach adopted by the first country with an extended period of training (1 month) during which newly hired RAs are gradually introduced to organisational workplace procedures and where specific role-related tests are undertaken to allow time for the deepening of mutual trust (Luhmann, 1979). This training included introduction to research methods and research ethics, and engaging in a

process of contextual adaptation of research tools and instruments, including the informed consent form. This process involves a gradual introduction to the research field, and provides both supervisors and RAs an opportunity to demonstrate their skills in using key research tools and instruments whilst inviting RAs to participate as active members of the research team through their role in contextual adaptation. This approach to training demonstrates a valuing of locally-embedded RA skills and expertise, whilst developing RAs' practical role expectations and providing an opportunity to instil an empathetic stance into RAs' interactions when conducting research on mental health with communities recently exposed to conflict. It also recognises that the "ethical conduct of research ultimately depends upon the personal integrity and training of researcher(s) themselves" (Ruiz-Casares, 2014, p. 796). This opportunity is important for underpinning social control, and to demonstrate trustworthiness, goodwill, and trust responsiveness (Baier, 1986; Pettit, 1995; Buchanan, 2000) that underpin the conduct of RAs in the field.

Additionally, recognising that ethical research practice is a product of more than auditable output controls such as the signed informed consent form (Hammersley, 2009), it is suggested that embedding into supervision reflexive consideration of the enacting of research procedures in practice to discuss ethically important moments (Guillemin and Gillam, 2004) could provide an opportunity for RAs to demonstrate their knowledge and skills and therefore deepen competence or merit trust (Buchanan, 2000). This recognises the reflexivity of both trust and control, as "trust...is not naïve faith, but based upon...reflexive monitoring" (Sydow, 2006, p. 385). Therefore, whilst it is accepted that monitoring and supervision of RAs is an essential function of research organisations, our call is to ensure these efforts do not degenerate into outward signs of distrust which may demotivate RAs who feel unable to exercise their autonomy as their actions are constricted to auditable procedures. Taking a more reflexive approach allows supervision to operate as an opportunity for shared learning and responsive development of research procedures and practice in light of the situated context in which research is conducted. Furthermore, this reflexive approach sidesteps the challenge of identifying or developing process and output controls that are reliable and objective in their assessment of ethical research practice when enacted in diverse social contexts globally.

Here the overarching connection between ethical research procedures and practice, and trust and control, is brought into focus. As is evidenced in this study, research procedures act as key sites for demonstrating trust through process and output controls, such as observing enacting informed consent, or evidence via the auditable signed informed consent

form, which in turn contribute to both competence and/or merit trust in individual RAs. These process and output controls also operate at the organisational level, acting as external signs of adherence to mechanisms that promote responsible conduct of research for research participants, ERBs, research funders, and the general public. This complex interplay of procedural and in-practice ethics and forms of trust and control are embedded within the social practice of research. As an inherently social practice, the ethical conduct of research, and by extension the underpinning role of trust and control, must always be considered in relation to situated context. Recognising and learning to respond to the balance to be struck between reliance upon procedural controls and trusting in trust is important for safeguarding the rights of individual participants, the promotion of research as a career in low and middle income country settings, and the reputation of the research enterprise overall.

Conclusion

As Bok (2014) notes, “once we accept trust as the fragile source that it is, we are led to ask about the extent to which our own actions debilitate or help protect that resource” (p.446). From a research ethics perspective the role of trust and control need to be open to scrutiny for the impact they have upon ethics-in-practice. This study has explored the manifestations and implications of trust and control upon the ethical grounding of research. As has been demonstrated, at each of the interpersonal, organisational, and societal levels, trust and control operate in various forms, some of which act to promote ethical research conduct, whilst others may be stifling it. This is the key message from this study: that researchers need to be cognisant of the balance to be struck between trust and control when seeking to promote ethical research in the practice of RAs in the field. This includes accepting that trust or trustworthiness is not something that can be injected, no matter how much attention is paid to monitoring, procedures, disciplinary measures, and reward for proving trustworthy (Nooteboom (2003; p. 85) quoted in Long and Sitkin, 2006). Awareness of the roles of trust and control, and their impact upon the application of ethical research aims to promote situational awareness that unpacks the complex web of human relations that go into the production of research. This will bring forward the moral practices inherent in fieldwork, locating ethical decision-making in the situated context in which research is practiced.

References

American Anthropological Association (2012) *Principles of Professional Responsibility*. Available at: <http://ethics.americananthro.org/category/statement/>: (Accessed: 03.03.2017).

Bachmann, R. (2006) 'Trust and/or power: towards a sociological theory of organizational relationships', in Bachmann, R. and Zaheer, A. (eds.) *Handbook of trust research*. Cheltenham: Edward Elgar, pp. 393-408.

Bachmann, R. and Zaheer, A. (eds.) (2006) *Handbook of trust research*. Cheltenham: Edward Elgar.

Baier, A. (1985) 'Theory and Reflective Practices', in *Postures of the mind: essays on mind and morals*. University of Minnesota Press [electronic book]. pp. 207-227. Available at: <http://ebookcentral.proquest.com/lib/liverpool/detail.action?docID=316610>.

Baier, A. (1986) 'Trust and Antitrust', *Ethics*, 96(2), pp. 231-260.

Beauchamp, T. L. (2007) 'The 'Four Principles' Approach to Healthcare Ethics', in Ashcroft, R. E., Dawson, A., Draper, H. and McMillan, J. R. (eds.) *Principles of health care ethics*. John Wiley [electronic book], pp. 3-10. Available at: <http://onlinelibrary.wiley.com/book/10.1002/9780470510544>.

Beauchamp, T. L. and Childress, J. F. (2001) *Principles of biomedical ethics*. 5th edn. New York: Oxford University Press.

Beauchamp, T. L. and Childress, J. F. (2013) *Principles of biomedical ethics*. 7th edn. New York: Oxford University Press.

Bok, S. (1978) *Lying: moral choice in public and private life*. New York: Pantheon.

Bok, S. (1995) 'Shading the Truth in Seeking Informed Consent for Research Purposes', *Kennedy Institute of Ethics Journal*, 5(1), pp. 1-17.

Bok, S. (2014) 'Trust but verify', *Journal of Medical Ethics*, 40(7), p. 446.

Boyatzis, R. E. (1998) *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks, CA: SAGE Publications.

Buchanan, A. (2000) 'Trust in Managed Care Organizations', *Kennedy Institute of Ethics Journal*, 10(3), pp. 189-212.

Chambliss, D. F. (1993) 'Is Bioethics Irrelevant?', *Contemporary Sociology*, 25(5), pp. 649-652.

Chimento, A., Khan, M. N., Frith, L. and Rahman, A. (2016) 'Managing ethical challenges to mental health research in post-conflict settings.', *Developing World Bioethics*, 16(1), pp. 15-28.

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online pre-print, available at: <http://journals.sagepub.com/doi/abs/10.1177/1468794117730121>.

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (in preparation) 'Writing to template: researchers' perspectives of procedural ethics in mental health research in post-conflict settings', *unsubmitted*.

Clouser, K. D. and Gert, B. (1990) 'A Critique of Principlism', *Journal of Medicine and Philosophy*, 15(2), pp. 219-236.

Council for International Organisations of Medical Sciences (CIOMS) (2015) *International ethical guidelines for biomedical research involving human subjects: Draft version*. Geneva: CIOMS. [Online]. Available at: <https://cioms.ch/new-cioms-ethical-guidelines-for-health-related-research-involving-humans/>.

Curry, D., Waldman, R. and Caplan, A. (2014) *An Ethical Framework for the development and review of health research proposals involving humanitarian contexts*. [Online]. Available at: http://www.elrha.org/wp-content/uploads/2015/01/FINAL-R2HC-Ethical-Framework_Final-Report_24-January-2014_0.pdf (Accessed: 03.02.2014).

Das, T. K. and Teng, B.-S. (2001) 'Trust, Control, and Risk in Strategic Alliances: An Integrated Framework', *Organization Studies*, 22(2), pp. 251-283.

Dollinger, M. J., Golden, P. A. and Saxton, T. (1997) 'The Effect of Reputation on the Decision to Joint Venture', *Strategic Management Journal*, 18(2), pp. 127-140.

Economic and Social Research Council (2015) *Framework for Research Ethics*. Available at: <http://www.esrc.ac.uk/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015/> (Accessed: 03.03.2017).

Eisen, A. and Berry, R. M. (2002) 'The Absent Professor: Why We Don't Teach Research Ethics and What to Do about It', *American Journal of Bioethics*, 2(4), pp. 38-49.

Eisenhardt, K. M. (1985) 'Control: Organizational and Economic Approaches', *Management Science*, 31(2), pp. 134-149.

Eyal, N. (2014a) 'Informed consent, the value of trust, and hedons', *Journal of Medical Ethics*, 40(7), p. 447.

- Eyal, N. (2014b) 'Using informed consent to save trust', *Journal of Medical Ethics: Journal of the Institute of Medical Ethics*, 40(7), pp. 437-444.
- Farmer, P. and Campos, N. G. (2004) 'New malaise: bioethics and human rights in the global era', *The Journal Of Law, Medicine & Ethics: A Journal Of The American Society Of Law, Medicine & Ethics*, 32(2), pp. 243-251.
- Farmer, P., Nizeye, B., Stulac, S. and Keshavjee, S. (2006) 'Structural violence and clinical medicine', *Plos Medicine*, 3(10), pp. e449-e449.
- Gambetta, D. (1988) 'Can we trust trust?', in Gambetta, D. (ed.) *Trust: making and breaking cooperative relations*. Oxford: Basil Blackwell, pp. 213-237.
- Gargiulo, M. and Ertug, G. (2006) 'The dark side of trust', in Bachmann, R. and Zaheer, A. (eds.) *Handbook of trust research*. Cheltenham: Edward Elgar, pp. 165-186.
- Giddens, A. (1994) *Beyond left and right: the future of radical politics*. Cambridge: Polity.
- Goffman, E. (1959) *The presentation of self in everyday life*. London: Penguin.
- Good, D. (1988) 'Individuals, interpersonal relations, and trust', in Gambetta, D. (ed.) *Trust: making and breaking cooperative relations*. Oxford: Basil Blackwell, pp. 31-48.
- Green, J. and Thorogood, N. (2014) *Qualitative methods for health research*. 3rd edn. London: SAGE Publications.
- Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.
- Guillemin, M., Gillam, L., Barnard, E., Stewart, P., Walker, H. and Rosenthal, D. (2016) "'Doing Trust": How Researchers Conceptualize and Enact Trust in Their Research Practice', *Journal of Empirical Research on Human Research Ethics*, 11(4), pp. 370-381.
- Hammersley, M. (2006) 'Are ethics committees ethical?', *Qualitative Researcher*, 2, pp. 4-8.
- Hammersley, M. (2009) 'Against the ethicists: On the evils of ethical regulation', *International Journal of Social Research Methodology*, 12(3), pp. 211-225.
- Hammersley, M. (2015) 'On ethical principles for social research', *International Journal of Social Research Methodology*, 18(4), pp. 433-449.
- Hammersley, M. and Traianou, A. (2012) *Ethics in qualitative research: controversies and contexts*. SAGE Publications [electronic book].

Hardin, R. (1993) 'The street-level epistemology of trust', *Politics & Society*, 21(4), pp. 505-529.

Hedgecoe, A. M. (2012) 'Trust and regulatory organisations: The role of local knowledge and facework in research ethics review', *Social Studies of Science*, 42(5), pp. 662-683.

Hessels, L. K., Lente, H. v. and Smits, R. (2009) 'In search of relevance: the changing contract between science and society', *Science & Public Policy*, 36(5), pp. 387-401.

Horsburgh, H. J. N. (1960) 'The Ethics of Trust', *The Philosophical Quarterly*, 10(41), pp. 343-354.

Hynes, T. (2003) *The issue of 'trust' or 'mistrust' in research with refugees: choices, caveats and considerations for researchers*. Geneva: UNHCR. [Online]. Available at: <http://www.unhcr.org/3fcb5cee1.html>. (Accessed: 16.01.2014).

Johnsson, L., Eriksson, S., Helgesson, G. and Hansson, M. G. (2014) 'Making researchers moral: Why trustworthiness requires more than ethics guidelines and review', *Research Ethics*, 10(1), pp. 29-46.

Kant, I. (2012 [1785]) *Groundwork of the metaphysics of morals*. Revised edn. Edited by Gregor, M. J. and Timmermann, J. Cambridge: Cambridge University Press.

Kass, N. E., Sugarman, J., Faden, R. and Schoch-Spana, M. (1996) 'Trust: The Fragile Foundation of Contemporary Biomedical Research', *The Hastings Center Report*, 26(5), pp. 25-29.

Kerasidou, A. (2017) 'Trust me, I'm a researcher!: The role of trust in biomedical research', *Medicine, Health Care & Philosophy*, 20(1), pp. 43-50.

Kingori, P. (2013) 'Experiencing everyday ethics in context: Frontline data collectors perspectives and practices of bioethics', *Social Science & Medicine*, 98, pp. 361-370.

Kingori, P. (2015) 'The 'empty choice': A sociological examination of choosing medical research participation in resource-limited Sub-Saharan Africa', *Current Sociology*, 63(5), pp. 763-778.

Latour, B. and Woolgar, S. (1986) *Laboratory life: the construction of scientific facts*. Princeton, N.J.: Princeton University Press.

Long, C. P. and Sitkin, S. B. (2006) 'Trust in the balance: how managers integrate trust-building and task control', in Bachmann, R. and Zaheer, A. (eds.) *Handbook of trust research*. Cheltenham: Edward Elgar, pp. 87-106.

Luhmann, N. (1979) *Trust and Power: two works*. Translated by Davis, H., Raffan, J. and Rooney, K. Edited by Burns, T. and Poggi, G. Chichester: Wiley.

Luhmann, N. (1988) 'Familiarity, confidence, trust: problems and alternatives', in Gambetta, D. (ed.) *Trust: making and breaking cooperative relations*. Oxford: Basil Blackwell, pp. 94-107.

Luna, F. (2009) 'Elucidating the concept of vulnerability: layers not labels', *International Journal of Feminist Approaches to Bioethics*, 2(1), pp. 121-139.

Luna, F. (2017) 'A way forward with layers: the two step process', *Oxford Global Health and Bioethics International Conference*. Oxford, 18/07/2017.

Luna, F. and Vanderpoel, S. (2013) 'Not the usual suspects: addressing layers of vulnerability', *Bioethics*, 27(6), pp. 325-332.

Mill, J. S. (1998) *Utilitarianism*. Edited by Crisp, R. Oxford: Oxford University Press.

Miltra, A. G. and Sethi, N. (2016) *Conducting research in the context of global health emergencies: identifying key ethical and governance issues*. Available at: <http://nuffieldbioethics.org/project/workshop-research-global-health-emergencies/background-paper> (Accessed 03.03.2017).

Mollering, G. (2006) 'Trust, institutions, agency: towards a neoinstitutional theory of trust', in Bachmann, R. and Zaheer, A. (eds.) *Handbook of trust research*. Cheltenham: Edward Elgar, pp. 355-376.

O'Neill, O. (2002) *Autonomy and trust in bioethics*. Cambridge University Press [electronic book] Available at: <http://ebookcentral.proquest.com/lib/liverpool/detail.action?docID=202188>.

Ouchi, W. G. and Maguire, M. A. (1975) 'Organizational Control: Two Functions', *Administrative Science Quarterly*, 20(4), pp. 559-569.

Oxford English Dictionary (2017) *Oxford English Dictionary: definition of defend*. Available at: <https://en.oxforddictionaries.com/definition/defend>. (Accessed: 06.04.2017).

Patel, V. (2007) 'Mental health in low- and middle-income countries', *British Medical Bulletin*, 82-81(1), pp.81-96

Pels, P. (2000) 'The trickster's dilemma: ethics and the technologies of the anthropological self', in Strathern, M. (ed.) *Audit cultures: anthropological studies in accountability, ethics, and the academy*. Routledge [electronic book], pp. 135-172. Available at: <http://www.tandfebooks.com/isbn/9780203449721>.

Pettit, P. (1995) 'The Cunning of Trust', *Philosophy & Public Affairs*, 24(3), pp. 202-225.

Power, M. (1997) *The audit society: rituals of verification*. Oxford: Oxford University Press.

Rapley, T. (2007) 'Interviews', in Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative research practice*. London: SAGE Publications, pp. 15-34.

Research Councils UK (2015 [2013]) *RCUK Policy and Guidelines on Governance of Good Research Conduct*. Available at: <http://www.rcuk.ac.uk/documents/reviews/grc/rcukpolicyguidelinesgovernancegoodresearchconduct-pdf/> (Accessed: 03.03.2017).

Research for health in humanitarian crises and ELRAH (n.d.) *Funding: how R2HC works*. Available at: <http://www.elrha.org/r2hc/funding/r2hc-works/> (Accessed: 04.10.2017).

Ruiz-Casares, M. (2014) 'Research ethics in global mental health: Advancing culturally responsive mental health research', *Transcultural Psychiatry*, 51(6), pp. 790-805.

Schutz, A. (1944) 'The Stranger: An Essay in Social Psychology', *American Journal of Sociology*, 49(6), pp. 499-507.

Schutz, A. (1945) 'On multiple realities', *Philosophy and Phenomenological Research*, 5, pp. 533-576.

Schutz, A. (1967) *The phenomenology of the social world*. Evanston: Northwestern University Press.

Siriwardhana, C. (2015) 'Rethinking Vulnerability and Research: Defining the Need for a Post-Research Ethics Audit', *Asian Bioethics Review*, 7(2), pp. 188-200.

Siriwardhana, C., Adikari, A., Jayaweera, K. and Sumathipala, A. (2013) 'Ethical challenges in mental health research among internally displaced people: ethical theory and research implementation', *BMC Medical Ethics*, 14(1), pp. 13-20.

Siriwardhana, C., Lignou, S., Doherty, S. and O'Mathúna, D. P. (2017) *R2HC Ethics Framework 2.0*. [Online]. Available at: http://www.elrha.org/wp-content/uploads/2017/06/R2HC-Ethics-Framework-2.0_Introduction.pdf (Accessed: 04.10.2017).

Sumathipala, A., and Siribaddana, S. (2004) 'Revisiting "freely given informed consent" in relation to the developing world: role of an ombudsman', *The American Journal of Bioethics*, 4(3), pp.w1-w7.

Stark, L. (2013) 'Reading Trust between the Lines: 'Housekeeping Work' and Inequality in Human-Subjects Review', *Cambridge Quarterly of Healthcare Ethics*, 22(4), pp. 391-399.

Steneck, N. H. (2003) 'The Role of Professional Societies in Promoting Integrity in Research', *American Journal of Health Behavior*, 27(Supp 3), pp. s239-s247.

Steneck, N. H. (2006) 'Fostering Integrity in Research: Definitions, Current Knowledge, and Future Directions', *Science & Engineering Ethics*, 12(1), pp. 53-74.

Sydow, J. (2006) 'How can systems trust systems? A structuration perspective on trust-building in inter-organizational relations', in Bachmann, R. and Zaheer, A. (eds.) *Handbook of trust research*. Cheltenham: Edward Elgar, pp. 377-392.

The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research (1979) *Ethical Principles and Guidelines for the Protection of Human Subjects of Research (The Belmont Report)*. Department of Health and Human Services [Online]. Available at: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>. (Accessed: 12.02.2014).

Thornicroft, G. (2006) *Shunned: discrimination against people with mental illness*. Oxford: Oxford University Press.

World Bank (2017) *World Bank Country and Lending Groups*. Available at: <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups> (Accessed: 04.07.2017).

World Health Organisation (2001) *Legal Status of Traditional Medicine and Complementary/Alternative Medicine: A Worldwide Review*. New York. [Online]. Available at: <http://apps.who.int/medicinedocs/en/d/Jh2943e/> (Accessed: 04.07.2017).

World Health Organisation (2013) *Investing in mental health: evidence for action*. Geneva. [Online]. Available at:

http://apps.who.int/iris/bitstream/10665/87232/1/9789241564618_eng.pdf (Accessed: 04.06.2017).

World Health Organisation (2017) *Countries*. Available at: <http://www.who.int/countries/en/> (Accessed: 04.07.2017).

World Medical Association (2013 [1964]) *WMA Declaration of Helsinki: ethical principles for medical research involving human subjects*. Available at: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/> (Accessed: 26.02.2016).

Yamout, R. and Jabbour, S. (2010) 'Complexities of research during war: lessons from a survey conducted during the summer 2006 war in Lebanon', *Public Health Ethics*, 3(3), pp. 293-300.

Yin, R. K. (2009) *Case study research: design and methods*. 4th edn. Los Angeles, California: SAGE Publications.

Zaheer, A., McEvily, B. and Perrone, V. (1998) 'Does Trust Matter? Exploring the Effects of Interorganizational and Interpersonal Trust on Performance', *Organization Science*, 9(2), pp. 141-159.

DISCUSSION

The discussion will draw the papers and chapters presented in this thesis together through three overarching meta-themes of trust, control, and voice. These are considered both in relation to research findings, and to methodological advances made through this study. Following this, key study limitations are identified and discussed alongside methodological, ethical, and personal reflections arising from the experience of conducting this research. The discussion then draws from this study overarching recommendations for mental health research in emergency settings, encompassing methodological recommendations and suggestions for adapting or enhancing procedural and in-practice research ethics. Following this, the discussion reflects upon the potential for influencing ethical research procedures and practice in the field of mental health research in emergencies at the current time, before offering some concluding thoughts.

Overview of research

This study is the first known attempt to explore researchers' understanding and experiences of research ethics in their everyday practice of post-conflict mental health research. The literature review revealed tensions in the operationalisation of ethical research principles to practice. It is this gap in knowledge that forms the focus of this study which explores the intersection between procedural and in-practice research ethics (Guillemin and Gillam, 2004). This has been achieved through a multi-site case study (Yin, 2009) conducted with 35 researchers in three post-conflict countries in South Asia. The underpinning phenomenological epistemology (Schutz, 1944; 1945; 1967) took as the point of departure questioning the essential nature of the phenomena of research ethics as a concept. This involved viewing research ethics within a common-sense morality framework (Eyal, 2014) which sees ethics as intuitive action in the everyday lives of researchers that is given meaning through participants reflections upon their lived experiences. Consequently, the research in this thesis focussed upon the sites of practice in which ethical norms are translated from the abstract to sites of situated practice (Kingori *et al.*, 2013). The process of conducting this research has led to contributions to the methodological literature on qualitative interviewing with interpreters and via online platforms, calling attention to the voices articulating the experiences which form the foundation for research findings.

The results from this thesis advance understanding of researchers' perceptions and experiences of procedural and in-practice research ethics (Guillemin and Gillam, 2004), and the interaction between the two. Applying the framework of boundary objects (Star and Griesemer, 1989) to the involvement of multiple social worlds in the development of

procedural ethical documents, attention is called to researcher's often strategic engagement with procedural research processes (Hammersley: 2009), suggesting that overall study participants viewed procedural ethics as a control mechanism to be negotiated. The application of the boundary object framework makes explicit the inherent limitations to procedural and bureaucratic audit processes (Hogle, 1995; Power, 1997; Guta *et al.*, 2013; Heimer, 2013; Douglas-Jones, 2015) that often frustrate researchers trying to balance the multiple demands of ethics, methodology, and field practicalities. In researchers' actions in the field, the role of trust is identified as mediating the relationship between procedural and in-practice ethics. This analysis deconstructs researchers' experiences of informed consent for the underpinning mechanisms of trust and its natural antithesis: that of control, both of which are operating at the interpersonal, organisational, and societal levels (Baier, 1986; Gambetta, 1988; Bok, 1995; Pettit, 1995; Buchanan, 2000).

The research findings presented in this thesis therefore draw attention to three overarching meta-themes of trust, control, and voice. These emerge both methodologically in qualitative interviewing through interpreters and via online platforms; and in relation to findings from this research which explore the intersection between procedural and in-practice research ethics. In the next section these three analytical meta-themes are considered in a broader social context, situating findings from this study in the wider field of research conducted in humanitarian settings.

Trust, control, and voice

When considering the ethical issues inherent to post-conflict mental health research trust, control, and voice emerge in a variety of ways. For example, the question of voice – whose voice is heard and counts - arises in the dominance of the evidence-based medicine paradigm for research (Adams, 2013; Biehl and Petryna, 2013) and biomedical practice (Hogle, 1995). This dominance is overtly seen in English as the principal language of research publication (Kohrt *et al.*, 2014), used to 'speak for' other languages which are written out (Temple, 2002; Shimpuku and Norr, 2012). It is also reflected in the subscription of procedural research ethics to principlism (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; Beauchamp, 2007; Beauchamp and Childress, 2013), often reducing ethical decision-making to rote application of a hierarchy of prescriptions or proscriptions rather than facilitating a balancing of research ethics, methods, and context through deliberation upon normative principles to inform situated decision making (Hammersley, 2009; Biehl and Petryna, 2013; Hammersley, 2015).

The limited voices heard through research ethics principles and procedures point to underlying control mechanisms which suffuse medicine and research, as authoritative jurisdiction over knowledge production is defined in relation to evidence-based methods and practices (Hogle, 2002; Adams, 2013; Biehl and Petryna, 2013). Examples of control identified in the literature review and by participants in this study include control by ethical review boards (ERBs), and funder control through setting priorities for what research receives funding (Olsen *et al.*, 2003; Hammersley, 2006; Dixon-Woods *et al.*, 2007; Douglas-Jones, 2012; Heimer, 2013; Chiumento *et al.*, in preparation-b). Furthermore, based upon descriptions of research assistants (RA) training in this study, it is possible to view training as a way to control researchers approaches to knowledge generation and research practice in line with the dominant evidence-based medicine paradigm and ethical procedures that ascribe to a biomedical model (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; Adams, 2013; Beauchamp and Childress, 2013).

These broad and overarching considerations relate to the dominant epistemological stances and views regarding the conduct of science and its regulation, and are therefore connected to this study by shaping the way ethical mental health research is conceptualised procedurally and in-practice. Some of these issues are touched upon by participants in this study, notably in examples of dissonance between ERBs and researchers over the cultural acceptability of mental health assessment tools in LMIC emergency-affected settings; as well as in examples of research practice that deviate from what has been stated in procedural research documents, challenging the authority of ERB's to pre-emptively define the parameters of ethical research in situated contexts (Chiumento *et al.*, in preparation-b). Consequently, whilst researchers in this study accept the principlist framework for procedural research ethics as applicable to settings in which they work, there is simultaneously an implicit cross-cultural critique of a model of research ethics from elsewhere (Widdows, 2007) that must be locally adapted, creating its own bioethic (Kingori *et al.*, 2013). Operating alongside this is a simultaneous critique of the globalising of procedural ethical governance systems (Douglas-Jones, 2012; 2015) that continue to give priority to more powerful, and frequently Western, voices such as those of international bodies (e.g. FERCAP: see <http://www.fercap-sidcer.org/index.php>). Consequently, whilst findings from this study reject the need for an extended ethical framework that views post-conflict mental health research as exceptional, they do highlight specific ethical

considerations inherent to working cross-culturally and in emergency-affected settings which demand close attention.

As outlined in the description of each South Asian research setting (see chapter on epistemology, methodology, and ethical considerations), all countries have experienced emergencies including conflict, terrorism, and earthquakes, floods, and tsunamis. Therefore, it is reasonable to consider research findings as applicable to broader emergency contexts. It is well documented that emergency settings are suffused with relations of trust, control, and voice (Agier *et al.*, 2002; Hynes, 2003; Kennedy, 2004; O’Mathúna, 2014). This includes for example control over which emergencies receive attention and subsequent disaster relief resource allocation (Olsen *et al.*, 2003), which is in part determined by whose voices are represented / re-presented, heard, and headed (Temple, 2002; Brown *et al.*, 2004; Zwi *et al.*, 2006; Allden *et al.*, 2009; Ficklin and Jones, 2009; Wessells, 2009). It is furthermore frequently the case that populations exposed to emergencies are forced into a position of dependency (Agier *et al.*, 2002; Allden *et al.*, 2009), with providers of aid, services, and those conducting research trusted to act in their best interests. That structural conditions may prevent those delivering aid and services from acting in the best interest of recipients is recognised (Buchanan, 2000; Farmer *et al.*, 2006) – something that is also recognised in the research literature (Kass *et al.*, 1996) - suggesting that trust in many instances may be misplaced.

Consequently, research findings echo existing literature which emphasise that the socio-cultural settings in which emergencies occur frequently have their own situated dynamics that carry specific normative implications for research and clinical ethics (Sumathipala and Siribaddana, 2005). These include the additional sensitivities when working with populations exposed to events that may lead to increased vulnerability (Luna, 2009; 2017); or when asking questions about mental health which may be stigmatised (Thorncroft, 2006). These are some situated contextual factors that participants in this study identify as shaping the management of ethical issues when conducting mental health research in emergency settings. Such considerations influence a range of research actions that carry normative weight, such as controlling ethical entry into a community (Citraningtyas *et al.*, 2010), and managing how researchers present themselves (Goffman, 1959) to not be too “dominating” in order to ameliorate power dynamics between research or clinical professionals and local populations (Chimento *et al.*, in preparation-a). A procedural research action that carries normative weight is the careful selection of wording in research information and informed consent forms to satisfy the controlling demands of ERBs, whilst avoiding raising concerns

amongst local populations (Chiumento *et al.*, 2016; Chiumento *et al.*, in preparation-b). These normative considerations continue through to in-practice ethics in the importance of hiring local RA's with knowledge of local socio-cultural norms to inform the ethicality of research practices in specific contexts and with specific populations; and developing RA integrity to trust their situated ethical decision making in-line with normative frameworks underpinning a given study (Chiumento *et al.*, in preparation-a).

Consequently, a key finding from this study relates to how ethical research is constructed in relation to each project. Through procedural ethical mechanisms such as ethical review, participants in this study implicitly accept control over the remit of ethical considerations which are narrowly defined in relation to principlism (Levi, 1996; Truman, 2003; Hammersley, 2015). In developing procedural ethical boundary objects, researchers reiterate and reinforce the principlist framework in procedural documentation that represent the voice of ethics for a given project. Acting as boundary objects, study participants describe how these generalised documents adopt the lowest common denominator shared between social worlds - including those of ERBs, researchers, and funders. Meeting the lowest common denominator is achieved by researchers meeting ERB requirements through writing to template and inserting procedures that have been previously approved (Chiumento *et al.*, in preparation-b). It is also reflected in researchers' frequently failing to tailor protocols to specific populations or studies (Chiumento *et al.*, in preparation-b), choosing instead to reflect a generic, homogenised, and universalised approach to research ethics (Riessman, 2005; Miller and Boulton, 2007).

Moreover, these same boundary object documents are then translated into research training materials for research assistants to apply in the field, potentially perpetuating a 'view from nowhere' rather than contextualising and situating the ethical issues inherent to each individual study for RA's going into the field. Consequently, the procedural documentation become a control mechanism that reassert the principlist voice of procedural research ethics, and stifle the lived-experience of field research assistants whose situated ethical encounters with research participants may challenge the stability of the narrative presented in procedural documents. This tension between stability and flexibility is echoed by others, notably Strathern (2000) who states: "Ethics is a social actor frequently enrolled to justify auditing practices, yet as frequently seen as betrayed or in resistance to them" (p. 5), foregrounding the tension between procedural and in-practice ethics at the centre of this study.

Extending this tension, the construction of each research project in procedural ethical documentation appears to influence organisational audit mechanisms to evaluating ethical research conduct (Chiumento *et al.*, in preparation-a). This is reflected for example in conducting an ethical examination (C1 only), and in all countries the covert and overt observation of researcher practice. All of these involve efforts to assess research assistants practice against approved procedural documentation (Chiumento *et al.*, in preparation-b). These documents and approaches act as extensions of generalised procedural boundary objects, constructed to apply across multiple projects and to reinforce ethical *procedures* over ethical *principles* or *deliberation* for situated ethical judgements. The result is researchers' auditing what is amenable to audit (Power, 1997), perpetuating a focus upon procedures at the expense of the situated decision making that sits behind enacting procedures to practice (Truman, 2003; Hammersley, 2015).

Consequently, in contrast to narratives that identify the importance of the role of trust, the actions of researchers indicate prioritising mechanisms of control. Furthermore, these approaches replicate the epistemology underpinning evidence-based medicine centred on the verification and falsification of practice that fails to fully appreciate the social context in which procedures are operationalised (Biehl and Petryna, 2013). This is a central finding from this study: that researchers continue to ascribe to, and indeed replicate, a procedural approach to research ethics. This occurs even whilst researchers simultaneously recognise the inherent limitations to these in situated cross-cultural and emergency affected contexts, including through defiance of procedural documents approved by ERBs, and in the assertion of spheres of autonomous action when applying procedures to practice (Chiumento *et al.*, in preparation-b). This balance between control and trust was something directly experienced in the course of conducting this study with interpreters, seeking to strike a balance between providing directive instruction about qualitative research interviewing and ethical considerations, and encouraging the development of critical research skills to trust in interpreter competencies. Therefore, it is suggested that achieving the balance between trust and control is not isolated to mental health research in emergency settings, but likely to affect all research.

One potential explanation for the contradiction between demands for trust and ascription to mechanisms of control can be found in the context in which organisations are working, employing short-term RAs who often lack background research methods and research ethics training. As a result, organisations must find ways to develop the methodological and ethical competencies of RAs, whilst simultaneously upholding organisational trustworthiness

including in their research and the actions of their researchers in the field. This is managed by adopting mechanisms of control that limit the remit of research ethics to predefined and auditable actions enforced through research training and ongoing monitoring. However, research findings do suggest an openness to complementing this approach with discursive and supportive supervision that adopts a reflexive lens through which situated ethical decision making can be explored (Eckenwiler *et al.*, 2015), and through which RAs are able to demonstrate their ethical competencies, thereby gaining trust in their actions in the field.

Another explanation is in the current research climate with pressures of funding, impact, and publication metrics, researchers' strategically adopt approaches that satisfy the demands of the hands that feed, accepting the control they wield over the construction of research. Whilst acknowledged as imperfect and limited, this study has found that such strategic approaches to ethics do not lead to conduct that would be considered unethical within a principalist framework. It is suggested that to promote alternative ways of approaching the ethical issues inherent to mental health research in emergencies depends upon the actions of researchers. These could include for example extending researchers' sphere of autonomous action to insert into procedural documents information about research context, and to adapt training programmes for research assistants to instil an ethical literacy that goes beyond rote application of principles and procedures. These efforts offer avenues for change that fall within the existing structure of principalist research ethics, whilst addressing the limitations to this structure identified by participants in this study and elsewhere.

Consequently, findings from this thesis call for researchers to pro-actively reclaim control over the ethical conduct of mental health research in emergencies. This would entail an assertion of ethics that fully balances the demands of ethical principles, research methodology, and field realities which recognise the socio-cultural context, including the impact of an emergency upon socio-cultural norms and potential participant vulnerabilities. Adopting this approach will provide researchers the autonomy they require to conduct methodologically and ethically robust research to meet the mental health needs of those exposed to emergencies.

Research limitations

This study sought to explore researchers' understanding and experiences of ethics in post-conflict mental health research. There are a number of inherent limitations to consider that arise from the qualitative methodology and approach to data analysis, as well as from practical considerations. Limitations discussed here include the generalisability and

representativeness of findings – notably some potentially atypical features of the organisations participating in this study against the broader field of emergency mental health research. Also discussed are limitations to the methodological approach to addressing research rigor and therefore reliability, and practical limitations of research resources and timelines. This discussion is intended to complement earlier discussions of research limitations in methodological papers (Chiumento *et al.*, 2017; Chiumento *et al.*, 2018) and chapters on epistemology, methodology, and ethical considerations (hereafter “epistemology chapter”), and data analysis.

Regarding the generalisability and representativeness of research findings, it is important to emphasise that the aim of this study was to draw plausible interpretations of research participants’ views and experiences of research ethics, grounded in their narratives. Given the exploratory nature of the study this was achieved through adopting a qualitative methodology that allows participant’s a high degree of control to identify and explore facets of the phenomena of interest (Frith and Gleeson, 2012), and allows the researcher an opportunity to probe to encourage additional detail, depth and vividness to participants’ responses (Rubin and Rubin, 2005). Adopting a multiple-case study approach aims to identify converging thematic categories (Yin, 2009; Silverman, 2013), underpinned by a phenomenological epistemology that seeks to uncover generalizable typologies (Schutz, 1975). In this process, efforts have been made to faithfully represent and interpret the reality of research participants day-to-day experience of ethics as these were expressed and represented in qualitative interviews (Silverman, 2013). This was extended through data analysis driven by comparisons to facilitate the identification of regularities and exceptions through which typologies are built for further comparison against existing literature and theoretical models (Green and Thorogood, 2014).

Considering the representativeness of organisations involved in this study, they notably exclude governmental, inter-governmental, and non-governmental humanitarian aid organisations engaged in the conduct of mental health research in emergencies. Such organisations include National Militaries, United National (UN) agencies e.g. the World Health Organisation or International Organisation for Migration, and international non-governmental organisations targeting emergency relief for example Medicines Sans Frontieres. Although the non-governmental organisations involved in this research often worked in partnership with these humanitarian aid or UN agencies, not speaking directly to researchers and practitioners at these organisations is a study limitation. Replication of this study with these organisations is recommended to see if the nature of organisational types

influences researchers understanding and experiences of ethics – in particular the prioritisation of ethical principles which could be anticipated to vary for those approaching research in emergencies from a humanitarian lens. Additionally, whilst a range of participants were included in this study, there are other important stakeholders in the field of research ethics in post-conflict mental health research – notably ethical review boards, funders, and research participants – whose views were not sought. Reasons for this include that there is an existing body of research with ERB members (Douglas-Jones, 2012; Hedgecoe, 2012), and research participants (Kass *et al.*, 1996; Swan and Collins, 2008). Therefore, this research sought to address the gap in existing literature by focusing upon the views of researchers themselves, building upon initial studies in this area (Kingori, 2013; Boulanger, 2015; Guillemin *et al.*, 2016).

By replicating the study across multiple sites, triangulating findings across multiple categories of respondents (primary investigators, field coordinators, and research assistants), and engaging in respondent validation, efforts have been made to ensure that findings resonate for a range of settings and researchers. However, it remains possible that respondents in this study have displayed social desirability (Green and Thorogood, 2014) when being asked about research ethics, for example due to fear of organisational or personal reputational harm. Whilst the possibility that the organisations in this study were atypical and therefore unrepresentative, and that participants' responses contained a social desirability bias cannot be ruled out, it is important to note the degree of convergence of research participant's views within this study and in relation to wider literature that suggest these are unlikely. A further possible check on these biases has been undertaken through respondent validation (Green and Thorogood, 2014), presenting study findings to research participants and other researchers at organisations involved in this study as well as to the wider public e.g. informally at data analysis sessions or with supervisors and colleagues, and at external conferences. In these interactions comments have been made regarding the extent to which findings resonate with the experiences of those working in the field of global mental health broadly, and emergency (mental) health research specifically.

Methodologically a number of steps were taken to enhance the rigor of findings, as discussed in the data analysis chapter and relevant methodological papers (Chiumento *et al.*, 2017; Chiumento *et al.*, 2018). A key limitation to the approach to data analysis is that analysis was driven by one coder alone, leaving open the possibility that other interpretations of the data have been missed (Boyatzis, 1998). However, the involvement of interpreters and transcribers in initial thematic analysis (Chiumento *et al.*, 2017), as well as sharing raw data

with supervisors and in the data analysis group, did ensure a check on the validity of interpretations of the data. An additional consideration is that reflexive engagement with the data was encouraged by the data analysis group, suggesting that my ethical experiences of conducting this study could be used as a reflexive device to explore research findings autobiographically. Furthermore, it is recognised that the nature of the research topic and data produced are highly amenable to empirical ethical analysis³⁶. Both of these approaches to data analysis present avenues for future research, and offer an opportunity to further explore the richness of the data to confirm findings presented here or suggest additional interpretations of participants' narratives.

An added consideration in this study reported via peer-review publications is the limitations inherent to this form of research reporting. In all peer-reviewed research publications efforts were made to transparently and fully explain and discuss research epistemology, methodology, and approaches to data analysis. However, given the inherent limitations of strict guidelines on word counts, these are always somewhat limited. By addressing complex methodological questions separately as standalone methodological papers, attempts were made to give the important questions of *how* research is conducted the attention they deserve. Moreover, this thesis presents an in-depth exploration of the epistemological and methodological considerations pertaining to this research, and how these were managed, complementing briefer explanations in peer-review papers.

In writing-up research findings for peer-review publications efforts have been made to avoid anecdotalism by presenting extended quotations that clearly illustrate each theme, and to report generalizable themes alongside diverging views. The validity of inferences made from the data was aided by triangulation in data analysis through the engagement of interpreters and transcribers in initial deductive analysis (Chiumento *et al.*, 2017); participant validation of findings (Green and Thorogood, 2014); sharing data extracts with colleagues at data analysis sessions; sharing summaries, mappings, or data extracts with supervisors; and the co-production of research publications with both co-authors and anonymous journal reviewers. Here the peer-review journal publications' anonymous review process presented an important opportunity not only to highlight potential research weaknesses, tighten up writing, and ensure coherence and consistency in research reporting; but also acted as an

³⁶ Examples of such methodologies include reflective equilibrium (van der Burg and van Willigenburg, 1998); Integrated Empirical Ethics (Molewijk *et al.*, 2004); Symbiotic empirical ethics (Frith, 2012); Pragmatic hermeneutics (Widdershoven, Abma and Molewijk, 2009); or Critical Bioethics (Hedgecoe, 2004)

important driver to challenging conceptual clarity in writing and to identify research implications at every stage. Therefore, whilst limited in format and length, the process of research reporting via peer-review publications is felt to have enhanced the study conduct and reporting overall, whilst making timely contributions to the existing research literature.

All research will face practical limitations, for example due to funding body criteria, publisher criteria, and resources such as time and money, and this study was no exception. A central practical limitation is that researchers' experiences of applying ethical principles to practice were accessed via interviews and not via direct observation. Whilst limited, the interview approach was deemed more feasible, recognising the practical and ethical complexities of conducting participant observation via an interpreter. This presents an area of future research to be undertaken by a local investigator who possesses the necessary methodological and linguistic skills. Equally however, it is important to note that this ethnographic approach is not without its own limitations, chiefly the influence of the observing researcher upon the conduct of those being observed (Silverman, 2013). Furthermore, as a result of short periods of time in-country for field trips the research was dependent upon the availability of research participants when the researcher was in-country. This limitation is unavoidable, and it is felt efforts made to ensure sufficient time to undertake travel to reach participants and successfully complete all research activities were sufficient in addressing this potential research limitation. Equally, the limited duration in-country may also have influenced the approach to interview interpreting which adopted a pragmatic approach to working with lay-interpreters (Chiumento *et al.*, 2017). It is however contended that this approach remains closer to the lived reality of global mental health research in emergencies which involve project-specific employment. Furthermore, in adopting this approach methodological contributions have been made upon which others can build.

This section has sought to transparently discuss some central limitations to this study, complementing earlier discussions, and where appropriate identifying why these limitation are deemed acceptable, how these limitations were managed, or suggesting avenues for future research.

Research reflections

To complement the above discussion, this section will reflect upon my personal positionality in relation to the research topic and social setting in which research was conducted; the methodological, theoretical, and functional approach to research; and reflect upon the

ethical grounding of this study and the reflexive impact of studying a process I was simultaneously experiencing. The aim of adopting a reflective stance towards these aspects of research is not to engage in a confessional dialogue, but to critically and transparently consider the impact of my (changing) positionality upon the research (Ritchie *et al.*, 2009), complementing similar discussions in the epistemology chapter. Such reflections are particularly relevant in a study driven by an underpinning phenomenological epistemology, as Schutz emphasises the importance of researcher detachment from their taken-for-granted biography to adapt to “being in a scientific situation” (Schutz, 1975, p. 276). This recognises that “to orient oneself to a phenomenon always implies a particular interest, station, or vantage point in life” (van Manen, 1990, p. 40), and that by rendering explicit research experiences the impact of the researcher’s role as an actor in the research process is rendered transparent (Emerson *et al.*, 1995; Spencer and Richie, 2012).

Personal positionality

As discussed in the epistemology chapter, my gender and social positions acted as a facilitator of research, allowing me to access males and females equally, and enabling open conversations about topics that may have been closed to local researchers – such as expressing a critical stance towards cultural and gender norms. However, due to my inherently “western” upbringing which has shaped a liberal attitude towards societal expectations of gender and social roles, my appreciation of the position of those who participated in this research could only ever be partial (MacKenzie, 2016). Furthermore, my perpetual “outsider” status to the world of mental health research in emergency settings, having never directly conducted any such studies, was both a strength in facilitating detachment from pre-existing understanding and take-for-granted assumptions, and a weakness by limiting full appreciation of the experiences of research participants. On balance however, in the context of the phenomenological epistemology the research interviews allowed me to adopt a position of estrangement to explore the research topic through the eyes and experiences of research participants who offered me their observations and experiences through which typologies could be built. Therefore, from an epistemological and methodological point of view this approach enables social science theorising (Haimes, 2002).

Relating to disciplinary positionality during data analysis, as a result of my inter-disciplinary background one challenge was to prevent an infinite ping-pong of potential avenues to explore from varying political, sociological, and philosophical perspectives. To focus my attention upon specific facets of key themes emerging from the data the opportunity to

discuss data extracts or mapping of findings with supervisors and the data analysis group was invaluable. From here I was able to re-capitalise upon my interdisciplinary stance to integrate multiple spheres of literature to analyse and explain research findings. This process has emphasised the importance of collaborative working to ensure clarity of research findings, a process that was enhanced through the experience of writing peer-review publications.

Methodological, theoretical, and functional reflections

Due to my personal positionality - including my Western nationality and professional status facilitating access to people and conversations - at no point did I gain any direct experience of the social or gender norms given high ethical priority by my research participants. This at times led to a barrier between myself and my research participants, who could become visibly frustrated by my requests for aspects of the taken-for-granted social or cultural milieu to be spelled out. Equally, forcing explicit explanation of social and cultural context can be seen as a research strength to protect against assumptions by the researcher, interpreter, or those being interviewed. In interviews where participants became frustrated by what I perceived as my lack of local cultural knowledge, it is possible I would be less likely to probe for detail and instead rely upon explanations from previous interviews or interactions, or speak with later interviewees to explore aspects I remained unclear about. This hesitance to ask for additional detail from some interviewees may in part have been driven by participants' projection of my "expert" status which in some interviews it was difficult to move away from – particularly where there was a language barrier; as well as a desire to keep interviewees motivated to answer subsequent questions. Equally however, due to the multiple categories of researcher and varying degrees of (in)formality in my relationship with participants, it was always possible to explore specific facets of cultural or gender norms in subsequent interviews or with interpreters. Therefore, overall it is felt the research methodology allowed an appropriate level of opportunities to fully appreciate the socio-cultural context in each country, whilst also ensuring individual research participants were not overburdened by requests for explanations of socio-cultural norms which could be gained in subsequent interviews or from interpreters.

A final challenge when conducting interviews was accepting the imperfections in my own position vis-à-vis procedural and in-practice research ethics, including the limitations to my approaches to enhance ethical research conduct. Notably in earlier interviews my thinking in relation to the research topic was driven by a procedural approach against which I found the lived experiences of participants challenging. Over time however I learnt that it was

helpful to have participants contest my thinking, and for me to question theirs. It is through these discussions that the socially-embedded nature of research ethics which requires adaptable procedures that prioritise the social-context in which ethical research is practiced was highlighted. This evolution in understanding and thinking correlates with the phenomenological approach to the study in which “what seems to be of highest relevance on one level may become entirely irrelevant on the other” (Schutz, 1975, p. 276), encouraging the researchers received understanding of a problem to be challenged through exposure to the lived-experience of participants. This process was actively complemented by my own lived-experience of research ethics of this project (discussed below), which further brought to the fore the messy complexity of what “ethical research” entails in any given setting. These experiences during data collection were retained in data analysis and were identifiable in the literature, strengthening my emphasis upon the socially-embedded features of research ethics in post-conflict mental health research, and indeed all research.

Ethical reflections

This section builds upon initial discussion of ethical reflections in the epistemology chapter by reflecting upon how ethical issues were managed in this study, and by reflexively unpacking the impact of conducting research that explores a topic I was simultaneously experiencing.

In this study only one potential participant declined to be involved in the research at the consent stage, providing no reason for their refusal. During research it is important to note that no participants or interpreters reported experiencing distress as a result of interview questions or procedures. A couple of interview participants did identify a degree of moral uncertainty as a result of identifying and reflecting upon their practice, questioning the ethicality of their own actions in the field. However, for no participants did this amount to a distressing experience, and their uncertainty was attributed by participants to this being the first opportunity they had had to actively and critically reflect upon and analyse their own practice. Indeed, many participants volunteered at the end of interviews that they had found the experience beneficial and they could see the potential for having facilitated discussions with similar questions to those in the interview as part of routine supervision to stimulate consideration of the specific ethical aspects of their day-to-day research conduct.

My experiences of procedural ethical review are worth briefly discussing for the insight they provided into in-country review procedures and multiple-levels of ethical review, and therefore for the extent to which they equipped me to conduct this study. The approach to

multi-site review that I adopted involved developing one core protocol which was submitted to all ethical review boards (ERBs) alongside each ERB's own template application form. This aimed to ensure consistency in the information provided to each ERB, despite differences in the questions posed in each ERB's form. Completing the ERB forms in itself provided insight into the prioritisation of ethical principles in each country (Hyder *et al.*, 2004), for example in C1 there were specific questions about the benefit of the study to the national organisation involved; in C2 a bureaucratic focus was evident in their request for a certain number of printed copies of the application form; and in C3 a request was made to develop a referral pathway for responding to potential participant or interpreter distress. After initial submission each ERB requested further information or clarification, including questions that suggested what each ERB perceived as core ethical issues – for example a focus upon participant vulnerability (C3) or upon the translation of informed consent materials (C2) – as well as suggesting the potential degrees of familiarity and capacity of each ERB when it came to reviewing qualitative research.

A central challenge to multi-site ethical approval was the progression of in-country and UK institutional review procedures (Israel and Hay, 2006). This was particularly evident in C2, where the national ERB required UK institutional approval prior to in-country review, whilst the UK institutional procedure requires in-country approval before conducting their review and providing overall approval. This process was managed by obtaining UK institutional *pre-approval*³⁷ which was acceptable for the in-country ERB to proceed with their review. All of these experiences were beneficial when conducting interviews with study participants, drawing upon shared experiences of in-country ERB processes, as well as the challenges of multi-site review. These discussions highlighted the pragmatism of researchers who encounter these challenges in their day-to-day work, adopting a stance towards procedural ethical mechanisms that prioritised obtaining approval to enable the research to be conducted. These discussions, alongside my own experiences, encouraged my stance on the management of ethical issues in research to embrace pragmatism and a fluid approach. Notable was the recognition that the ethicality of a given project and action was premised not upon adherence to mechanisms of procedural bureaucracy, but on complex social interactions and situated dynamics that shape ethically responsive research designs and the subsequent application of ethical principles to practice.

³⁷ Also known as “approval in principle”. This confirms the intention to fully review the proposed study in line with institutional procedures.

Considering in-practice ethics, as identified above, there were instances where I felt challenged by participant's at times exasperated explanation of the situated context in which they were working, or their rebuttal of ideas I had for how the management of ethics could be enhanced. Equally, research participants would also ask for my "expert" opinion about how to manage specific ethical issues that had arisen in their practice, or if their management of a specific ethical dilemma had been "correct". These conversations opened-up the study focus upon in-practice ethics, continually challenging both my and the participants' approaches to ethical issues encountered in day-to-day practice light of the situated context in which participants work. Through this reorientation my focus shifted from an initial stance which adopted a universalistic "view from nowhere" – as encapsulated in principlisms procedural approaches to ethics – to foreground the situated context in which ethics is practiced.

Equally, as a result of bringing a focus to each organisations management of research ethics, attention was drawn to their own procedures and practice. Insights from interviews and informal discussions led to organisations working to update procedures such as research training, or to suggest approaches they could incorporate into their organisational practice such as RA supervision. These all recognised the value in increasing the space for the discussion of everyday ethical issues, facilitating ongoing evolution of the ethical literacy of individuals and organisations. Seeing this commitment to search for ways to enhance the management of ethical issues was particularly rewarding, and strengthened my own commitment to supporting this process with partner organisations.

In summary, my journey through the conduct of this research has both challenged and enriched my approach to procedural and in-practice research ethics that arise in the complex situated practice of post-conflict mental health research. In every research step from developing the research design and methodology, to ethical approval processes, to encounters with participants or interpreters, I was actively learning about the topic I was simultaneously studying. These in turn shaped my approach to research conduct, data analysis, and the recommendations that have emerged from this research.

Research recommendations and future research directions

The papers in this thesis have presented recommendations specific to each. Rather than repeat these, this section will draw together overarching recommendations relating to ethical mental health research in post-conflict settings, and will not discuss the methodological recommendations that have already been detailed (see Chiumento *et al.*,

2017; Chiumento *et al.*, 2018). This section will revisit the empirical ethical reflection model outlined in Chiumento *et al.* (2016), before considering recommendations to enhance ethical procedures, and finally address recommendations to strengthen ethics-in-practice. For each recommendation the relative strengths and limitations are raised, complemented by discussion in the section that follows which considers the potential for implementing a few of the recommendations in the current socio-political-historical context.

In Chiumento *et al.* (2016) recommendations were made for conducting empirical ethical reflection to strengthen the ethical grounding of research. This reflective process that addresses both procedural and in-practice ethics remains relevant and applicable in light of the findings from this study. Furthermore, wider literature include similar proposals, such as that of Eckenwiler *et al.* (2015) who foreground the importance of an ongoing, iterative, and circular reflexive stance for researchers and ERBs, encapsulated in a “real-time responsiveness” approach. Here the concept of responsiveness entails self-critical attention to the moral features inherent to engagement with communities through research (Eckenwiler *et al.*, 2015, p. 656). Integrating responsiveness to ethical issues as and when they arise and in collaboration with ERB’s represents an extension of the empirical ethical reflection approach outlined in Chiumento *et al.* (2016). This extension correlates with research findings which draw attention to the situated moral experiences of frontline data collectors, doing so through enhanced attentiveness to the development of researchers’ ethical capacities (Eckenwiler *et al.*, 2015, p. 659). Moreover, the “real-time responsiveness” approach attends to the breadth of ethical considerations that may arise and that frequently extend beyond the pre-defined scope of principalist procedural ethical frameworks, and may be contextually related to the features of a specific emergency. Attending to the breadth of ethical considerations is in line with the proposed model for empirical ethical reflection which seeks to act as a tool to develop new approaches to ethical evaluation of emergency research that recognises the agency and contributions to be made by researchers, communities being researched, ERBs, and research funders (Chiumento *et al.*, 2016; in preparation-b). As discussed below, many of the challenges facing these approaches are embedded within the circumscribed remit of ERBs, and the inherent practical challenges to developing spaces for the co-production of ethical norms of specific research proposals between parties (researcher’s, ERB’s, funders, and local communities) who often have diverging interests and varying strengths of voices to be heard.

Procedurally streamlining multi-site ethical review is recognised as a challenge to be negotiated by researchers (Israel and Hay, 2006; Barchi *et al.*, 2014; Chiumento *et al.*, 2017;

Chiumento *et al.*, in preparation-b). Findings from this study suggest the importance of in-country review for addressing ethical issues that arise in the specific socio-historical-cultural context in which a study is to be conducted; and international review for scientific expertise and familiarity with research methodologies. Therefore, findings from this study correlate with the widely accepted view that both levels of review are relevant and important for comprehensively assessing the ethical issues inherent to a given study (Hyder *et al.*, 2004; Barchi *et al.*, 2014). However, it has been highlighted that this process requires mechanisms to balance feedback from multiple ERBs that doesn't leave researchers in a "double bind" (Zwi *et al.*, 2006), or enforce compliance to one ERB's pre- or pro-scriptions. Here findings from this study suggest that it would be useful to develop a process whereby each ERB has a circumscribed remit to review, based upon their expertise. Drawing from the findings in this study, this could for example involve the in-country ERB assessing the contextual appropriateness of the research question to a particular population, and the cultural appropriateness of proposed interview questions or research instruments; whilst the international or funder ERB assess the scientific validity of the research design and analysis procedures. To achieve differential review remits would require agreement over the relative review scope for each ERB in advance of review and likely requiring negotiation on a project-by-project basis. It also requires that the division of labour ensures that the ethical aspects of a study are comprehensively reviewed, without leading to duplication or worse, contradictory feedback that the researcher must then negotiate.

International guidelines already promote collaboration in multi-site review - such as harmonizing review procedures, deferring responsibility to one ERB, or establishing ERB committees with representation from funder and host countries (World Health Organisation (WHO), 2000; United Nations Educational Scientific and Cultural Organization (UNESCO), 2005; Council for International Organisations of Medical Sciences (CIOMS), 2016). Others have emphasised the need to streamline procedures and increase flexibility to ensure timeliness of review of research conducted in emergencies, including via a fast-track review (World Health Organisation (WHO), 2010) or a central ERB to assess all proposed research for a given country (Siriwardhana *et al.*, 2012). With regards review procedures that are specific to research conducted in emergencies, some operational organisations such as Medicines Sans Frontieres have established their own review procedures in recognition of the volume of studies being conducted and to ensure reviews still occur in settings where ERBs may not exist (Ford *et al.*, 2009; Schopper *et al.*, 2009). However, such instances are rare, and most organisations continue to need to navigate international and national review

systems as appropriate. To manage multiple levels of review, Ng *et al.* (2015) recommend that the in-country ERB coordinate all reviewing ERBs, arguing that the in-country ERB are best placed to provide oversight because of their contextual knowledge. This recognises that: “[t]he additional administrative burden research teams face to meet the requirements of [ERB’s] might, paradoxically, reduce the time and attention given to the execution of research projects, weakening ethical oversight” (Ng *et al.*, 2015, p. e516). Whilst important suggestions, to have an in-country ERB take responsibility for coordinating review faces obstacles such as the ERBs capacity to manage the additional administrative burden, especially where the ERB is based in a low and middle income country; and sponsor country ERBs (frequently based in high-income countries) accepting deferral of ethical oversight. It has been documented that ERBs in sponsor countries may be unwilling to cede oversight to LMIC’s whose skills and expertise may not be appreciated (Barchi *et al.*, 2014). Furthermore, ceding oversight would require acceptance that the ERB coordinating review may differentially interpret and apply ethical principles (Ramcharan and Cutcliffe, 2001) and ethical guidelines (Emanuel *et al.*, 2004; Gold and Dewa, 2005; Menikoff, 2010). This may be a particular obstacle in settings where ethical review entails aspects of organisational risk and reputational management.

Furthermore, the proposal from Eckenwiler *et al.* (2015) focussing upon the ethical specificities of emergency research advocates for “real-time responsiveness” (p. 656) which seeks to address the shortcomings of the pre-emptive ethical predictability of protocols for researchers and ERB members alike. They argue that the ethical specificities of emergency research require of researcher’s and ERB’s a “particular sort of ongoing critical engagement” (p.656), advocating for a “sustained, iterative, and cyclical” (p. 656) engagement with ethical review that facilitates identifying and addressing ethical issues as they emerge. Whilst addressing the limitations of pre-emptive review, familiar challenges to this proposal are that it is resource intensive, will often necessitate the coordination of multiple ERBs, and requires redefinition of the ERB/researcher relationship, particularly in settings where ethical review can be more akin to institutional risk management.

Consequently, whilst proposals to enhance and streamline multi-site review are available, what seems to be lacking is their translation into routine practice through efforts to address potential administrative and jurisdictional barriers. It is recommended that efforts to explore the potential alternatives outlined here are complemented by research to evaluate the effectiveness of each proposed solution. This is critical for ensuring a revised procedure addresses rather than adds to the limitations of the current system. As has been

acknowledged, ERB's face their own structural pressures (Guta *et al.*, 2013), and solutions are unlikely to come as a one-size-fits-all, necessitating approaches that address each opportunity for multi-site ERB collaboration as they arise (Hyder *et al.*, 2004; Barchi *et al.*, 2014).

Regarding a more contextualised and active ethical review process, suggestions from this study include revising ERB forms to require contextual information about the situated setting in which research principles are to be applied, moving away from writing to template (Chiumento *et al.*, in preparation-b). Another suggestion is to have face-to-face interaction between ERB's and researcher's, offering an opportunity to appreciate the research context and the skills and experience of the research team to manage potential ethical issues – recommended to include plans for researcher training and supervision, with a focus upon support to foster critical ethical thinking to respond to ethical issues that may arise in the field. Given the global locations of research conducted in post-conflict or other humanitarian settings, adjustment to include face-to-face interactions in ERB procedures would need to incorporate the use of technological solutions such as online voice calling platforms or conference calling facilities where internet infrastructure may not be strong enough. Further research is recommended here to explore different approaches to integrating contextual information into ERB protocol templates, and to the addition of face-to-face interactions between researcher's and ERBs, assessing the impact these have upon the ethical assessment of proposed research as well as upon the levels of connection between researchers and ERBs, and between research protocols and subsequent in-practice application of ethics in the field.

It is felt that the proposed procedural ethical recommendations discussed here seek to address the fundamental disconnect between ERBs and researchers through anticipatory regulation that frustrate the purpose of procedural ethics. Moreover, by addressing shortcomings to ethical review processes to support the establishment of research on a grounding that accurately reflects the situated contextual realities that a study will face, it is anticipated that researchers will be better equipped to face the in-practice ethical issues that arise during study conduct (Truman, 2003; Guillemin and Gillam, 2004; Hammersley, 2009).

The central recommendations relating to in-practice research ethics orient around clarifying researcher role's and career paths, and enhancing researcher training and supervision – from research assistant training to the continuing professional development of senior researchers. To clarify researcher role's and career paths involves actions at an organisational level,

including planning an organisational hierarchy with defined oversight mechanisms, reporting structures, and career progression opportunities. Additional clarification of job descriptions could also be beneficial for allowing researcher's to conduct activities in line with the requirements of their role, increasing the likelihood of reward and opportunities for deepening trust in role performance between individual researchers and their organisation (Luhmann, 1979; Das and Teng, 2001). Equally, clearly specified role boundaries defining actions amounting to misconduct and the repercussions for such conduct are important and should be consistently enforced. Finally, senior staff at organisations should remain cognisant of their status as role-models and be supported to act in line with norms underpinning the research profession (Steneck, 2006; Hammersley and Traianou, 2012) which include for example honesty and integrity, practicing with due care and diligence, prioritising the rights of research participants, transparently reporting findings, acknowledging contributions of co-workers, and so on.

Due to the reality of research assistants working as short-term hires in emergency settings the need to develop research training with an integrated research ethics component that is short and accessible to those for whom technical ethical and research terminology may not be familiar is a high priority. This study and others suggest that the research methods content – the *how* of research – is clearly articulated in existing researcher training (Eisen and Berry, 2002; Chiumento *et al.*, in preparation-a). To complement this an ethical component of training that moves away from prescriptive approaches that may stifle moral judgement (Israel and Hay, 2006) is required as an integrated aspect of researcher training. Eisen and Berry (2002) suggest that the content of this could include: an introduction to professional ethical norms, an overview of basic forms of ethical reasoning (for example introducing deontological and utilitarian approaches to ethical decision making), and approaches to assessing the social value of research. This content should address specific considerations relating to mental health which was found in this study to augment ethical considerations (Chiumento *et al.*, in preparation-b), and ensure contextualisation of ethical principles, particularly following emergencies where pre-existing social norms may be disrupted, thereby avoiding the dangers of assuming ethical homogeneity (Riessman, 2005). The format of such training would require a mix of taught materials, self-directed learning, and discussion sessions structured around case studies to stimulate assessment of the ethicality of different actions.

Training would be greatly enhanced through drawing upon the direct experiences of research organisations, using experience as a pedagogical tool (Harper, 2007; Yamout and

Jabbour, 2010), which also embeds the concept of learning from experience, thereby supporting ongoing supervision. Within this there is the potential to develop some components of training as online modules. These could be developed by relevant standard-setting international organisations – for example by the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergencies – and hosted on an access platforms (e.g. www.mspss.net). It is important to emphasise that such online training should always be complemented by context specific training, ensuring that ethical decision-making is considered in the situated socio-historical-cultural context in which a study is to be conducted and ethical principles are to be operationalised. Therefore, online modules would only enhance classroom teaching, and not replace it as a standalone activity.

Concerning the continuing professional development of senior researchers it is suggested that by acting as facilitators for researcher training and supervision their ethical knowledge and competencies will continue to be exercised. Additionally, senior researchers should make adjustments to their supervision of RAs to ensure ethical issues that arise in the day-to-day conduct of field RAs are identified as ethical rather than practical issues, and include opportunities to discuss and resolve challenges faced. Reflections from research participants in this study suggest that asking open questions of the sort used in interviews in this study are an appropriate catalyst for ethical reflection and discussion (see Appendix 2). Importantly, by foregrounding ethical discussions in supervision, it is anticipated that ethical considerations will become part of a natural research discourse rather than viewed as a discrete step that is addressed at the research outset alone.

Considering the potential for change

This section will briefly reflect upon the potential for key recommendations arising from this research be enacted at this point in time. This assessment is not intended to be exhaustive, but to highlight central considerations acting as barriers or facilitators to the uptake of research recommendations. This will first consider this process of change in the field of qualitative research methods; and will then assess the current system of procedural ethics and opportunities for reform, before finally reflecting upon adapting approaches to researcher training to promote in-practice ethics.

As Silverman (2011) has emphasised, true learning is based upon doing. This applies to research methods as well as research outcomes. Qualitative research encompasses a wide range of data gathering methods, tools and techniques which are built upon a complex range of methodological approaches and disciplinary orientations that draw upon the

epistemologies, discourses, and conceptual frameworks of the human and social sciences (Smith, 1998). Given this breadth it is unsurprising that the methods for conducting qualitative research are continually evolving, notable currently in methodological advances in response to new technologies. This continual evolution is evident in multiple editions of qualitative research methods textbooks, and in methodological works focused upon specific settings such as internet research (Hewson *et al.*, 2003) or research in emergencies (Norris *et al.*, 2006; Le and Lê, 2013). By making contributions to this broad methodological literature - through this study specifically addressing the methodological complexities of interviewing with interpreters and conducting interviews online - the experiences and recommendations from this research become available to other researchers. This is not to say that these should be uncritically accepted. Indeed in the methodological papers it is made explicit that any recommendations are provisional and should be tested and refined (Chiumento *et al.*, 2017; Chiumento *et al.*, 2018), such as is evident in existing literature which includes examples of methodological recommendations being open to scrutiny and rebuttal (see e.g. Squires, 2009; Croot *et al.*, 2011). Therefore, recognising the active critical engagement of qualitative researchers with the continual evolution of qualitative research methods, it is anticipated that the methodological contributions from this study will be built upon in the future.

Systems for procedural research ethics derive from a specific geopolitical and historical context (Beecher, 1966; Becker, 2005) that shaped the content of international guidelines (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979; World Medical Association, 2013 [1964]). From these initial pronouncements, procedural research ethics has evolved in line with the principlist model of bioethics (The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research, 1979), which adheres to an inherently medicalised model of research ethics (Beauchamp, 2007; Beauchamp and Childress, 2013). Implicit in this framework is the rational, individualised, and modernist research participant (Miller and Bell, 2002; Riessman, 2005), a concept critiqued for entailing an inherent western bias (Hoeyer *et al.*, 2005; Swift, 2006; Widdows, 2007). Whilst amenable to procedural research ethics structures as a result of its claim to universality (Emanuel *et al.*, 2004), simplicity in standardising and homogenising ethical conduct across settings (Petryna, 2005; Douglas-Jones, 2012; Douglas-Jones, 2015), and amenability to audit cultures (Strathern, 2000); there is also recognition of the inherent limitations to principlism (Hammersley, 2006; Israel and Hay, 2006; Hammersley, 2009; Douglas-Jones, 2015; Chiumento *et al.*, in preparation-b),

particularly its inability to respond to evolving social science or ethnographic research (Pels, 2000; Miller and Boulton, 2007). Despite limitations, this model of ethical research oversight has become globally embedded (Douglas-Jones: 2015). Against this geopolitical-historical backdrop all of the recommendations to improve procedural research ethics face obstacles to implementation.

As discussed above in relation to multi-site ethical review procedures, practical challenges such as the administrative burden and procedures for ceding review to another ERB must be overcome for multi-site ethical review to be streamlined. Of the barriers identified, differential interpretation of ethical principles and guidelines are the only ones that relates to *ethical* considerations, with all others being a product of administrative and bureaucratic systems of institutional governance and jurisdiction. That existing systems, procedures, policies, and laws would have to be negotiated and potentially amended in order to accommodate multi-site review presents a significant, but not insurmountable, barrier to change. Currently both my experiences of conducting this research and findings from this study suggest that translation of any of the recommendations to streamline multi-site ethical review or introduce special mechanisms for review of research protocols to be implemented in emergency settings into practice is lacking. Given the increasing numbers of studies conducted in such settings, this is an area for attention by ERBs, researchers, and funders globally.

As in this study, the majority of organisations conducting mental health research in emergency settings are often dependent upon negotiating existing procedural ethics structures which cater to all research conducted in a country, by an institution, or funded by a particular body. To enhance the ethical assessment of such research, this study recommends adapting existing procedural ethics documents to promote inclusion of contextual information relevant to the operationalisation of ethical principles. A barrier to this recommendation is that by introducing this level of contextualisation and flexibility, procedural ethics will lose the stability inherent to its standardisation (Petryna, 2005). In the same way as researchers report the limitations to existing ethical review forms and procedures to respond to the nuances inherent to social science and ethnographic research (Truman, 2003; Ryan, 2007), including calls for increased flexibility (Zwi *et al.*, 2006; Lavery *et al.*, 2013), there seems little scope for making similar changes to meet the demands of research conducted in emergency settings. Therefore, this recommendation is considered to face potentially greater resistance than achieving a streamlined process for multi-site review.

However, whilst structural adjustments to the forms may not be likely, there remains scope for researchers to autonomously insert contextual information into existing forms, prioritising the inclusion of socio-cultural-historical information to situate the ethical considerations inherent to a given project. Through researchers taking responsibility for providing this information - including highlighting the limitations of existing forms rather than adjusting to the constraints of the template - it is possible that protocol templates will expand to accommodate this additional information, or ERBs will come to expect this level of socio-cultural-historical information. As a result of researcher-led modifications to the protocol template it is envisaged that change would proceed via individual ERBs adapting their forms or expectations, with this potentially affecting wider templates for protocols through efforts to promote “best practice” such as via conferences or national ERB training. This seems particularly likely if the information in the expanded form is identified as informative when assessing the ethicality of a given project, reinforcing the importance of research to assess the impact of any changes.

Currently procedural systems for research ethics are supported by statements about research integrity, for example from the United Kingdom (UK) Research Councils (Research Councils UK, 2017 [2013]) or the Universities UK Concordat to Support Researcher Integrity (Universities UK, n.d.); and internationally the Singapore Statement on Research Integrity (Staneck *et al.*, 2010) which aims to unify policies, guidelines, and codes of conduct into a common statement³⁸. All of these frameworks integrate ethical, legal, and professional codes, standards, frameworks, and governance structures with best practice. They highlight the need for a supportive research environment in which suitable training and mentoring opportunities to support researcher’s development are available, whilst fostering working environments that support research integrity. Therefore, these frameworks all highlight the link between procedures and practice. Whilst useful for providing a sense of where the land currently lies in relation to the promotion of ethical or responsible research conduct and researcher integrity, what these statements do not provide is how to effectively impart or uphold these standards. It is here that calls are made for enhancing the ethical literacy of

³⁸ It is important to note that this Statement was led by Staneck who defines integrity in line with professional standards and norms, not in relation to moral disposition. See e.g. Staneck, N. H. (2003) 'The Role of Professional Societies in Promoting Integrity in Research', *American Journal of Health Behavior*, 27(Supp 3), pp. s239-s247, Staneck, N. H. (2006) 'Fostering Integrity in Research: Definitions, Current Knowledge, and Future Directions', *Science & Engineering Ethics*, 12(1), pp. 53-74.

researchers (Eisen and Berry, 2002; Miller and Boulton, 2007), drawing attention to the *who* of bioethics to complement the *what* and *why* (Kingori, 2013).

When considering researcher training, it has been observed that “[m]ost research programmes in Global Health have begun to train a cadre of intervention-oriented researchers who can think through international health by way of RCT-based language and skills” (Adams, 2013, p. 66). This observation, whilst applying more to graduate Global Health courses in University environments, does suggest the need to expand research training in global health and embrace a critical stance towards the ethicality of a myopic focus upon the evidence-based medicine model of research, instead promoting assessment of social justice as an important ethical concern (Benatar *et al.*, 2005), particularly in emergency affected settings.

As discussed in Chiumento *et al.* (in preparation-a), one of the challenges for global health research conducted in emergencies is the transience of research assistants. This impacts upon the development of researcher training that balances the need for ethically literate and competent researchers, whilst ensuring training efficiency that recognises this may be the only study some researchers are involved in. The content and format of suggested ethical training has been outlined above, and includes the expectation that training would contain some “generic” components (e.g. ethical theories and professional norms), but that these would be contextualised and discussed in relation to the situated country setting, complemented by specific case study examples – preferably drawn from the organisations lived-experiences. Therefore, whilst the generic elements of training could be developed centrally for universal application (including by international organisations and hosted on freely-available online spaces), individual organisations would need to complement this material with their own contextually-specific materials. Whilst this approach may require organisational time and resources, the benefit of having ethically competent RA’s making situated ethical decisions in the field emphasises the ethical importance of dedicating resources to this. A further important consideration when developing courses that require reading materials such as journal articles or book chapters is their accessibility to global audiences, for example ensuring that barriers such as journal paywalls are overcome. Similarly for online courses, these need to be accessible in remote locations with poor internet infrastructure, potentially requiring their availability on USB drives or CD-ROM as well as via the internet.

Concluding comments

This study set out to explore researchers' understanding and management of ethical issues encountered in their everyday practice of post-conflict mental health research. Through qualitative interviews with researchers active in this field, findings suggest that researchers strategically engage with procedural research ethics to facilitate moving to the work of conducting research where they can assert their autonomy over ethical research practice. Findings also draw attention to mechanisms of trust and control that underpin ethics-in-practice, as organisations integrate procedural and audit-based responses to managing the conduct of their research assistants, despite recognising the limitations to these.

Therefore, this study has emphasised the situated nature of ethical decision making (Guillemin and Gillam, 2004; Hammersley, 2006; 2009) shaped by the forces of social change (Miller and Boulton, 2007). These foreground the complexity of individual lives and social interactions that are unstable and always "on the move" (Adams, 2013). This context emphasises the role of research ethics-in-practice in which normative issues of trust, confidentiality, anonymity, unanticipated disclosure, and other ethically important moments arise (Guillemin and Gillam, 2004; Miller and Boulton, 2007). In this space the potential for the creation of knowledge through practice is central (Hogle, 1995). Approaches such as qualitative research therefore become critical in aiding understanding of the fit between standardised ethical procedures and policies; the role of researcher training in equipping field RAs for everyday ethical encounters; and to unpack the socially embedded nuances of ethics-in-practice in situated contexts.

Whilst acknowledging some study limitations, this research contributes to the existing literature on procedural and in-practice research ethics in mental health research in emergency settings. Research findings draw attention to the role of the researcher at the centre of procedural and in-practice research ethics, with recommendations drawn to support reclaiming the voice of the frontline researcher in asserting the scope of ethics and its application to post-conflict mental health research.

References

- Adams, V. (2013) 'Evidence-based global public health: subjects, profits, erasures', in Biehl, J. G. and Petryna, A. (eds.) *When people come first: critical studies in global health*. Princeton: Princeton University Press [electronic book], pp. 54-90.
- Agier, M., Nice, R. and Wacquant, L. (2002) 'Between war and city: Towards an urban anthropology of refugee camps', *Ethnography*, 3(3), pp. 317-341.

Allden, K., Jones, L., Weissbecker, I., Wessells, M., Bolton, P., Betancourt, T. S., Hijazi, Z., Galappatti, A., Yamout, R., Patel, P. and Sumathipala, A. (2009) 'Mental health and psychosocial support in crisis and conflict: report of the Mental Health Working Group', *Prehospital and Disaster Medicine*, 24(Suppl 2), pp. s217-s227.

Baier, A. (1986) 'Trust and Antitrust', *Ethics*, 96(2), pp. 231-260.

Barchi, F., Kasimatis Singleton, M. and Merz, J. F. (2014) 'Fostering IRB Collaboration for Review of International Research', *American Journal of Bioethics*, 14(5), pp. 3-8.

Beauchamp, T. L. (2007) 'The 'Four Principles' Approach to Healthcare Ethics', in Ashcroft, R. E., Dawson, A., Draper, H. and McMillan, J. R. (eds.) *Principles of health care ethics*. John Wiley [electronic book], pp. 3-10. Available at: <http://onlinelibrary.wiley.com/book/10.1002/9780470510544>.

Beauchamp, T. L. and Childress, J. F. (2013) *Principles of biomedical ethics*. 7th edn. New York: Oxford University Press.

Becker, G. J. (2005) 'Human subjects investigation: timeless lessons of Nuremberg and Tuskegee', *Journal of the American College of Radiology*, 2, pp. 215-217.

Beecher, H. K. (1966) 'Ethics and clinical research', *New England Journal of Medicine*, 274(24), pp. 1354-1360.

Benatar, S. R., Daar, A. S. and Singer, P. A. (2005) 'Global health challenges: The need for an expanded discourse on bioethics', *PLoS Medicine*, 2(7), pp. 587-589.

Biehl, J. G. and Petryna, A. (2013) 'Critical global health', in Biehl, J. G. and Petryna, A. (eds.) *When people come first: critical studies in global health*. Princeton University Press [electronic book], pp. 1-20.

Bok, S. (1995) 'Shading the Truth in Seeking Informed Consent for Research Purposes', *Kennedy Institute of Ethics Journal*, 5(1), pp. 1-17.

Boulanger, R. (2015) *Ethics in humanitarian research: insights on the experiences of researchers*. Master of Science in Experimental Medicine (Bioethics) thesis. McGill (Accessed: 12.09.2017).

Boyatzis, R. E. (1998) *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks, CA : Sage Publications, 1998.

Brown, N., Boulton, M., Lewis, G. and A., W. (2004) *Social science research ethics in developing countries and contexts*. [Online]. Available at: https://www.york.ac.uk/res/ref/docs/REFpaper3_v2.pdf (Accessed: 10.02.2014).

Buchanan, A. (2000) 'Trust in Managed Care Organizations', *Kennedy Institute of Ethics Journal*, 10(3), pp. 189-212.

Chiumento, A., Khan, M. N., Frith, L. and Rahman, A. (2016) 'Managing ethical challenges to mental health research in post-conflict settings.', *Developing World Bioethics*, 16(1), pp. 15-28.

Chiumento, A., Machin, L., Rahman, A. and Frith, L. (in preparation-a) 'Trust in ethical research practice: manifestations, methods, and implications', *Unsubmitted*.

Chiumento, A., Machin, L., Rahman, A. and Frith, L. (2018) 'Online interviewing with interpreters in humanitarian contexts', *International Journal of Qualitative Studies in Health and Well-being*; 13(1): pp. 144487-144496

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (2017) 'Mediated research encounters: methodological considerations in cross-language qualitative interviews', *Qualitative Research*, Online early view, pp. 1-19.

Chiumento, A., Rahman, A., Machin, L. and Frith, L. (in preparation-b) 'Writing to template: researchers' perspectives of procedural ethics in mental health research in post-conflict settings', *unsubmitted*.

Citraningtyas, T., Macdonald, E. and Herrman, H. (2010) 'A Second Tsunami? The Ethics of Coming into Communities following Disaster', *Asian Bioethics Review*, 2(2), pp. 108-123.

Council for International Organisations of Medical Sciences (CIOMS) (2016) *International ethical guidelines for health-related research involving humans*. Geneva: CIOMS. [Online]. Available at: <https://cioms.ch/new-cioms-ethical-guidelines-for-health-related-research-involving-humans/>. (Accessed: 12.02.2014).

Croot, E. J., Lees, J. and Grant, G. (2011) 'Evaluating standards in cross-language research: A critique of Squires' criteria', *International Journal of Nursing Studies*, 48(8), pp. 1002-1011.

Das, T. K. and Teng, B.-S. (2001) 'Trust, Control, and Risk in Strategic Alliances: An Integrated Framework', *Organization Studies*, 22(2), pp. 251-283.

- Dixon-Woods, M., Angell, E., Ashcroft, R. E. and Bryman, A. (2007) 'Written work: The social functions of Research Ethics Committee letters', *Social Science & Medicine*, 65(4), pp. 792-802.
- Douglas-Jones, R. (2012) 'A single broken thread', *Durham Anthropology Journal*, 18(2), pp. 13-27.
- Douglas-Jones, R. (2015) 'A 'good' ethical review: Audit and professionalism in research ethics', *Social Anthropology / Anthropologie Sociale*, 23(1), pp. 53-67.
- Eckenwiler, L., Pringle, J., Boulanger, R. and Hunt, M. (2015) 'Real-time Responsiveness for Ethics Oversight During Disaster Research', *Bioethics*, 29(9), pp. 653-661.
- Eisen, A. and Berry, R. M. (2002) 'The Absent Professor: Why We Don't Teach Research Ethics and What to Do about It', *American Journal of Bioethics*, 2(4), pp. 38-49.
- Emanuel, E. J., Wendler, D., Killen, J. and Grady, C. (2004) 'What makes clinical research in developing countries ethical? The benchmarks of ethical research', *Journal of Infectious Diseases*, 189(5), pp. 930-937.
- Emerson, R. M., Fretz, R. I. and Shaw, L. L. (1995) *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press.
- Eyal, N (2014) 'Inform consent, the value of trust, and hedons', *Journal of Medical Ethics*, 40(7), p.447.
- Farmer, P., Nizeye, B., Stulac, S. and Keshavjee, S. (2006) 'Structural violence and clinical medicine', *Plos Medicine*, 3(10), pp. e449-e449.
- Ficklin, L. and Jones, B. (2009) 'Deciphering 'Voice' from 'Words': Interpreting Translation Practices in the Field', *Graduate Journal of Social Science*, 6(Special Issue 3), pp. 108-130.
- Ford, N., Mills, E., Zachariah, R. and Upshur, R. (2009) 'Ethics of conducting research in conflict settings', *Conflict and Health*, 3(1), pp. 7-15.
- Frith, H. and Gleeson, K. (2012) 'Qualitative data collection: asking the right questions', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester: John Wiley & Sons., pp. 55-68.
- Gambetta, D. (1988) 'Can we trust trust?', in Gambetta, D. (ed.) *Trust: making and breaking cooperative relations*. Oxford: Basil Blackwell, pp. 213-237.

- Goffman, E. (1959) *The presentation of self in everyday life*. London: Penguin.
- Gold, J. L. and Dewa, C. S. (2005) 'Institutional Review Boards and Multisite Studies in Health Services Research: Is There a Better Way?', *Health Services Research*, 40(1), pp. 291-308.
- Green, J. and Thorogood, N. (2014) *Qualitative methods for health research*. 3rd edn. London: SAGE Publications.
- Guillemin, M. and Gillam, L. (2004) 'Ethics, reflexivity, and "Ethically important moments" in research', *Qualitative Inquiry*, 10(2), pp. 261-280.
- Guillemin, M., Gillam, L., Barnard, E., Stewart, P., Walker, H. and Rosenthal, D. (2016) "'Doing Trust": How Researchers Conceptualize and Enact Trust in Their Research Practice', *Journal of Empirical Research on Human Research Ethics*, 11(4), pp. 370-381.
- Guta, A., Nixon, S. A. and Wilson, M. G. (2013) 'Resisting the seduction of "ethics creep": using Foucault to surface complexity and contradiction in research ethics review', *Social Science & Medicine*, 98, pp. 301-310.
- Haimes, E. (2002) 'What can the social sciences contribute to the study of ethics? Theoretical, empirical and substantive considerations', *Bioethics*, 16(2), pp. 89-113.
- Hammersley, M. (2006) 'Are ethics committees ethical?', *Qualitative Researcher*, 2, pp. 4-8.
- Hammersley, M. (2009) 'Against the ethicists: On the evils of ethical regulation', *International Journal of Social Research Methodology*, 12(3), pp. 211-225.
- Hammersley, M. (2015) 'On ethical principles for social research', *International Journal of Social Research Methodology*, 18(4), pp. 433-449.
- Hammersley, M. and Traianou, A. (2012) *Ethics in qualitative research: controversies and contexts*. SAGE Publications [electronic book].
- Harper, I. (2007) 'Translating ethics: Researching public health and medical practices in Nepal', *Social Science & Medicine*, 65(11), pp. 2235-2247.
- Hedgecoe, A. M. (2012) 'Trust and regulatory organisations: The role of local knowledge and facework in research ethics review', *Social Studies of Science*, 42(5), pp. 662-683.
- Heimer, C. A. (2013) "'Wicked' ethics: Compliance work and the practice of ethics in HIV research", *Social Science & Medicine*, 98, pp. 371-378.

Hewson, C., Peter, Y., Laurent, D. and Vogel, C. (eds.) (2003) *Internet Research Methods: A Practical Guide for the Social and Behavioural Sciences (New technologies for social research)*. SAGE Publications [electronic book].

Hoeyer, K., Dahlager, L. and Lynoe, N. (2005) 'Conflicting notions of research ethics. The mutually challenging traditions of social scientists and medical researchers', *Soc Sci Med*, 61(8), pp. 1741-9.

Hogle, L. F. (1995) 'Standardization across Non-Standard Domains: The Case of Organ Procurement', *Science, Technology, & Human Values*, 20(4), pp. 482-500.

Hogle, L. F. (2002) 'Introduction: Jurisdictions of Authority and Expertise in Science and Medicine', *Medical Anthropology*, 21(3/4), pp. 231-246.

Hyder, A. A., Wali, S. A., Khan, A. N., Teoh, N. B., Kass, N. E. and Dawson, L. (2004) 'Ethical review of health research: a perspective from developing country researchers', *Journal of Medical Ethics*, 30(1), pp. 68-72.

Hynes, T. (2003) *The issue of 'trust' or 'mistrust' in research with refugees: choices, caveats and considerations for researchers*. Geneva: UNHCR. [Online]. Available at: <http://www.unhcr.org/3fcb5cee1.html>. (Accessed: 16.01.2014).

Israel, M. and Hay, I. (2006) *Research ethics for social scientists: between ethical conduct and regulatory compliance*. SAGE Publications [electronic book]. Available at: <http://srmo.sagepub.com/view/research-ethics-for-social-scientists/SAGE.xml>.

Kass, N. E., Sugarman, J., Faden, R. and Schoch-Spana, M. (1996) 'Trust: The Fragile Foundation of Contemporary Biomedical Research', *The Hastings Center Report*, 26(5), pp. 25-29.

Kennedy, D. (2004) *The dark sides of virtue: reassessing international humanitarianism*. Princeton: Princeton University Press.

Kingori, P. (2013) 'Experiencing everyday ethics in context: Frontline data collectors perspectives and practices of bioethics', *Social Science & Medicine*, 98, pp. 361-370.

Kingori, P., de Vries, R. and Orfali, K. (2013) 'Special issue introduction: Bioethics in the field', *Social Science & Medicine*, 98, pp. 260-263.

Kohrt, B. A., Upadhaya, N., Luitel, N. P., Maharjan, S. M., Kaiser, B. N., MacFarlane, E. K. and Khan, N. (2014) 'Authorship in Global Mental Health Research: Recommendations for

Collaborative Approaches to Writing and Publishing', *Annals of global health*, 80(2), pp. 134-142.

Lavery, J. V., Green, S. K., Bandewar, S. V. S., Bhan, A., Daar, A., Emerson, C. I., Masum, H., Randazzo, F. M., Singh, J. A., Upshur, R. E. G. and Singer, P. A. (2013) 'Addressing Ethical, Social, and Cultural Issues in Global Health Research', *PLoS Neglected Tropical Diseases*, 7(8), pp. e2227-e2232.

Le, T. and Lê, Q. (eds.) (2013) *Conducting research in a changing and challenging world*. New York: Nova Publishers.

Levi, B. H. (1996) 'Four approaches to doing ethics', *The Journal Of Medicine And Philosophy*, 21(1), pp. 7-39.

Luhmann, N. (1979) *Trust and Power: two works*. Translated by Davis, H., Raffan, J. and Rooney, K. Edited by Burns, T. and Poggi, G. Chichester: Wiley.

Luna, F. (2009) 'Elucidating the concept of vulnerability: layers not labels', *International Journal of Feminist Approaches to Bioethics*, 2(1), pp. 121-139.

Luna, F. (2017) 'A way forward with layers: the two step process', *Oxford Global Health and Bioethics International Conference*. Oxford, 18/07/2017.

Mackenzie, C. A. (2016) 'Filtered meaning: appreciating linguistic skill, social position and subjectivity of interpreters in cross-language research', *Qualitative Research*, 16(2), pp. 167-182.

Menikoff, J. (2010) 'The paradoxical problem with multiple-IRB review', *New England Journal of Medicine*, 363(17), pp. 1591-1593.

Miller, T. and Bell, L. (2002) 'Consenting to what? Issues of access, gate-keeping, and 'informed' consent', in Mauthner, M. L., Birch, M., Jessop, J. and Miller, T. (eds.) *Ethics in qualitative research*. SAGE [electronic book], pp. 53-69. Available at: <http://srmo.sagepub.com/view/ethics-in-qualitative-research/SAGE.xml>.

Miller, T. and Boulton, M. (2007) 'Changing constructions of informed consent: Qualitative research and complex social worlds', *Social Science & Medicine*, 65(11), pp. 2199-2211.

Ng, L. C., Hanlon, C., Yimer, G., Henderson, D. C. and Fekadu, A. (2015) 'Ethics in global health research: the need for balance', *The Lancet Global Health*, 3(9), pp. e516-e517.

Norris, F. H., Galea, S., Friedman, M. J. and Watson, P. J. (eds.) (2006) *Methods for disaster mental health research*. New York: Guilford Press.

O'Mathúna, D. (2014) 'Disasters', in Ten Have, H. A. M. J. and Gordijn, B. (eds.) *Handbook of Global Bioethics*. Netherlands: Springer, pp. 619-639.

Olsen, G. R., Carstensen, N. and Høyen, K. (2003) 'Humanitarian Crises: What Determines the Level of Emergency Assistance? Media Coverage, Donor Interests and the Aid Business', *Disasters*, 27(2), pp. 109-126.

Pels, P. (2000) 'The trickster's dilemma: ethics and the technologies of the anthropological self', in Strathern, M. (ed.) *Audit cultures: anthropological studies in accountability, ethics, and the academy*. Routledge [electronic book], pp. 135-172. Available at: <http://www.tandfebooks.com/isbn/9780203449721>.

Petryna, A. (2005) 'Ethical Variability: Drug Development and Globalizing Clinical Trials', *American Ethnologist*, 32(2), pp. 183-197.

Pettit, P. (1995) 'The Cunning of Trust', *Philosophy & Public Affairs*, 24(3), pp. 202-225.

Power, M. (1997) *The audit society: rituals of verification*. Oxford: Oxford University Press.

Ramcharan, P. and Cutcliffe, J. R. (2001) 'Judging the ethics of qualitative research: considering the 'ethics as process' model', *Health & Social Care in the Community*, 9(6), pp. 358-366.

Research Councils UK. (2017 [2013]) *Policy and Guidelines on governance of good research conduct*. Available at: <http://www.rcuk.ac.uk/documents/reviews/grc/rcukpolicyguidelinesgovernancegoodresearchconduct-pdf/> (Accessed: 10.07.2017).

Riessman, C. K. (2005) 'Exporting ethics: A narrative about narrative research in South India', *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 9(4), pp. 473-490.

Ritchie, J., Zwi, A. B., Blignault, I., Bunde-Birouste, A. and Silove, D. (2009) 'Insider-Outsider Positions in Health-Development Research: Reflections for Practice', *Development in Practice*, 19(1), pp. 106-112.

Rubin, H. J. and Rubin, I. S. (2005) *Qualitative interviewing: the art of hearing data*. 2nd edn. Thousand Oaks, California: SAGE Publications.

Ryan, A. (2007) 'Ethical Issues', in Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative research practice*. SAGE [electronic book], pp. 218-35 Available at: <http://ebookcentral.proquest.com/lib/liverpool/detail.action?docID=1138447>.

Schopper, D., Upshur, R., Matthys, F., Singh, J. A., Bandewar, S. S., Ahmad, A. and van Dongen, E. (2009) 'Research Ethics Review in Humanitarian Contexts: The Experience of the Independent Ethics Review Board of Médecins Sans Frontières', *PLoS Medicine*, 6(7), pp. 1-6.

Schutz, A. (1944) 'The Stranger: An Essay in Social Psychology', *American Journal of Sociology*, 49(6), pp. 499-507.

Schutz, A. (1945) 'On multiple realities', *Philosophy and Phenomenological Research*, 5, pp. 533-576.

Schutz, A. (1967) *The phenomenology of the social world*. Evanston: Northwestern University Press.

Schutz, A. (1975) *Alfred Schutz on phenomenology and social relations: selected writings*. 3rd edn. Edited by Wagner, H. Chicago: University of Chicago Press.

Shimpuku, Y. and Norr, K. F. (2012) 'Working with interpreters in cross-cultural qualitative research in the context of a developing country: systematic literature review', *Journal of Advanced Nursing*, 68(8), pp. 1692-1706.

Silverman, D. (2011) 'Introducing qualitative research', in Silverman, D. (ed.) *Qualitative research : issues of theory, method and practice*. 3rd edn. London: SAGE Publications, pp. 3-12.

Silverman, D. (2013) *Doing qualitative research*. 4th edn. London: SAGE Publications.

Siriwardhana, C., Hewage, S. and Deshabandu, R. (2012) 'Psychosocial and Ethical Response to Disasters: A SWOT Analysis of Post-Tsunami Disaster Management in Sri Lanka', *Asian Bioethics Review*, 4(3), pp. 171-182.

Smith, M. J. (1998) *Social science in question*. London: SAGE Publications in association with the Open University.

Spencer, L. and Richie, J. (2012) 'In pursuit of quality', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester: John Wiley & Sons, pp. 227-242.

Squires, A. (2009) 'Methodological challenges in cross-language qualitative research: a research review', *International Journal of Nursing Studies*, 46(2), pp. 277-287.

Staneck, N., Mayer, T. and Anderson, M. (2010) *The Singapore Statement on Research Integrity*. Available at: <http://www.singaporestatement.org/statement.html> (Accessed: 10.07.2017).

Star, S. L. and Griesemer, J. R. (1989) 'Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39', *Social Studies of Science*, 19(3), pp. 387-420.

Steneck, N. H. (2003) 'The Role of Professional Societies in Promoting Integrity in Research', *American Journal of Health Behavior*, 27(Supp 3), pp. S239-S247.

Steneck, N. H. (2006) 'Fostering Integrity in Research: Definitions, Current Knowledge, and Future Directions', *Science & Engineering Ethics*, 12(1), pp. 53-74.

Strathern, M. (2000) 'Introduction: new accountabilities', in Strathern, M. (ed.) *Audit cultures: anthropological studies in accountability, ethics, and the academy*. Routledge [electronic book], pp. 1-18. Available at: <http://www.tandfebooks.com/isbn/9780203449721>.

Sumathipala, A. and Siribaddana, S. (2005) 'Research and clinical ethics after the tsunami: Sri Lanka', *Lancet*, 366(9495), pp. 1418-1420.

Swan, D. J. and Collins, M. A. (2008) 'Sign on the dotted line: The informed consent process (ICP) as induced compliance', *Journal of Applied Social Psychology*, 38(11), pp. 2637-2647.

Swift, A. (2006) *Political philosophy: a beginners' guide for students and politicians*. 2nd rev. and expanded edn. Cambridge: Polity.

Temple, B. (2002) 'Crossed wires: Interpreters, translators, and bilingual workers in cross-language research', *Qualitative health research*, 12(6), pp. 844-854.

The National Commission for the Protection of Human Subjects in Biomedical and Behavioural Research (1979) *Ethical Principles and Guidelines for the Protection of Human Subjects of Research (The Belmont Report)*. Department of Health and Human Services. [Online]. Available at: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>. (Accessed: 12.02.2014).

Thornicroft, G. (2006) *Shunned: discrimination against people with mental illness*. Oxford: Oxford University Press.

Truman, C. (2003) 'Ethics and the ruling relations of research production', *Sociological research online*, 8(1). Available at: <http://www.socresonline.org.uk/8/1/truman.html>. (Accessed: 17.03.2017).

UK Universities. (n.d.) *The Concordat to support research integrity*. Available at: <http://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2012/the-concordat-to-support-research-integrity.pdf> (Accessed: 10.07.2017).

United Nations Educational Scientific and Cultural Organization (UNESCO). (2005) *Universal declaration on bioethics and human rights*. Available at: http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html (Accessed: 10.07.2017).

van Manen, M. (1990) *Researching lived experience: human science for an action sensitive pedagogy*. State University of New York Press [electronic book] Available at: <https://ebookcentral.proquest.com/lib/liverpool/detail.action?docID=3408268>

Wessells, M. G. (2009) 'Do No Harm: Toward Contextually Appropriate Psychosocial Support in International Emergencies', *American Psychologist*, 64(8), pp. 842-854.

Widdows, H. (2007) 'Is Global Ethics Moral Neo-Colonialism? An Investigation of the Issue in the Context of Bioethics', *Bioethics*, 21(6), pp. 305-315.

World Health Organisation (WHO) (2000) *Operational guidelines for ethics committees that review biomedical research*. Geneva. [Online]. Available at: <http://www.who.int/tdr/publications/documents/ethics.pdf> (Accessed: 20.07.2017).

World Health Organisation (WHO) (2010) *Research ethics in international epidemic response: WHO technical consultation, meeting report*. Geneva. [Online]. Available at: https://extranet.who.int/iris/restricted/bitstream/10665/70739/1/WHO_HSE_GIP_ITP_10_1_eng.pdf (Accessed: 10.07.2017).

World Medical Association (2013 [1964]) *WMA Declaration of Helsinki: ethical principles for medical research involving human subjects*. Available at: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/> (Accessed: 26.02.2016).

Yamout, R. and Jabbour, S. (2010) 'Complexities of research during war: lessons from a survey conducted during the summer 2006 war in Lebanon', *Public Health Ethics*, 3(3), pp. 293-300.

Yin, R. K. (2009) *Case study research: design and methods*. 4th edn. Los Angeles, California: SAGE Publications.

Zwi, A. B., Grove, N. J., MacKenzie, C., Pittaway, E., Zion, D., Silove, D. and Tarantola, D. (2006) 'Placing ethics in the centre: negotiating new spaces for ethical research in conflict situations', *Global Public Health*, 1(3), pp. 264-277.

APPENDIX 1: RESEARCH PROTOCOL



ANNA CHIUMENTO

PhD PROJECT PROTOCOL³⁹

PROJECT TITLE:

Researcher's construction and management of ethical issues in post-conflict mental health research: a qualitative study.

Short title: Ethical issues in post-conflict mental health research (for use on information sheets, consent forms, and interview and workshop guides)

PRINCIPAL INVESTIGATOR / PRIMARY SUPERVISOR:

<i>Title</i>	<i>Name</i>	<i>Post</i>	<i>e-mail</i>	<i>tel</i>
Prof.	Atif Rahman	Professor of Child Psychiatry: PhD Supervisor	atifr@liverpool.ac.uk	0151 252 5509

CO-APPLICANTS:

<i>Title</i>	<i>Name</i>	<i>Institution</i>	<i>Post</i>	<i>e-mail</i>	<i>tel</i>
Miss	Anna Chiumento	University of Liverpool	PhD Student	Anna.Chiumento@liverpool.ac.uk	0151 795 5357
Dr	Lucy Frith	University of Liverpool	Senior lecturer	frith@liverpool.ac.uk	0151 795 5333
Dr	Laura Machin	University of Lancaster	Lecturer	l.machin@lancaster.ac.uk	01524 594 973

PROJECT START / END DATES:

As soon as ethical approval is granted. Anna Chiumento's PhD Studentship commenced October 1st 2013 until September 30th 2017⁴⁰.

PROJECT SUMMARY:

Increased numbers of conflicts worldwide have led to more people suffering adverse mental health consequences. This has led to researcher and policy makers calls to conduct mental health research in humanitarian and post-conflict contexts, including calls to concentrate upon ethical issues inherent to conducting such research. These follow documentation of unethical research practice including abuse of humanitarian populations in health and social research. Consequently, there are aspects to mental health research with post-conflict

³⁹ Please note the appendices identified as accompanying this protocol are not provided as part of this thesis.

⁴⁰ A 3-month extension was granted as a result of undertaking a 3-month internship with the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergencies, extending the PhD end-date to December 2017.

populations that require investigation in order to improve the ethical conduct of such research, protecting both participants and researchers.

This study will critically examine the research question “How do researcher’s construct and manage ethical issues experienced in mental health research with post-conflict populations in three countries in South Asia⁴¹?” This will be answered through a qualitative study involving talking with researchers active in mental health research with post-conflict populations in three countries in South Asia. These three case-study countries have been chosen because of their recent history of conflict. Following multiple-case studies in three countries aims to identify converging findings from multiple sources of evidence.

Discussions will be conducted in two stages: individual in-depth interviews and group participatory workshops. Additional observation of meetings and documentary analysis of research protocols and working notes will be undertaken where available in English. The estimated time each participant will be involved in research activities including recruitment and dissemination is 8 hours. Interpreters will be involved to ensure full participation. All interpreters will be required to sign a confidentiality agreement, and will be trained for the purpose of this study.

The PhD candidate Anna Chiumento (AC) is embedded within the South Asian Hub for Advocacy, Research and Education on Mental Health which provides access to partner institutions in each site. Study participants will be identified by in-country partner institutions. Participant inclusion criteria includes being active in mental health research with post-conflict populations in three countries in South Asia. Three categories of researchers will be included: (1) study leads; (2) researchers managing field research teams; (3) front-line data collectors. Inclusion of all three levels of researcher recognises that ethics issues arise at all stages of the research process. Sample size will be determined by theoretical saturation which occurs when no new data is being generated.

All participants will be required to provide written informed consent. Consent will emphasise the voluntary nature of participation, the right to withdraw from the study at any point without penalty, and the use of anonymised data in publications. Consent will be obtained following a participant information session led by AC outlining the study purpose and design, with opportunity for questions to be addressed. This information session aims to ensure genuine comprehension of the study, and freely given informed consent.

Individual in-depth interviews will follow a semi-structured topic guide (list of potential questions) to steer interviews, complemented by attention to interviewee responses that present further lines of inquiry. Group participatory workshops will be conducted in each country after interview analysis. Workshops are to share initial research findings and refine thematic categories emerging from the data with participants; to capture shared understandings of “ethics”; and to set further research priorities relating to the ethical conduct of mental health research with post-conflict populations.

All interviews and workshops will be digitally recorded and transcribed for analysis. Research methodology follows a broad phenomenological approach aiming to explore the lived-through quality of individual experience – in this case experience of conducting mental health research with post-conflict populations. Interrogation of the “fit” between procedural

⁴¹ For the purpose of this thesis the PhD research protocol has been fully anonymised, removing all references to countries and organisations involved in this study.

ethics (guidelines) and ethics in practice will be achieved through application of an empirical ethics approach, aiming to explore how far research ethics guidelines are compatible with researchers' experiences.

Research will fill a gap in knowledge through the systematic investigation of how researchers construct and manage ethical issues arising in mental health research with post-conflict populations. Research findings will be applicable to the development of research guidelines, processes and policy concerning the conduct of mental health research in post-conflict contexts.

PROJECT SITES AND KEY CONTACTS:

This study will be conducted in three case study countries: C1, C2 and C3. These sites have been chosen for their recent experience of conflict, briefly:

- C1: Experienced ethnic and nationalist internal conflict since the 1990's. Whilst the conflict ended in 2006, on-going political instabilities including failure to produce a new Constitution leave a significant political vacuum. The UNHCR identifies 56,734 persons of concern, and 69,000 nationals have been offered durable resettlement in countries worldwide (UNHCR Statistical Snapshot: 2013).
- C2: The roots of C2's civil war were ethnic, with violence used to express discontent since decolonisation. Cessation of hostilities in 2009 mean the core humanitarian challenges today are durable solutions to displacement, and addressing the health-related deficit caused by civil war. The impact of the 2004 South Asian Tsunami further complicates the post-conflict context in C2. The UNHCR identify that at the end of September 2012 468,000 people had returned from displacement to their places of origin. As of January 2013, the UNHCR document that C2 hosts 139,945 persons of concern including refugees, asylum seekers and internally displaced persons (UNHCR Statistical Snapshot: 2013).
- C3: Experienced internal conflict since 2001 as a result of Taliban, Al-Qaida and other non-state rebel forces maintaining bases on C3's soil. The national military has conducted numerous operations against these groups. Whilst conflict officially ended in 2011, pockets of violence continue. Amnesty International called the situation in C3's North Western Province a "humanitarian crisis" (2010). The UNHCR identifies that C3 hosts 2,455,919 persons of concern (UNHCR Statistical Snapshot: 2013).

For the last 2 years the AC has been working in a US National Institute of Health funded Global Hub. The programme entitled SHARE: "South Asian Hub for Advocacy, Research and Education on Mental Health" is co-led by Professor Atif Rahman (Principal Investigator and PhD supervisor).

SHARE brings together 12 regional partners from across South Asia, 5 of which are active in post-conflict settings. The applicant has been working closely with researchers at organisations based in each of the three South Asian countries involved in this study.

These contacts fully support this proposed study (letters of support: Appendix 1⁴²). Each institution will host AC's study, providing a venue for research events and supporting with logistical issues. Agreement to host these events and management of this relationship are outlined in Terms of Reference with each host institution (Appendix 2).

RESEARCH ASSISTANTS / SUB-CONTRACTING:

Local in-country logistical support to facilitate this study will be provided by in-country partners, outlined in the agreed Terms of Reference. This includes the recruitment of interpreters required for this study.

All interpreters involved in this study will be required to sign a confidentiality agreement (Appendix 3), and will undergo training. Interpreters must not have been involved in research with the proposed participants in this study in the past, to protect against assumptions in interviews.

FUNDING:

AC's PhD is fully funded by an Economic and Social Research Council +3 PhD Studentship. This award is for the period 01/10/2013 – 30/09/2017. Student number: 200863693. Project funding is being sought from the Economic and Social Research Council Overseas Fieldwork Allowance, and additional charitable sources.

BACKGROUND:

(Brief description of the context)

The long-term impact of conflict upon the mental health of affected populations is well documented (Summerfield: 2000; Tol *et al*: 2011; Attanayake: 2009). As global conflicts increase, the numbers of post-conflict settings multiply (Themner and Wallenstein: 2012). To respond to the mental health needs of conflict affected populations there have been calls for increased ethical research to inform mental health interventions in post-conflict settings (Tol *et al*: 2011; Mfutso-Bengo, Masiye and Muula: 2008; Allden *et al*: 2009; Ford *et al*: 2009).

The abuse of conflict- and disaster-affected populations for medical and social research has been documented (i.e. Asian Bioethics Review 2 (2); Ford *et al*: 2009; Mackenzie *et al*: 2007). Conducting mental health research in post-conflict settings poses ethical challenges, including: potentially traumatised populations vulnerable to exploitation; researchers and research participants fearing for their safety (Mackenzie *et al*: 2007); and adherence to ethical guidelines may be problematic, i.e. requiring disclosure of research funding which carries implications for research reporting (Personal correspondence: 2012). These practical barriers to implementing research ethics guidelines in post-conflict settings have not been empirically explored in detail.

Attempts to formulate ethical guidelines specific to mental health research in humanitarian settings have been made (Allden *et al*: 2009; Sumathipala *et al*: 2010; Sphere: 2004, ISAC: 2007), and ethics review board implementation challenges discussed (Schopper *et al*: 2009). However, little systematic research to understand the constraints and enablers to ethical mental health research in post-conflict settings has been conducted.

The case-study sites of C1, C2, and C3 have been chosen for their recent history of conflict. Different case study contexts enable comparison of how researchers conceptualise and

⁴² Please note: the research question in the letters of support has since been revised to the question in this protocol.

manage “ethics” in specific settings. Consequently, these three countries offer relevant case-study sites, with findings broadly representative of researchers’ experiences in the South Asia region.

Empirically examining barriers and facilitators to conducting ethical mental health research in post-conflict settings will fill an important gap in knowledge about how research is conducted in practice. This will be used to inform a conceptual discussion of which theoretical ethical frameworks are most appropriate to this setting, and how these might be employed in practice.

PROJECT OBJECTIVE:

The research objective is to empirically examine the construction and management of ethical issues raised when conducting mental health research in post-conflict settings, from the perspectives of researchers active in this field.

Research will explore how:

- “ethics” is defined and understood;
- situations stimulating “ethical considerations” are identified;
- “ethics” is applied and managed, focusing upon the interaction between constructions of “ethics” and situations identified as entailing “ethical issues”;
- procedural ethics are interpreted and applied to ethics in practice (Guillemin and Gillam: 2004);
- ethics in practice and procedural ethics relate, synthesising insights from the above.

This study aims to produce findings applicable to the development of research guidelines, processes and policy concerning the conduct of mental health research in post-conflict contexts.

PROJECT DESIGN:

The primary research question is: *How do researchers construct and manage ethical issues experienced in mental health research with post-conflict populations in C1, C2 and C3?*

What constitutes an “ethical issue” and how this could be understood will not be defined as a primary study aim is to explore how researchers define, understand and apply “ethics” to their research practice (Frith: 2009).

The subsidiary research question is: *Are “ethical issues” understood differently when applied to populations deemed vulnerable such as women, children, the mentally disabled and minority ethnic groups?*

Methodology:

Research adopts a broad phenomenological approach (Schutz: 1932/67). Insights into researchers’ sense-making of “ethical issues” will be achieved through in-depth interviews, allowing the interviewee to reveal an account of their experiences. Adopting a phenomenological approach seeks to emphasise the lived-through quality of these experiences, focusing upon how “ethics” is constructed and managed. To explore the “fit” between empirical findings and normative principles found in research guidelines empirical ethical approaches will be critically applied (including i.e. reflective equilibrium [van der Burg and van Willigenburg: 1998]; Integrated Empirical Ethics [Molewijk *et al*: 2004]; Symbiotic empirical ethics [Frith: 2012]; Pragmatic hermeneutics [Widdershoven, Abma and Molewijk: 2009] and Critical Bioethics [Hedgecoe: 2004]).

Research will follow a multiple-case study method (Yin: 2009), involving in-depth interviews and participatory workshops with researchers. This method aims to produce generalizable theoretical propositions through incorporation of multiple sources of evidence allowing converging lines of enquiry to emerge, supported by data triangulation through replication of the empirical study. Interviews and workshops will be complemented by observation of meetings and documentary analysis including research protocols and working notes to better understand “ethics in practice”.

Exact research design will be finalised following conduct of a literature review and according to peer review from researchers active in post-conflict mental health research.

Qualitative interviewing:

Case studies will involve individual in-depth interviews and participatory workshops. A semi-structured topic guide has been designed to steer interviews (Appendix 4), complemented by attention to emerging meanings within interviews that present pertinent lines of enquiry. The topic guide will be piloted in each country to ensure appropriateness of questions, language and phrasing.

Interviews will be digitally recorded to capture individual narratives and facilitate transcription. Written transcriptions will be used for analysis.

In-depth interviews have been selected for their flexibility in exploratory research, allowing new dimensions to the topic to be identified and pursued. Furthermore, individual interviews facilitate exploration of the ways in which researchers give coherence to their experiences, moving beyond public accounts of research practice. Limitations of in-depth interviews are recognised, notably that accounts draw upon experiential resources available to the interviewee at a specific time and place, acting to both allow and constrain the resulting narrative (Gurbium and Holstein: 1998). These will be addressed by maintaining a reflective field-journal, encouraging transparency and reflexivity towards the context in which narrative accounts are produced.

In addition to interviews, methods to facilitate examination of “ethics in practice” will be explored. These include observation at meetings, documentary analysis of research protocols and reports, and informal discussions with key informants. A key enabling factor to these methods will be their availability in English.

Participatory Workshops:

Following analysis of interviews three participatory workshops will be held, one in each country. Workshops will bring participants together to share initial findings and refine emerging thematic categories (Knightbridge, King and Rolfe: 2006). Discussions will be digitally recorded and transcribed for analysis, adding a further layer to data.

Workshops will be driven by the subsidiary research question: *How can the “ethical issues” identified be managed?* Workshops will involve collaborative activities to explore normative frameworks applicable to post-conflict mental health research. Consequently, this stage of the research aims to stimulate “moral conversation” (Dunn *et al*: 2012), developing practice-orientated normative frameworks for mental health research ethics in post-conflict settings.

Workshops are important to:

- a) obtain respondent validation of research findings;
- b) ensure ecological validity of research findings;

- c) capture researchers shared narratives of “ethics” experienced in mental health research with post-conflict humanitarian populations;
- d) identify future research priorities.

The workshop format is outlined in Appendix 5.

Interpreters:

Interpreters will be involved in the conduct of interviews and participatory workshops to ensure representation of the target sample of researchers (see below for details). AC has experience of managing and conducting qualitative interviews and workshops with interpreters in previous studies conducted with asylum seeking and refugee populations in the UK (Chimento and Bristow: 2013).

Interpreters will be recruited through in-country host institutions, based upon local recommendation, level of experience and where possible qualifications. Interpreters will be matched according to language, gender and where possible age of the respondents in order to facilitate open discussion. Critical awareness of potential cultural conflicts arising as a result of different sub-cultures within each case study country will be maintained as a factor potentially influencing participant responses. All interpreters will be required to sign a confidentiality agreement to participate in this study (Appendix 3), and will be paid for their involvement at a pre-agreed local rate.

All interpreters will undergo a 2 hour training session in interpreting for research purposes covering the study purpose, design, and key research questions. Ethical responsibility to minimise participant distress, let the interviewee lead the conversation, and for accurate verbatim interpreting will be stressed to ensure the reliability of data collected (see Appendix 6: Interpreter Guidelines). Interview topic guides will be shared and discussed with interpreters for feedback. Training is critical to the quality of interpretation, and for AC and interpreters to build a rapport, learning from one another’s experience. Previous experience of the benefits of these events are a deeper understanding of interpreters professional experience of communication nuances in different cultures, and exploration of ways to express key ideas in the topic guide and relating to the subject. These discussions will form one aspect of the piloting and refining of interview topic guides.

All interpreters involved in the collection of research data are viewed as co-producers of research findings and critical stakeholders in the research process (Temple and Edwards: 2002). A quality check on each interpretation will be conducted by a second independent interpreter not involved in primary data collection, aiming to ensure critical reflexivity towards the quality of data produced through interpreters.

Observation of meetings and documentary analysis:

Where possible, observation of research meetings and documentary analysis of research protocols, meeting minutes and other working notes will be explored to enhance understanding of “ethics in practice”. This will be of on-going mental health research with post-conflict populations only. Consent to AC’s observation of meetings and access to documentation for analysis is included in consent forms (Appendix 7). This method of data collection is dependent upon the availability of documentation in English, and will adhere to ethical approval standards of each country.

ANALYSIS:

Analysis will be driven by phenomenology, emphasising the lived-through quality of researchers' experiences of "ethics" in mental health research in post-conflict settings to build a conceptual understanding of this phenomenon.

Analysis will be managed using the Framework approach, providing a clear analytic framework across case studies (Ritchie and Spencer: 1994). Framework supports movement between data sets to produce overarching theoretical propositions that can be explored thematically, by case, and by embedded unit. It is furthermore appropriate to applied policy research (Ritchie and Spencer: 1994).

Analysis will be supported by NVivo 9 software developed for framework (QSR International: 2011).

Interrogation of the "fit" between procedural ethics and ethics in practice will be achieved through application of empirical ethical approaches including (i.e. reflective equilibrium [van der Burg and van Willigenburg: 1998]; Integrated Empirical Ethics [Molewijk *et al*: 2004]; Symbiotic empirical ethics [Frith: 2012]; Pragmatic hermeneutics [Widdershoven, Abma and Molewijk: 2009] and Critical Bioethics [Hedgecoe: 2004]). This will synthesise findings from the empirical study with guidelines developed for mental health research in the humanitarian context to explore how far guidelines are compatible with researchers' experiences.

SAMPLING:

Participant inclusion criteria are researchers active in mental health research with post-conflict populations in three countries in South Asia, comprising three embedded categories:

4. Primary Investigator / supervisor;
5. Mid-level researcher: managing a field research team; and
6. Front line data-collector: involved in administering questionnaires and/or conduct of interviews

Broad classification of researcher recognises that experiences of "ethics" arise at all stages of the research process. Furthermore, embedded units of analysis allow for corroboration and contrasting of experiences.

Purposive sampling methods will be employed, with potential participants identified by in-country partners based upon fit to the inclusion criteria and embedded units of analysis. Sample size will be determined by theoretical saturation. The final sample will comprise equal numbers of researchers from each country, representing each embedded unit of analysis.

How participants will be approached and recruited:

Potential participants will be approached via in-country partners who will publicise the study. This will be followed by a research information event in each country conducted by AC, providing background information including the research questions, research process, anticipated risks and benefits to participating, and the opportunity to ask questions. Principles of voluntary informed consent, anonymity and confidentiality will be reinforced, and data management and storage procedures outlined. Time will also be given to reporting and dissemination procedures, highlighting measures taken to protect research participants as outlined in the accompanying position statement on ethical research reporting (Appendix 8).

Given recruitment processes that are assisted by in-country partner institutions it is important to guard against perceived institutional pressure to participate in the study. The right to decide not to participate in the study will be made explicit, highlighting that there will be no penalty for non-participation and that participants have the right to withdraw their consent to the research at any time. A research information sheet will be provided for participants to take away and consider consenting to participate in the study (Appendix 9).

CONSENT:

Informed consent is a central tenant of ethical research practice. Participants will be asked to provide written informed consent to participate in this research. Consent will be preceded by in-country Research Information Events (see above).

All information and consent materials will be written in English. Understanding of this material will be assisted by interpreters who will participate in in-country Research Information Events, individual in-depth interviews and workshops as required by individual participants. Interpreters will be required to sign a confidentiality agreement and undergo training to interpret for this study (see above).

Written consent will be obtained from participants either at research information events, or at interviews if participants would like additional time to consider their participation. Consent forms will be collected directly from participants by AC for safe storage. At subsequent research events consent will be reconfirmed verbally with participants, initiating a process of continual consent which seeks to ensure participants have the opportunity to raise concerns about their on-going participation or withdraw from the study.

Participants will receive reimbursement of travel expenses for participating in this study, to an approximate value of £25 per participant. This will be given in the form of a gift rather than money i.e. washing powder / food items. Refreshments at research events (information events, interviews, workshops and dissemination) will be provided, according to the time of day and local customs. No further incentives will be offered.

RISKS AND ETHICAL ISSUES:

A key ethical consideration is the protection of research participants. The risks of this study are negligible with only a small risk of participant distress or adverse reactions to recounting personal experiences. This will be addressed by a referral pathway for counselling support with each host institution. Furthermore, should interpreters experience distress as a result of being involved in the conduct of interviews they will be referred for additional support following the procedures for responding to participant distress.

The potential for disclosure of unethical research practice will be addressed following in-country procedures. Reporting unethical research practice will not be required of researchers but will be actively encouraged. This position is taken because to require reporting of unethical practice may prevent initial disclosure, thereby biasing research findings. Disclosure of criminal behaviour, or relating to child or other abuse will be reported following in-country procedures. All disclosures will be collectively managed with host institutions.

The potential risk of participant distress or adverse reaction to this study must be weighed against possible collateral benefits resulting from reflection upon ethical issues when conducting mental health research in post-conflict settings. Furthermore, participatory workshops will bring together a community of researchers working in the field of mental health research in post-conflict contexts in each country, establishing a peer environment

through which common experiences and mutually agreed standards of best practice can evolve. Consequently, the benefits of participation in this study have been assessed as outweighing potential risks.

A primary ethical concern for this study is the confidentiality and anonymity of descriptive narrative information provided by participants. It is paramount to protect both research participants and field research teams from reprisals as a result of discussing ethical challenges in post-conflict mental health research. Critical exploration of the ethical risks and responsibilities of identifying research sites and partner organisation will be considered. Consultation with key international and in-country experts on ethical reporting standards has been conducted, developing a position statement on ethical research reporting (Appendix 8). This position statement identifies the agreed standard of best practice reporting which will be discussed with participants at research information events. Final reporting of the study will adhere to ethical standards agreed at participatory workshops by participants taking part in the study.

All research materials will adopt a consistent ethical position on the potential risks and benefits of this study. Clear referral pathways and protocols for managing participant distress or adverse reaction; for reporting disclosures of criminal activity or abuse; and for reporting research practice that fails to meet ethical standards will be developed with each in-country institution prior to the conduct of research activities, and will be implemented where required. These protocols will be reviewed should the University of Liverpool or in-country host institutions update their procedures.

A further ethical consideration is protection of the research team. For this study all primary data collection will be conducted by AC at research events hosted by in-country partner institutions. A risk assessment will be conducted prior to the conduct of research, taking all reasonable steps to ensure the protection of researchers and interpreters during field visit and data collection. AC will undergo regular supervision by her PhD supervisors, with skype communication during field visits. AC will furthermore have an identified in-country researcher available for advice and consultation during field visits as required (Appendix 2 identifies this individual). All field visits will be accompanied by an in-country researcher not participating in the study.

Expert Advisory Committee:

An expert advisory committee has been formed to support and provide guidance to this study. The advisory group is comprised of experts in the field of health research in humanitarian contexts including post-conflict context and mental health research, qualitative research and bioethics. The Committee will be consulted bi-annually via e-mail and other distance communication methods.

DATA ACCESS AND STORAGE:

The primary custodian of all study data is AC.

Research data will include Dictaphone audio-files and computer files. One Dictaphone will be used for this study, which will be managed by AC. Transcripts will be made of audio-files, at which point they will be anonymised using pseudonyms and all identifiers and potential identifiers removed. Once transcribed, audio-files will be deleted from Dictaphone hard drives.

All study printed material will be kept in a locked filing cabinet. Any notes made by interpreters during interviews will be destroyed at the end of interviews. All computerised

data will be held on approved University computers, which are password protected and virus checked. Data will be stored on the University's managed network server and not on the computer's own hard drive (which is less secure). Only AC and her supervisors will have access to the data.

Consent forms will require completion of participants name, contact telephone and signature. Once completed, consent forms will be scanned and held on the secure Liverpool University drive for reference during data collection. Hard copies will be transferred to Liverpool University to be stored in a locked filing cabinet. All consent forms contain a statement about the transcription and storage of anonymised data. Voluntary informed consent will include consenting to the procedures for data management. The data held at Liverpool will be destroyed 5 years after the end of the project.

Networks to share data with:

Any shared data will adhere to the ethical standards agreed with participants regarding the type and format of data that may be shared - i.e. appropriately anonymised. No raw data will be shared.

Data appropriately cleaned will be shared within the NIH South Asian Hub network of institutions working in the field of mental health research in low resource settings, including the post-conflict contexts. Sharing data that reflects upon the ethical issues that arise in the conduct of mental health research in post-conflict settings will support ongoing efforts within the region to strengthen normative frameworks for ethics in mental health research. Identified data appropriate for sharing will be shared within academic networks such as the Inter-Disciplinary and Empirical Ethics Network, and the Qualitative Data Analysis Workshops that form part of Liverpool's Advanced Qualitative Methodologies Course for PhD students.

DISSEMINATION OF RESEARCH FINDINGS:

Dissemination and publication procedures have been developed in consultation with in-country and international experts. A key concern of this study is the protection of research participant anonymity, and the anonymity and confidentiality of descriptive data. This is an ethical issue concerning the risks to participants taking part in the study, and the research teams they work with. In particular, given the specialist nature of mental health research in post-conflict settings the ethical duty to protect research participants from potential reprisals is paramount i.e. through processes of anonymising data or abstracting the research to not identify its location. A position statement on ethical research reporting has been developed (Appendix 8) and will be outlined to participants at research information events.

Ethical reporting standards will form one aspect of workshop discussed with participants (see Appendix 5). Final study reporting will adhere to the most stringent ethical standards identified by research participants if these differ from those outlined at research information events. This will include the formulation of an ethical position relating to the sharing of full transcription data identifying research sites. Due to these ethical considerations raw, unedited study data may not be made available immediately.

Publications arising out of this study will adhere to the identified procedure for dissemination and publication. Some publications may occur prior to data collection, and will follow ethical reporting standards outlined in the position statement, developed through expert consultation which includes in-country partners. Final research reporting including quotations and other research materials will adhere to the ethical reporting standards

identified by participants at workshops. All publications will be reviewed by in-country partners prior to submission for publication, as outlined in Appendix 2.

Conference presentations and other dissemination will adhere to the same level of ethical reporting standards. Study findings will be reported back to in-country partner organisations, and disseminated at regional and global hub meetings. A full PhD Thesis will be deposited in the University of Liverpool Library. These will similarly adhere to ethical reporting standards, and will critically reflect upon the benefits and constraints of the approach taken. Given the potential for participants to be identifiable given the small network of researchers working in post-conflict mental health a position statement on academic integrity and ethical standards will be covered in dissemination events to reinforce the public benefit this research brings to prevent any reprisals for individuals or institutions.

PEER REVIEW:

This research protocol has undergone the following peer reviews:

- By PhD Supervisors Professor Rahman, Dr Frith and Dr Machin
- By in-country partners, namely by XXXXXXXXXX
- By external experts in the Advisory Group

All research materials have been developed to ensure consistency with guidelines and policies of The University of Liverpool, in-country institutions, and the Economic and Social Research Council's Framework for Research Ethics.

Study lead AC has undergone compulsory Liverpool University Research Ethics Training. She has furthermore completed the online Research Integrity Training for Social and Behavioural Sciences, and participated in Informed Consent training at Liverpool University on 29th February, 2013. AC furthermore subscribes to online training portals such as Disaster Ready and The Sphere Project which provide trainings in safety, ethical conduct, and professional integrity in humanitarian and disaster contexts. AC continues to undertake personal professional development activities in research ethics.

ETHICAL REVIEW:

Following peer review, ethical approval will first be sought from each of the review boards in case-study countries. In addition, institutional approval from The University of Liverpool's Institute of Psychology, Health and Society Ethics Committee will be obtained. This will contain the opinions of in-country reviewers for consideration.

BUDGET:

Item	Cost per item	Total cost	No of items	Total
Round-trip flights i.e. flying from the UK to South Asia and moving from C1, to C2 and C3 before returning to UK.	£700 + £400 + £300 + £400	£1,800.00 per trip	4 trips	£7,200.00
Visa's	C1: £200 C2: £200 C3: £368	£768.00	One off cost	£768.00

Accommodation + food	C1: £700 / week C2: £600 / week C3: £600 / week	£1,900.00 per week	5 weeks in total across 4 trips.	£9,500.00
Local transportation	C1: £100 / trip C2: £200 / trip C3: £150 / trip	£450	4	£1,800.00
Interpreters	C1: £40 / day C2: £35 / day C3: £25 / day	N/A	7 days	£700.00
Participant reimbursement (for time and transport)	Per person in all countries: £25	£675.00	2 research events: Individual interviews and Workshops.	£1,350.00
Admin costs of hosts (printing, provision of workspace etc)	£150 for all organisations	£450	One off cost	£450.00
Refreshments at research events	C1: £15 / event C2: £30 / event C3: £20 / event	£65 per event	4 (Participant Information, Individual interviews, Workshop and Dissemination)	£260.00
Transcription	1:1 interviews w/o interpreters = £900.00 1:1 interviews with interpreters = £960.00 Workshops with interpreters = £1,890.00	£3750.00	One off cost	£3,750.00
GRAND TOTAL:				£25,778.00

TIMELINE:

	Y1	Y2	Y3
Literature review			
Develop research materials (Participant information sheet and presentation; consent forms; interview guide). Formalise relationship with partner institutions.			
Obtain ethical approval – in-county and Liverpool University			
Preliminary visit to case-study sites. Conduct PIS. Pilot interview guide.			

Refine interview guide. Contact consenting participants to coordinate interviews.				
Conduct interviews				
Data analysis				
Workshops				
Write up				
Public engagement				
Dissemination				

A flowchart of the research process is provided in Appendix 10.

INSURANCE:

AC has explored insurance implications of the proposed study with the University of Liverpool Insurance and Risk department, and no additional covers are deemed necessary.

BIBLIOGRAPHY (Alphabetical):

Allden, K., L. Jones, I. Weissbecker, M. Wessells, P. Bolton, T. Betancourt, Z. Hijazi, A. Galappatti, R. Yamout, P. Patel and A. Sumathipala (2009). "Mental health and psychosocial support in crisis and conflict: report of the Mental Health Working Group." Prehospital And Disaster Medicine **24 Suppl 2**: s217-s227

Amnesty International (2010) "‘As if hell fell on me’: The Human Rights Crisis in NorthWest C3" <http://www.amnesty.org/en/library/asset/ASA33/004/2010/en/1ea0b9e0-c79d-4f0f-a43d-98f7739ea92e/asa330042010en.pdf> (Accessed 22.03.2013).

Attanayake, V., R. McKay, et al. (2009). "Prevalence of mental disorders among children exposed to war: a systematic review of 7,920 children." Medicine, Conflict and Survival **25**(1): 4-19.

Asian Bioethics Review 2 (2) "Special Issue: Ethics of Disaster Research"

Chimento, Anna and Katie Bristow (2013) "Resources utilised by refugees and asylum seekers in the North West that foster resilience and promote wellbeing" NRES study no: 11/NW/0580

Dunn, M., M. Parker, M. Sheehan and T. Hope (2012). "Toward methodological innovation in empirical ethics research." Cambridge Quarterly of Healthcare Ethics **21**(4): 466-480

Ford, N., E. Mills, R. Zachariah and R. Upshur (2009). "Ethics of conducting research in conflict settings." Conflict and Health **3**(1): 7

Frith, L. (2009). "Process and consensus: ethical decision-making in the infertility clinic--a qualitative study." Journal of Medical Ethics **35**(11): 662-667

Frith, L. (2012). "Symbiotic Empirical Ethics: A Practical Methodology." Bioethics **26**(4): 198-206

- Guillemin, M. and L. Gillam (2004). "Ethics, Reflexivity, and "Ethically Important Moments" in Research", Qualitative Inquiry, **10**(2): 261-280
- Gubrium, J. F. and J. A. Holstein (1998). "Narrative Practice and the Coherence of Personal Stories." The Sociological Quarterly **39**(1): 163-187
- Hedgecoe, A. (2008) "Critical bioethics: beyond the social science critique of applied ethics" Bioethics **18** (2): 120-143
- Knightbridge, S. M., R. King, and T. J. Rolfe: (2006) "Using participatory action research in a community-based initiative addressing complex mental health needs" Australian and New Zealand Journal of Psychiatry **40** (4): 325-32
- Mackenzie, C., C. McDowell, et al. (2007). "Beyond 'do no harm': The challenge of constructing ethical relationships in refugee research." Journal of Refugee Studies **20**(2): 299-319.
- Mfutso-Bengo, J., F. Masiye, A. Muula (2008). "Ethical challenges in conducting research in humanitarian crisis situations." Malawi Medical Journal: The Journal Of Medical Association Of Malawi **20**(2): 46-49
- Molewijk, B., A. M. Stiggelbout, W. Otten, H. Dupis and J. Kievit (2004). "Empirical data and moral theory. A plea for integrated empirical ethics." Medicine, Health Care, And Philosophy **7**(1): 55-69
- QSR International (2010) NVivo qualitative data analysis software; QSR International Pty Ltd: Version 9
- Ritchie, J. and L. Spencer (1994) "Qualitative data analysis for applied policy research" in Bryman, A. And R. G. Burgess (eds) Analyzing Qualitative Data (London: Routledge): 173–194
- Summerfield, D. (2000). "Conflict And Health: War And Mental Health: A Brief Overview." BMJ: British Medical Journal **321** (7255): 232-235
- Schopper, D., R. Upshur, F. Matthys, J. Singh, S. Bandewar, A. Ahmad and E. van Dongen (2009). "Research Ethics Review in Humanitarian Contexts: The Experience of the Independent Ethics Review Board of Médecins Sans Frontières." PLoS Medicine **6**(7): 1-6
- Schutz, A. (1967) The Phenomenology of the Social World (North Western University Press) Translated by Walsh, G. And G. Lehnert
- The Sphere Project (2011). Humanitarian Charter and Minimum Standards in Humanitarian Response (Rugby: Practical Action Publishing)
- Sumathipala, A. and A. Jafarey (2010). "Ethical Issues in Post-Disaster Clinical Interventions and Research." Asian Bioethics Review **2**(2): 124-142
- Inter-Agency Standing committee (IASC) (2007). IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings (Geneva: IASC)
- Temple, B and R. Edwards (2002) "Interpreters/translators and cross-language research: reflexivity and border crossings", International Journal of Qualitative Methods **1**(2): 1-12
- Themnér, L. and P. Wallensteen (2012). "Armed Conflicts, 1946–2011." Journal of Peace Research **49**(4): 565-575

Tol, W. A., V. Patel, M. Tomlinson, F. Baingana, A. Galappatti, C. Panter-Brick, D. Silove, E. Sondorp, M. Wessells, and M. van Ommeren (2011). "Research Priorities for Mental Health and Psychosocial Support in Humanitarian Settings." *PLoS Med* **8**(9): e1001096

United Nations High Commissioner for Refugees (2013) "2013 Country Operations Profile – C3" <http://www.unhcr.org/pages/49e487016.html> (Accessed 22.03.2013).

United Nations High Commissioner for Refugees (2013) "2013 Country Operations Profile – C2" <http://www.unhcr.org/cgi-bin/texis/vtx/page?page=49e4878e6&submit=GO> (Accessed 22.03.2013).

United Nations High Commissioner for Refugees (2013) "2013 Country Operations Profile – C1" <http://www.unhcr.org/cgi-bin/texis/vtx/page?page=49e487856&submit=GO>. (Accessed 22.03.2013).

van der Burg, W. and T. van Willigenburg (1998) "Introduction" in van der Burg, W. and T. van Willigenburg (eds) *Reflective Equilibrium. Essays in Honour of Robert Heeger* (Dordrecht: Kluwer Academic Publishers)

Widdershoven, G., T. Abma, B. Molewijk (2009). "Empirical ethics as dialogical practice." *Bioethics* **23**(4): 236-248

Yin, R. K. (2009). *Case study research : design and methods*, Los Angeles, California: SAGE Publications. (4th ed)

APPENDIX 2: INTERVIEW TOPIC GUIDE



ETHICAL ISSUES IN POST-CONFLICT MENTAL HEALTH RESEARCH

Note: This is a draft topic guide. Exact questions will be refined to up to 6 main questions with follow-up prompts to elicit detail, depth, vividness, nuance and richness of narrative accounts (Rubin and Rubin: 2005). This will be achieved through in-country piloting, feedback from interpreters during training, and expert opinion. The topic guide will be in English only. At interpreter training translation of specific questions will be discussed and agreed by consensus.

1. Introduction:

- AC introduction, brief reminder of study including confirming consent.
 - Digital recorder.
- Interpreter introduction (if present)
- Ask participant to introduce themselves
- Brief overview of discussion:
 - No right or wrong answers. Interested in your experience as a researcher.
 - Talk for as long as would like about each topic.
 - In total would like to talk about nine topics. I may take notes as you are talking to help me remember what you have said.
 - Expect discussion to last approx 90 minutes, but it may go on for longer. Refreshments available. We can take a break at any point, please just ask if you would like to do this.

2. Participants background:

- How came to be researcher.
- How came to work for X organisation.
- What they enjoy about research, and what they find challenging.

3. Description of current research: (grand tour question)

- Mental health research with conflict / insurgency affected populations
- Describe experience of being involved in / conducting this research?

4. Brief explanation of upcoming questions:

- All relate to the way in which “ethics” is understood and applied when conducting mental health research in post-conflict settings.
- Interested in how procedural ethics (i.e. ethical guidance) relates to research practice.
- As mentioned, there are no right or wrong answers. Am interested in your experiences as a researcher and how ethics and ethical issues are managed in everyday research.

5. Procedural ethics (i.e. ethical guidance) - defining ethics:

- Describe your understanding of what “ethics” in mental health research with post-conflict populations means?
- What would your definition of “ethics” in mental health research with post-conflict populations include?
 - Does definition remain same for all groups i.e. women / children / severe mental difficulties?
 - If changes: what does this mean for how “ethics” is defined – is it a static or changing concept?
- Thinking about the definition of “ethics”: where does understanding come from?
 - E.g. something read / been taught / follows routine practice / learnt from observing others / a feeling / etc....
- Define unethical mental health research with post-conflict populations. Example?
- Define an “ethical consideration” in mental health research with post-conflict populations?
 - Revisit definition of “ethics” and explore differences. Why are there differences?
- Any key principles / beliefs that underpin definitions and understanding of ethics / ethical considerations?
 - Describe / illustrate these.

6. Ethics in practice:

- Thinking about the research process / research projects with post-conflict populations you are / have been involved in, when do you view “ethics” as arising? Examples?
 - Explain how situations involving ethics are identified?
- Describe areas of research practice that carry “ethical considerations”? Examples?
 - What is it about a situation / setting / event that highlights ethical considerations are involved?
- Describe situations conducting research with post-conflict populations where bad ethical decisions have been made / where you have felt research practice is unethical?
 - How did / would you manage this / these situation(s)?
 - Any reporting structure / processes in place to support this?
- Thinking about ethical practice, describe underlying principles / main beliefs that drive your practice?
- Are there processes that you / team / organisation follow to monitor how ethics is applied in everyday practice?
 - If yes: please describe. How effective are these at promoting ethics?

7. Interaction: procedural ethics (i.e. ethical guidance) and ethics in practice:

- What do you think the purpose of ethical review of research is?
- Describe understanding of the ethical review process i.e. developing research protocols / submitting to ethical review committees / getting ethical approval
 - Describe level of involvement in / contribution to this process.
 - Relation to / impact upon day-to-day research practice?
- Do you think ethical review processes help researchers to think about ethical issues that arise in research practice?
 - How / why / why not / examples?
- Describe ethics training you’ve had
 - Did this prepare you for thinking about ethics in practice / in the field?

8. Researcher integrity:

- Understanding of the idea of reflecting upon ethical research practice?
 - Importance of this for researchers?
 - What reflective tools do you engage with, if any (i.e. research diaries; supervision meetings or team meetings; etc)
- Understanding of the term “researcher integrity”?
 - If “don’t know” ask: Do you understand the term integrity? If no, explain: integrity means honesty / truthfulness / reliability. Can you now tell me what you think the term “researcher integrity” might mean?

9. Ethical awareness:

- Describe understanding of the relationship between ethics and mental health research?
- When do ethics / ethical considerations start in a research project with post-conflict populations?
- Role of ethics in everyday practice of mental health research with post-conflict populations?
- Should the role ethics plays in mental health research with post-conflict populations change?
 - Explore both procedural ethics roles and ethics in practice roles.
 - If so / if not: why / why not? How?

10. Closing:

- Anything to add? Other topics relevant to this discussion that have been missed?
- Anything else relating to your research experience that you would have liked to talk about today?
- Option: If you would like, am happy to share a full written transcript in English for you to read what you have said.
- Inform about group workshop plans. Is there anything based on this discussion you think it would be good to explore at the workshop?
- Thank participant (and interpreter if present).

APPENDIX 3: INTERPRETER GUIDELINES



ETHICAL ISSUES IN POST-CONFLICT MENTAL HEALTH RESEARCH

These guidelines provide an outline of conduct for interpreters engaged in interpreting for Anna Chiumento's PhD research project: ***Researcher's construction and management of ethical issues in post-conflict mental health research: a qualitative study.***

Interpreters' role:

- ❖ To aid participants in fully engaging with the research process
- ❖ To support, advise, and feedback to the researcher where appropriate
- ❖ To protect the interests of participants
- ❖ To maintain ethical standards of practice

Ethical considerations:

- Ensure fully informed consent of participants
- Ensure maintenance of confidentiality and anonymity
- Discuss any concerns or disclosures with the researcher at the earliest opportunity
- Remain vigilant towards research participant distress

Support for interpreters:

- The researcher will be available to support interpreters during in-country visits in resolving problems that may arise
- Debriefing following any interpretation
- One-to-one support available if required

Format of interpretation:

All translation is to use the third person.
Verbatim translation.
Consistency of translation is vital.
Accuracy and quality of all translation will be verified by third party.

Should you have queries relating to any of the above please contact:

Principal Investigator:

Prof Atif Rahman
University of Liverpool
0151 252 5509
atifr@liverpool.ac.uk

PhD Researcher:

Anna Chiumento
University of Liverpool
0151 795 5357
Anna.Chiumento@liverpool.ac.uk

APPENDIX 4: REFLECTIVE E-MAILS TO SUPERVISORS ON FIELDWORK PROGRESS FROM C1

e-mail 1: C1: 08.09.2014:

I thought I would just give you all a quick update on the progress of my fieldwork this past week:

- I conducted 9 interviews with potential interpreters on the first day I arrived. These were conducted jointly with 2 local staff who assisted in the selection process. I then selected 2 interpreters to work on the project (3 met the criteria and were equally as strong, after discussions with a member of staff who was working with one of them and some concerns about being able to train him I selected the other 2). These are 2 female interpreters, one straight out of her undergraduate degree who is with me in the field, and the second with a masters degree who is doing the quality checks.
- I conducted a 3 day training with the interpreters. The format came to be 2 days of background / getting to know one another / going through the slides; and a third day of just practice interviews. I learnt a lot through this process to do with training and also highlighting points that made me think about the interviews themselves (i.e. whilst both had experience of research for their degrees, neither had ever applied for ethics or read a set of ethical guidelines). Both interpreters were very engaged and active throughout, and quick to grasp the concepts. The pace of training was more than manageable, with plenty of time for reflection, feedback from them and to do additional side activities to support clarifying things. The final practice day was absolutely crucial and led to a steep learning curve for all of us – we were lucky to have a member of staff act as a practice interviewee which made a massive difference in terms of collective preparation. Some key thoughts on this:
 - Needing to keep concepts and the content of training focused upon what interpreters *need* to know to fulfil their role.
 - Getting a clear background of interpreters exposure to ethics and working with this – as in this training, adding in detail around what ethical review is, what a protocol looks like, what ethical guidelines typically cover etc.
 - Keeping language simple!
 - Allowing plenty of time for translation, re-translation, simplification of terms etc. In translating the research materials we have gone through 2 or 3 different versions for each, from the literal to the slightly simplified and restructured, to the key meanings in simple terms. In this we came across many terms that do not translate very well and where using the English is easier to understand i.e. for “ethics” there is not a word in {C1 language} that the interpreters had ever heard used. But the English is understood by all. Equally terms such as “research” has multiple translations, and in general the English is used. The position statement in particular has been a bit of a challenge because it uses more technical language – my mistake there! This process has been greatly assisted through informal discussions with experienced staff who have advised on the language they use with RA’s / within the organisation which we have then incorporated – thinking about internal organisational discourses and aiming to remain as close to participants understandings as possible this I believe makes sense.
 - This process also led to comments on the relative formality of the consent process as compared to what is normally practiced. Detail on data security – where stored, the protection of computers, that it is kept for 5 years etc, this is all overkill for this setting, and in fact may serve to create fear and thus socially desirable responses. I have basically found the best way to manage this is to work to make it as informal as

- possible and to again change terms i.e. from learning about “criminal behaviour and protection concerns” change this to “learning about harm to participants or self”.
- I think this process of translation and re-visiting terms / phrasing will need to be critically reflected upon. I am continually asking myself if these adaptations mean that I am moving away from what is contained in the document and therefore am I doing the same consent process – i.e. am I getting consent for what has been approved or for something different? And does glossing over some of the technical information invalidate consent, or make it more robust by increasing the validity of subsequent responses by the consent process being part of rapport building. On a broader level the fact that I have organisational support here makes me question the full informed consent process which is essentially confirming an implicitly agreed arrangement anyway – how free are the RA’s in particular to say no?!! So plenty to think about there.....!!
- Support from the main office staff has been amazing and has made all of my fieldwork logistics very smooth. I am in one field office again tomorrow, then move onto another on Wednesday and back to the capital on Saturday.
 - I arrived in the field on Saturday. The office days here are Sunday until Friday so was able to get stuck in on Sunday! Since then I have conducted 5 interviews: 2 with senior staff (one international, one head office) and 3 with field RA’s. Some thoughts on the interviews themselves:
 - Overall I think they are going well. Different topics are coming up and being explored, and there are also repeated key themes / ideas i.e. in relation to what ethics is / means.
 - As expected, senior staff have more to say – the 2 interviews with senior staff have been 1 hour 30 minutes each roughly (solely in English). With RA’s they are around an hour with interpretation.
 - My interview schedule has had to be flexible! 3 of the interviews have been rescheduled. 3 have taken place in the restaurant of the hotel I am staying in as this is most convenient. Every day I adapting to schedules and re-working when interviews will take place. Flexibility all round is a key theme!!
 - Interviews are complementing and building on each other, and I am doing de-briefing with the interpreter as well as us jointly listening back to recordings which is leading to (a) clarifications from interviews; and (b) identification of topics to explore in subsequent interviews.
 - There are also challenges, i.e. I have learnt that “training” here means something that is accredited. Therefore when asking about any ethics “training” they have had as part of their role here I am now using the term “orientation” which is much better understood. There are other words / phrases that I have learnt to avoid i.e. “checking” which carries connotations of right / wrong whereas I mean something more informal. So lots of language and phrasing issues to try and convey the questions I want to ask.
 - I have also added more grounded questions alongside the more abstract ones. Whilst the abstract questions are fine with senior staff who have a more in-depth understanding of ethical issues, for the RA’s they are producing off-topic / repetitive answers. The revised and more concrete questions are yielding results, for example asking if they have ever had an experience where a participant has become distressed or required a referral and exploring how this took place / what guided their actions in this context.

- There are many suggestions of things that could be implemented to further support ethics in practice. The senior staff are keen to pursue these – I am going to explore the possibility of my involvement in developing these and then using these as things to reflect upon in workshops which I think follows the research design and will hopefully lead to direct impact / benefits for the organisation – which ultimately is what I want to achieve!
- In terms of my interviewing practice / skills:
 - I feel as though whilst I am actively listening, taking notes, and identifying follow-up probes there is a niggling concern about whether I am taking the right directions and generating useful data for my research questions, or just following things that interest me.....! Having listened back to some of the interviews I don't think I am going to array. Or at least I hope not. I am putting this down to just being concerned about wanting to get the best and the "right" data – which of course is nonsense.
 - I need to be careful to formulate a question before communicating it! I am working on not speaking whilst I am still thinking – particularly where the interpreter is involved as this just leads to confusion all round!
 - Listening back to the interviews is often reassuring, and is making me identify where I should be asking for examples / where I have used a more closed or leading question and reminding me to avoid this etc.
 - A key challenge is actually that there are so many directions that I could explore I have to make a choice and probably miss out on exploring something else because the moment is lost as the conversation moves on. I guess that suggests the interviews are rich in data and I should stop worrying.....?!
 - I am trying to get new data in each interview as well as reconfirming key themes. For example, more recent interviews have explore researcher self-care / support more than initial ones which looked more at organisational systems.
- I will in total conduct 17 interviews here in C1. This includes 8 RA's; 3 field coordinators; 3 head office research coordinators; and 2 directors (one international, one local). I see the data in this country as almost being a case study within a case study i.e. data from across projects yields learning about standardisation across an organisation and across different projects working with different populations and focusing upon different aspects of mental health / psychosocial support. Therefore whilst this is a lot of interviews I think this is justified and will lead to a range of learning from this country. I also think as the first country some room for error / learning is required which hopefully will be less so in the other 2 countries as I will have this experience to draw upon.
- Each participant is being given a USB pen as a gift for participating in interviews – this was after some consultation with those in the office about an appropriate gift of the right value. I haven't actually spent all the funds I had allocated for this gift (makes me wonder if what I am providing is ethical as I said I would be giving them something more), but I am thinking I will carry these funds over to the workshops and perhaps bring chocolate from the UK for these as this is something I keep being asked for!!!
- Due to the nature of being embedded within the organisation for a month, and the informal conversations i.e. over lunch / whilst travelling etc I am getting a lot of general field notes to complement interviews (in case I need any additional data.....).

A big piece of learning from this study so far is that whilst I am researching this topic in relation to how others / the organisation manage ethics, it is also stimulating massive self-

reflection / learning and questioning of how ethical *my* project is, and indeed what it means to be conducting research ethically – is it about sticking to the protocol / the rules, or about behaving ethically and a deeper commitment? The nature of this topic really lends itself to this and I am trying to capture as much as possible this self-reflection in my research diary. I think a chapter in my final thesis on this would be really useful??

I will stop there. I could go on with more information about my experiences and data collection and thoughts. I am thoroughly enjoying this experience and am excited by the prospect of what comes out of the data, as well as loving spending time here in C1 trying new foods and seeing more and learning more about the country – including the odd word / phrase!

Any thoughts / reflections / suggestions you have based on what I have said above are welcomed. I will try to send weekly updates as I think this process of feeding back in some sort of structured way is also helpful for me – I hope you don't mind receiving the long e-mails!!

e-mail on transcription format: 15/09/2014

Just a quick e-mail to get your thoughts on transcription of interviews and the format that they should take. My aim is to get 3 interviews transcribed by the time I return – one by myself and one by each of the interpreters. This is in part because one of the interviewees spoke in English and his accent is so strong I don't fully understand the interview, so I feel this should be translated by one of the {C1 lanugae} speakers rather than myself.

Other thoughts in relation to transcription:

- Each of myself / the participant / the interpreter to have text in a different colour font, or size / type of font.
- To put a note of discussions in {C1 language} including the timing i.e. from 12:35 – 13:07. I was also thinking of identifying these sections of text using a symbol font to make it clear in the written transcription that a discussion is ongoing which I am not able to understand / be part of. This links with the aim of rendering the role of the interpreter explicit.
- Also to leave wrong grammar etc to retain the way things were said originally, again rendering the role of the interpreter explicit.
- To identify pauses / long pauses – in some interviews there were many thoughtful pauses and I think it is useful to identify this in the transcripts to demonstrate that the responses were considered. This is not for all pauses, but for those which are significant i.e. that signify a break in conversation.
- Through the quality check process we have additional points of clarifications. I was thinking of putting the transcript into a table format where the left hand column documents the discussion as recorded on the Dictaphone, with the right hand column for additional points of clarification / notes. This can also include things from my field notes i.e. hand gestures / thunderstorms / having tea provided etc which are not picked up by the recording itself.
- I was going to put line numbers in the transcripts too to aid analysis.
- In terms of identifying people I need to remove names etc, so will have to come up with pseudonyms for everyone that are used consistently throughout, i.e. X name becomes Y pseudonym. We have had one or two people identify pseudonyms they want to have which I shall use, but for the rest I was going to try and identify names from across the South Asian region and randomly assign them. This is in part to

ensure confidentiality and anonymity i.e. to have all names from C1 would again make it obvious where the study was conducted.

I have tried to think about what information it would be useful to include for the purpose of analysis. I don't want to go overboard, I am only doing thematic analysis hence don't feel I need detailed transcripts identifying absolutely everything, but there are some details which I think are relevant and useful to have.

Do you have any thoughts on this proposed format for transcripts? Anything from your experiences would be helpful.

e-mail 2: C1: 17.09.2014

This is instalment 2 of the reflections on fieldwork progress.....

- I have now conducted 14 interviews in total. Have another one tomorrow with the final RA, and then 2 next week one with the Executive director and another with a research coordinator. In terms of the interviews themselves:
 - Each one is still generating new information! For example during an interview this afternoon we discussed the issue of researcher self-care and its importance from an ethical perspective which had only been briefly touched upon until now. It is also only in interviews yesterday that I began to explore ethical issues around dissemination. I am also trying to get more examples / illustrations to bring the data to life as much as possible which is paying off. In terms of specific post-conflict I am asking this question and frequently being told that it applies equally, although from some with more direct experience i.e. of research with child soldiers am told that it depends on the time since the conflict. I think this is something that will be explored more in the other 2 countries where the conflict is closer / in the front of peoples minds and therefore the attitude may be different.
 - On Sunday after returning from the field I spent a few hours re-reading all of my notes on the interviews and pulling out key themes / things of interest / overarching ways to organise the information (whilst eating lunch in the "Garden of Dreams" which was a lovely peaceful environment). The common prevalent ethical principles identified / referred to are: informed consent processes; do no harm; voluntariness; protection of participant and researchers; confidentiality / anonymity; avoidance of stigma; risk / benefit; and cultural context. Also from the senior staff there is a framework of milestones or boundaries vs. in-between or grey areas which overlaps in many ways with procedural / in practice tensions. This review was great for helping me take stock and plan for the next set of interviews this week and next. It was also very reassuring to see how much was covered overall and the way themes were already jumping out of the data.
 - I am also finding moving from senior researchers to RA's and back again really helpful for cross-checking the information gathered and clarifying points of confusion. As such the data generated is very much a full set as opposed to discrete individual interviews. This also re-emphasises points about the knowledge of those at different levels and how well this is being shared / communicated.
 - I am still getting participants reflecting that they are enjoying the interview experience, and that it has been a learning opportunity for them to see how it feels to be in the chair being asked questions rather than asking them!
 - My interviewing practice:
 - I am relying upon the topic guide less and less. In some interviews this is just because the conversation is taking its own direction. In those where there is less to probe / follow-up I return to the guide more frequently. I am not sure if this is always a good thing, and in a couple of interviews have been

concerned that perhaps I have as a result of this followed-up on things which are somewhat off-topic but that interest me as a researcher. I think I raised this concern last time too.....there is a just a tension between exploring the topic from my understanding of what ethics encompasses, and from the (narrower) perspective of what many of the respondents view as ethics. I am checking this by exploring something and then asking participants if what has been discussed falls under ethics or something else, so am not exploring things and imposing my framework but exploring them and then asking where this fits for the participant.

- I feel a lot more relaxed, and as a result of the quality check process am very confident in the skills of the field interpreter who is in the interviews with me.
- Informed consent:
 - This is also becoming more elastic. Some is done in groups, some individually. 2 examples:
 - With a group of RA's yesterday they had the English sheet to read, and the interpreter provided a direct translation – i.e. the sheet was not read out in English at all. I then asked if there were any questions from participants and responded to these, and checked comprehension by asking a couple of clarifying questions. We are then discussing the ethical research reporting statement, and reading the principles themselves via direct translation.
 - Conversely this morning the participant requested just to read the sheet himself. We then had questions and I checked-back his understanding.
 - Still mulling over the ethics of these processes.....!
- Quality check:
 - This has also evolved. My plan was to check 10 minutes at the beginning, middle and end of each interview and rate the quality. However, through the experience of listening to the full interview with the interpreter whilst in the field this has also expanded. It includes:
 - The three of us (me and 2 interpreters) collectively listening to the recordings. Each of us can pause / clarify at any time. There is a lot of back and forth / checking / discussing as a result. A 1.5 hour interview takes 2- 2.5 hours to listen back in this way. When the field interpreter and I are conducting another interview then the quality check interpreter is either listening to an interview that I and the interpreter have already listened to, or is doing a new interview. In either case we then sit and discuss her findings as a team, and again listen back to sections where things have been identified that need to be clarified / changed / discussed.
 - In this process the interpreter conducting the quality check is making fresh notes on the conversation, the interpreter involved in the interview from the outset is checking her notes, and I am checking my notes.
 - All discrepancies – i.e. things missed or words that are not quite right - are being noted with time stamps in the {C1 language} text and where to add in the English text. This information will be used to insert these clarifications into the transcripts.
 - I see this evolved process as having many benefits, including:
 - My confidence in the data itself!
 - Me reviewing each interview and thinking about the lines of probing that have been followed / missed opportunities / things that I should have clarified etc. Also identifying poorly phrased or structured questions.

- As above, I see moving back and forth across the interviews as very useful – moving across the data to get to know key themes better and to be reminded of things to revisit / clarify / explore in more depth.
 - I also think it is helpful for the interpreter involved in interviews to clarify with the quality check interpreter the language she has used / better phrasing a etc. And to just discuss the information i.e. to learn about what a RCT is or what community health volunteer does – we are passing information back and forth across the team.
 - Essentially it encompasses a lot of reflection / self-reflection and in many ways is a capacity building exercise as well as a methodological check on the data quality.
- I also did some reflecting upon my status out here within this organisation / coming in as an outside researcher and doing this research etc. Basically thinking about power and relationships and positionality. I think there is certainly scope for me to think more about this, but getting down some notes whilst here felt very important to do!

That is the update on fieldwork itself.

I have also been starting to think about and have been asked a few times by researchers here about what next?! They like the workshop design and I am getting lots of requests to ensure I plan it for when people are around! Again there are also concrete ideas and things happening – for example the organisation have decided to develop ethical guidance / standards for internal use as a result of my study and recognising the importance of the topic. I have said I would like to support this process where possible. I have also been thinking in more depth about “what next” – I am wondering about the possibility of moving beyond this organisation itself to policy makers / other institutions and (with organisational support) disseminating general learning more widely. This could form the basis of “what next” in terms of a post-doc thinking about how to embed a wider research culture that is ethical – a key challenge here is that whilst there is a lot of research much of this is unethical i.e. no consent, no approval etc. So there is a need to train in ethical research when people arrive at this organisation because their prior experience relates only to unethical practice. In my mind I have been thinking about the ESRC opportunity of getting a(nother) extension to disseminate more widely – they offer 3 months so one month in each country - and use this as an opportunity to formulate follow-up research / implementation questions or proposals for future research. In essence I get the impression that what I am uncovering is the tip of a far bigger iceberg and there is plenty here to continue to explore and work with in the future.

Anyway, that is enough for this update! It is getting late and I need to cycle home before it gets dark (I hired a bike and helmet – made my journey into the office and back a quick 10 minutes which is great!). I am also planning on visiting another part of the country this weekend and taking a couple of clear days off to avoid burning out. It has been an intense 3 weeks and I think taking a step back over the weekend is a good idea to re-energise for the final week!

e-mail 3: C1: 25.09.2014

A little late, but this is my third and final fieldwork update instalment!

Firstly, I have been asked to present back preliminary findings from the research, which I am doing tomorrow lunchtime just before I leave. This is an open staff meeting at lunchtime and I have asked the interpreters to talk about their roles – one in the interviews and the other conducting the quality checks. In order to come up with the preliminary findings the interpreters and I read through all our notes from interviews / listening back to interviews and pulled out key themes. I have tried to summarise a few of these to share back and discuss. Every time I revisit my notes / the data there is a lot more that I could be adding in, but I have tried to focus on the points that are more organised / coherent (and probably a bit less interesting because of this!) I would appreciate any thoughts / comments based the attached. I realise that the slides are too busy but don't really have time to work on cutting them down etc.

Aside from that this week has also been productive. I was a bit unwell at the start of the week but all better now.

Transcription:

- o With the interpreters we have been focusing upon transcribing one interview each so I have the 3 shortest interviews all transcribed already.
- o It took the interpreters about 5 hours longer to complete than me – I think this was in part because I have transcribed before so found the process a bit quicker. But essentially a 1 hour 13 minute interview took me around 10 hours to transcribe. So I am going to be spending many an hour at this over the next month or so!
- o This has made me realise that I would benefit from transcription software to aid this process. I have been looking at f4 which looks good – has anyone used it / has any thoughts on it? They also have a cheap licence for student researchers, and I was going to contact them to check that the software would support the format that I am using so that it is compatible with the work already undertaken.
- o I would like to share and discuss the transcription we have done so far – Lucy / Atif, do you have any time next week to meet about this?

Interviews:

- o I completed the rest of the interviews, all of which were in English only and were with senior research staff so have allowed exploring ideas at an organisational level. More interesting data from these.
- o Looking back over all interviews there is clear progression in my skills and in the questions / probes asked. There is also evidence of different styles of interviewing with those in the field / who are data collections and those who are more senior. I think this is also reflected in my having worked with a number of the senior staff for longer so having a relationship – this comes through in the more “informal” approach to interviewing, and also to a certain extent a more challenging approach – i.e. I feel more comfortable challenging what they are saying than I do with the RA's. Of course this may also reflect the fact the interviews are more often in English and just my own comfort at not having the language barrier.

Administration:

- o I have certificates of participation in the training for the interpreters, and have written recommendation letters for them both. I will give these to them tomorrow and also pay them for their work! I have been extremely impressed with both of them and will conduct an exit interview / session tomorrow to get more feedback from them on this experience. I am also going to ask if they would be open to me

contacting them when I return for the workshop to participate as an interpreter again in those – this continuity would be a real bonus!!

- o I'm also tying up what I owe {C1 organisation} for administrative costs / time costs – they have been incredible in supporting all logistics, it really shows how much a knowledgeable in-country partner is required!

Potential spin-off projects from this research:

- o I have been asked to be involved in facilitating a workshop next time I come to C1 around qual research / data analysis. A number of the staff have been particularly interested in my approach to transcription and would like to know more about this. I am also being asked to do a training on ethics – which doesn't surprise me – but is something I may try to avoid until the final dissemination session when I should hopefully be very clear on what it would be useful to cover and how – i.e. what will be culturally relevant!
- o I have also been talking with one of the research coordinators who is heavily involved in national policy development. He is currently working with the government to develop a 5-10 year strategic research plan for C1, and would like to discuss with them bringing me on board to develop a specific section in this policy which speaks directly to ethical research conduct. He would also like to explore broader capacity building / ways to promote a research culture across institutions including the national health research council and universities – i.e. strengthening procedural ethics which is still pretty new in C1. I think there may be cross-learning here from C2 as I know that XXXXX and his team are currently working on strengthening the capacity of IRB boards in all hospitals in C2 – it could be interesting to learn from this approach for the Nepali context.
- o I have said I would like to explore / deliver / be involved in all of the above (The second bullet the colleague from C1 is talking about securing funding for so this would be supported time). From my PhD perspective this is great networking / exposure and speaks directly to impact – reaching beyond the academic to influence policy / practice etc. Finding the time for it all may be another separate challenge.....!!

C2 fieldwork:

- o I have been in contact to try and firm up revised dates for C2 fieldwork. I have been asked to teach on an introduction to qualitative research course they are running in December (which I agreed to a while ago as part of giving back to the organisation) and it is then being proposed that I stay and conduct fieldwork from 8th December, probably returning between Christmas and new year. I have a phone call with XXXX from C2 to discuss this next week. Timing isn't ideal for me in terms of missing family Christmas time, but equally I am keen to continue the momentum with data collection, and with the team all being available in the field at this time it seems practically to have this logistical support will be beneficial (it has certainly proven essential here in C1!).

Overall I am exhausted – it has been a tough but exhilarating 4 weeks! I'm really pleased with how everything has gone, I have certainly learnt a lot and will tweak things for the next country. I'm looking forward to getting back and getting stuck into transcription and analysis (and returning to the ethical approval paper which I have also been mulling over / discussing etc), and discussing all of this experience and the data with you all!

APPENDIX 5: TERMS OF AGREEMENT WITH HOST ORGANISATIONS & POSITION STATEMENT ON ETHICAL RESEARCH REPORTING



ETHICAL ISSUES IN POST-CONFLICT MENTAL HEALTH RESEARCH

TERMS OF REFERENCE TO ACT AS HOST INSTITUTION

These terms of reference relate to the conduct of Anna Chiumento's PhD study "Researcher's construction and management of ethical issues in post-conflict mental health research: a qualitative study" (hereafter "PhD study"). The agreement is between Anna Chiumento (hereafter AC) and The Organisation (hereafter "The Organisation").

The terms and conditions of this agreement are as follows:

1. Hosting AC's PhD Study:

The Organisation agree to host AC's PhD study for the agreed duration (see item 3), entailing:

- a. Reviewing PhD study materials to ensure study appropriateness to the country context, providing timely feedback to AC;
- b. Advise and support obtaining in-country ethical review;
- c. Provide logistical support during country visits for the conduct of research activities including: providing a workspace and internet connection, printing research materials, advising on in-country accommodation and local transport, etc.;
- d. Provide a venue for research events including: study related trainings (i.e. interpreter training), participant information session, individual in-depth interviews, participatory workshops, and dissemination events;
- e. Facilitate introductions to potential research participants;
- f. Identify and support recruitment and retention of interpreters;
- g. Respond to AC findings of unethical research practice, and / or criminal disclosure, following in-country procedures and in collaboration with AC;
- h. Review all publications, conference presentations and other dissemination resulting from AC's PhD study, commenting in a timely manner (additional publication terms: item 4).

2. AC responsibilities towards [name of organisation]:

- a. AC will provide The Organisation with all PhD study research materials for review by The Organisation prior to the conduct of research;
- b. AC will complete all required documents for ethical review, and will submit them to the identified ethical review committee in a timely manner;
- c. AC will liaise with Dr XXXXXXX at The Organisation to arrange in-country visits and agree dates and times for research events. Reasonable costs incurred by The Organisation in respect of time and materials will be agreed between The Organisation and AC to be reimbursed;

- d. AC will report to The Organisation any unethical research practice that is reported, or any criminal disclosure, to be responded to jointly between AC and The Organisation;
- e. AC will provide The Organisation with all publications resulting from this study for review prior to submission to academic journals, conferences or other dissemination for review and comment in a timely manner (additional study publications terms: item 4).
- f. AC will provide findings from the PhD study to The Organisation. This will be with the aim of improving ethical research practice at The Organisation, highlighting best practice, and identifying potential areas to strengthen organisational capacity. This may involve:
 - i. Development of The Organisation internal ethical procedures and / or documents;
 - ii. Delivery of research ethics training to organisation staff;
 - iii. Other appropriate activities, as agreed between AC and The Organisation.

3. Duration:

The terms of this agreement shall take effect on 1st October 2013, and terminate on 30th September 2017, or until the submission of AC's PhD thesis if an earlier date. Termination of these terms can be made by either party at any point during this study.

4. Publications resulting from AC's PhD Study:

All publications will be reviewed and approved by The Organisation prior to submission for publication. The Organisation reserve the right to request removal of text within publications if it believes publishing such materials will detrimentally impact the research services, relationships with funders, or reputation of The Organisation.

5. Confidentiality:

Unless by the requirement of national law, The Organisation agree to keep confidential and not to disclose to any third party the terms of this agreement and any information, know-how and intellectual property acquired in connection with the conduct of AC's PhD study.

6. Agreement modification:

Changes to the terms of this agreement shall be valid only if the change is made in writing and approved by mutual agreement of authorised representatives of the parties hereto.

The terms and conditions of this agreement are deemed confirmed by representatives of both parties signing this document.

Anna Chiumento:

Accepted by (signature):

Date:

{Organisation name}

Accepted by (signature):

Date:



POSITION STATEMENT ON ETHICAL RESEARCH REPORTING

ETHICAL ISSUES IN POST-CONFLICT MENTAL HEALTH RESEARCH

A key concern of the study “Ethical issues in post-conflict mental health research” is the protection of research participant anonymity, and the anonymity and confidentiality of descriptive data. This is an ethical issue concerning the risks to participants and the research teams they work with.

In particular, given the specialist nature of mental health research in post-conflict settings the ethical duty to protect research participants from potential reprisals is paramount. This is achieved through processes of anonymising data or abstracting the research to not identify its location. The targeting of health workers in the case study countries has been known, reinforcing the importance of developing clear consensus on protecting participants through ethical reporting.

Principles of ethical reporting:

1. Confidentiality of research participants will be maintained by the use of pseudonyms in the place of names in all research reports. Participants will be allocated a pseudonym. Should the participant be unwilling to identify a pseudonym one will be allocated to them by AC.
2. No raw, unedited data will be made publically available immediately after the study. A timeframe for public access to this data will be agreed with each country participants.
3. Research sites will not be identified i.e. no country names, regions or sites will be identified.
Instead, research will be identified as conducted at “three South-Asian countries with recent histories of conflict”.
4. Identifying details of research studies such as the sites, populations and mental health condition being researched will be abstracted. For example: “a study conducted in a South-Asian country with women”.
5. All potential identifying information will be removed from quotations such as names, places, and details of research studies. This removal of information will extend to details about rebel or militant activities such as names of groups, and specific events.
6. Partner organisations facilitating this study will not be identified. They will instead be referred to as “in country partner organisation(s)”.
7. Funding source will be identified as the Economic and Social Research Council.

Consultation on these principles:

Ethical reporting standards will form one aspect of workshop discussions with participants. As such, final study reporting will adhere to the most stringent of the ethical standards identified and approved by research participants.

Publications and dissemination activities arising out of this study will adhere to the standards agreed with participants. Some publications may occur prior to data collection, and will follow ethical reporting standards outlined in the position statement, developed through expert consultation including in-country partners. Final research reporting including quotations and other research materials will adhere to the ethical reporting standards identified by participants at workshops.

Conference presentations and other dissemination will adhere to the same level of ethical reporting standards. Study reporting to in-country partner organisations, dissemination at regional and global NIH hub meetings, and a full PhD Thesis deposited in the University of Liverpool Library will similarly adhere to ethical reporting standards.

The approach towards ethical research reporting taken by this study will be critically reflected upon in the PhD thesis and publications as appropriate, examining the benefits and constraints.

APPENDIX 6: DISSEMINATION HANDOUT

RESEARCH ETHICS FOR MENTAL HEALTH RESEARCH IN POST-CONFLICT SETTINGS

FINDINGS FROM A QUALITATIVE STUDY

INTRODUCTION:

Conducting research in post-conflict settings is essential to evidenced-based responses to mental health and psychosocial needs of individuals and communities. Research in all settings must be conducted ethically. The relevance of ethical standards to diverse settings is contested. For example, some argue that mental health research investigates a topic that can be sensitive and stigmatised; or that post-conflict or emergency settings can increase research participants' vulnerability to exploitation as a result of their dependent living status. In both cases the response is to call for more stringent ethical standards to ensure research participants are protected from harm.

Researchers' experience of mental health research ethics in emergency-affected settings has not been investigated. To address this gap this study involved speaking with researchers conducting mental health research in three post-conflict settings in South Asia. As Kingori et al (2013) observe, research ethics "comes into being when it is translated from the abstract into the local idioms of the places where it is enacted" (p.262). Therefore, to understand it we must look to the sites where research ethics is practiced, and to the people who are practicing it.

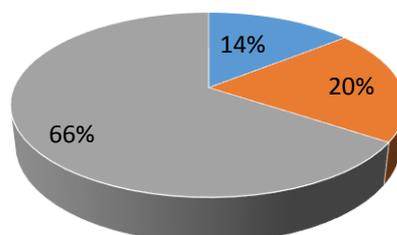
Research findings show that researchers are equipped for following procedural research processes such as ethical review. However, the focus of procedural ethics upon auditable outputs including signed informed consent forms leads to suppression of the socio-culturally embedded nature of obtaining such documents. This focus on procedures impacts upon organisational approaches to ethics which prioritise training fieldworkers about rules to be followed. To balance this, organisations promote paying attention to the social context in which fieldworkers operate through training in communication skills and cultural competency, and practicing interviewing. Therefore, from the pre-written rules ethics is locally adapted when applied to practice. It is recommended that further approaches are developed to better connect procedural ethics to ethics-in-practice. This can be achieved by moving away from research ethics as governance and auditing, to recognise research ethics as ultimately embedded within social interactions.

RESEARCH APPROACH:

Research was conducted in three countries between September 2014 and February 2015. It involved individual interviews with 35 researchers, including principal investigators, research / field coordinators, and fieldworkers / data collectors:

Research participants

- Principal investigators (n=5)
- Research / field coordinators (n=7)
- Field researchers / data collectors (n=23)



Where required, interpreters participated in interviews. All interpreters were employed for the duration of in-country data collection, and were trained and supervised in their role by the lead researcher (AC). Interviews were recorded on Dictaphones and the English conversation transcribed for analysis. Data analysis involved reviewing all interviews to identify key themes and illustrating quotes, presented in the results.

RESULTS:

Researchers felt that ***“ethics is the soul of research”***. When discussing levels of ethical oversight, researchers felt that the *“mental health field is more sensitive”* in their settings due to the stigma attached to mental health problems. Addressing this was not seen to require separate or more detailed ethical standards. Instead, giving ethical considerations *“more stress”* was seen as the best way to address the sensitivity of mental health research. Therefore, **researchers viewed existing standards as sufficient for addressing the ethical considerations in mental health research, but emphasised attention to how the topic of mental health requires cultural sensitivity.**

Researchers highlight recognising and addressing contextual considerations that arise as a result of exposure to conflict or disaster. Contextual factors identified by researchers included awareness of potential individual and community vulnerability to harm following an emergency. Researchers felt being locally embedded was an important way to identify and respond to such factors by gaining a *“deep understanding”* of the population. This involved, for example, building community links to appropriately enter settings; knowledge of how research and mental health are understood by the local population; and of the different social, age, gender, economic, ethnic and religious statuses of those that research may engage with. These emphasise that **what is and is not ethical is determined by the context in which research is carried out.**

Procedural research ethics:

Procedural research ethics includes the processes involved in applying for and securing ethical approval. Researchers viewed the requirement to obtain ethical review of research positively, recognising the value of having someone independent *“to have seen what you’re*

going to do and approved it". Researchers described the role of ethical review boards⁴³ (ERB) as a "guardian", "protector", and "gatekeeper" with responsibility for "safeguarding" ethical duties. In carrying out this role, researchers felt that ERB's should facilitate research and not be punitive.

When describing developing documents for ethical review, researchers acknowledged that **"ethics forms are almost written to template now"**. This meant that procedures approved in the past were often recycled, rather than thinking about what may be required for a specific study. As one researcher recognised *"do we tailor make our ethical processes enough to the population? Er, the short answer is probably not."* Reasons for this stem from the necessity of gaining ethical approval to allow research to go ahead. This encourages

Box 1: Ethical review boards overstepping their remit?

Researchers described a Western ERB removing research questions about suicide prevalence because they felt this topic was sensitive in South Asian cultures, and therefore could not be asked. Whilst the researchers recognised that suicide was a sensitive topic in the community, they felt had ways to manage this sensitivity through researcher training and how such questions were positioned.

However, because researchers must follow the instructions of the ethical review board, these questions were removed to allow research to go ahead.

The researchers questioned if making these changes was this was the ERBs role. They felt their local knowledge and experience made them better placed to make decisions about what could and could not be asked to the community without causing harm.

researchers' to ignore the context in which ethics is to be applied when writing ethics forms. As a result, researchers present an ideal vision of a research studies potential ethical issues on ethics forms that may not relate to the realities of research-in-practice. This led to researchers viewing procedural ethics as *"us trying to make [the reviewers] happy and [the reviewers] are looking for those...answers that make them happy"*.

One reason for researchers prioritising what they thought ERB's wanted to hear was experiences of ERB's acting as *"law enforcement officers....getting carried away with enforcing the law"* (see box 1). Researchers felt that **the expertise lacked by ethical review boards included both knowledge and experience of mental health research, and of working in emergency settings**. This lack of expertise led to ERB's unjustifiably limiting the scope of research in the name of ethics. Such experiences led to the suggestion that researchers are *"vulnerable to the ethics...review"*.

Therefore, researcher's descriptions of procedural ethics saw the process as one of external control with which they had to comply to enable research to take place.

Whilst in some cases this process was seen to enhance research conduct, the overriding view was that this is a hurdle that must be overcome to allow research to commence.

In-practice research ethics:

⁴³ The term "ethical review board" is used here, however other terms include "ethical review committee" and "institutional review board". All refer broadly to the same system of a body that reviews and approves research for conduct.

In-practice research ethics refers to the day-to-day practice of ethics in research, often including ethical considerations not foreseen at the ethical approval stage. Following researchers' views that procedural ethics processes discourage attention to the context in which research is to be conducted, one researcher observed that ***“the issues actually come when you go into the field...most of the things we experience...are not written in books, you don't find them in guidelines”***. This highlights the gap between procedural and in-practice ethics.

All organisations stressed the importance of addressing cultural context. One way they sought to ensure cultural sensitivity was by hiring and training local community members as field data collectors, seen as important for *“developing the capacity of the local peoples on research and...mental health”*.

Developing fieldworker capacity was achieved through targeting training to the specific research project being conducted. Training content included background theory about research methods and an introduction to mental health. Training also addressed research practice through developing communication skills such as using lay language and suitable terminology when discussing mental health, and understanding how to dress appropriately. **All researchers felt an important aspect of training was learning by doing.** This included practicing taking informed consent and using mental health instruments, and was essential to putting knowledge into practice: *“you can give theoretical training but unless you go and put them in the field [they] will never learn”*.

Therefore, researchers were clear that ethical research practice requires more than the knowledge of procedures to be followed, emphasising the importance of understanding and responding to research context. This was seen as one aspect of researcher integrity: *“integrity...are people confidential...do they have interviewing skills that...are matching the*

Box 2: Ethical exams: a way to confirm competency for ethical practice?

Principal Investigators (PI's) described ethical exams mandated by funders as: *“incredibly crap...[a] tick box for the PI, well that's pretty shit...you've got to answer the question if you're not sure go back to your text and get the answer ((laughing)). I mean come on!”* Thus the exam process was described as tick-box ethics that is out of line with the PI role which entails ultimate responsibility for ethical research conduct.

Despite these criticisms, in one organisation an ethical exam was replicated for fieldworkers. A short questionnaire aimed to assess basic knowledge of key ethical principles that arise in fieldwork, such as obtaining informed consent and maintaining confidentiality. An arbitrary pass mark was set to be deemed competent to go into the field. This was viewed as a *“defence against...malpractice because you could easily say everybody's trained, let's go!”*

Senior researchers viewed the ethical exam as helpful for assessing fieldworkers' understanding, recognising that after training *“we cannot...assume that all people...have the same level of understanding”*. However, it was acknowledged that the exam could only assess basic knowledge, and not how this knowledge was applied in practice.

Therefore, at both the international and local level, efforts to ensure ethics through check-box exams were recognised to only be able to assess theoretical knowledge, and never how ethics is contextually applied in practice. This inherent limitation means ethical exams can never confirm competency of ethical practice.

vulnerabilities and sensitivity...we have quite a bit of emphasis on... communication...and...sensitive interviewing skills. Training in these aspects were important for equipping fieldworkers with skills *“to handle the situations”* that arise in the field. Support for fieldworkers continued during research conduct through regular supervision with opportunities to share and address difficulties that arose in the field.

Despite recognising the importance of moving beyond research procedures, the ethical component of fieldworker training was described to focus upon auditable governance steps such as obtaining informed consent and managing the physical informed consent form. This was based on the purpose of training being: *“not to give a whole education in bioethics because that’s not the purpose, they were recruited to collect data”*. Therefore, the ethics component of training was reduced to the *“rules and regulations”* that fieldworkers must apply.

Supervisors and senior researchers delivering training described aiming to ensure a *“standardised”* and *“uniform”* process where everyone conducts research in the same way (see box 2 for how this was assessed). The reason for this focus was acknowledged by a senior researcher as the pressure of multiple large projects. This suggests that external organisations such as funders encourage researchers to prioritise producing auditable ethical outputs. This results in organisations searching for standardised ways to conduct research that are unlikely to respond to the complexities that arise when applying ethics in the field, as commented by a fieldworker: ***“you will be er neutral. You will...take the information...as if you are a machine”***.

Training for supervisors and senior researchers was described as more in-depth and less structured. This was required to instil a deeper appreciation of ethics that enabled supervisors to support fieldworkers flexibly applying ethical principles in the field. Above the supervisors, the Principal Investigator role in conducting research ethically was viewed as: *“crucially important, you are responsible for the integrity of the research”*.

Ultimately, when considering ethics-in-practice senior researchers saw the role of trust as central: ***“the trust he has on his...research assistants, that is enough, rather than...checking on every aspect”***. This emphasises that no amount of procedures, exams, or checks in the field can *assure* ethical practice. Rather, what are required are relationships between fieldworkers and supervisors that promote honesty and mutual support to conduct research ethically.

CONCLUSION:

This study investigates researcher’s views of research ethics when conducting mental health research in post-conflict settings. It has explored procedural ethics processes such as ethical review, and how these procedures are translated into practice through training. Findings emphasise that ***“if they are [a] researcher then already they are bonded with the ethics”***, and that organisations are striving to find ways to achieve ethical practice.

Results show that organisations are confident about procedural ethics processes. They also recognised the limitations to these processes, notably the disconnect between procedural ethics and ethics-in-practice. This emphasises how form-filling is inherently limited in its ability to capture and respond to complex social realities that fieldworkers will encounter when conducting research. To address this, fieldworker training aims to instil ethical integrity that promotes the socio-culturally appropriate application of ethics. This is

achieved for example through sensitivity to research participant's potential vulnerability to harm, and effective communication skills. Therefore, the organisations in this study are working to "bring the question of ethics – too often neglected to a one off aspect of the research process – to something that suffuses all we do" (Harper: 2007, p.2241). Steps to support these efforts are suggested in the implications and recommendations.

IMPLICATIONS AND RECOMMENDATIONS:

Research implications are that:

- If procedural ethics better reflected in-practice field realities this would help researchers prepare for fieldwork by considering the context in which ethics is applied.
- The focus on auditable procedures by funders and ethical review boards such as checking signed informed consent forms detracts from the processes behind obtaining these documents which are socio-culturally embedded.

Key recommendations are:

- Research ethics committees and researchers should explore ways to ensure the ethical review of research is responsive to the context in which research is to be practiced. This could be achieved by adjusting the research protocol to allow space for documenting cultural and social context and how these may affect ethics-in-practice; or by including face-to-face contact between research ethics boards and researchers to discuss how procedures are to put into practice.
- Identify content and methods for fieldworker research ethics training that bridge the gap between procedural and in-practice ethics.
- Develop supervision approaches that encourage open reflection upon the ethical challenges that arise in fieldwork.
- Researchers should continue to document and disseminate their experiences of research ethics from which others can learn.

References:

Harper, I (2007) "Translating ethics: researching public health and medical practices in Nepal"; *Social Sciences and Medicine*; **65**: 2235-2247

Kingori, P; de Vries, R; and Orfail, K (2013) "Special issue introduction: bioethics in the field"; *Social Sciences and Medicine*; **98**: 260-263

Acknowledgements:

Research was conducted by Anna Chiumento for her Doctoral studies, supervised by Professor Atif Rahman and Drs' Lucy Frith and Laura Machin. She is funded by the UK Economic and Social Research Council [ES/J500094/1]. We would like to thank interpreters for their role in facilitating participation in this study, and the participating organisations and researchers for sharing their views on this topic.