How Mental Health Lived Experience Roles are Experienced by Those Undertaking Them and Perceived by Those Working Alongside Them.

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Contents

	Word Count	**References**	**Total**
Thesis Overview	406	193	599
Systematic Review	6999	1561	8560
Empirical Research	14061	1801	15862
Appendices	3051		3051
Total	24517	3555	28072

Thesis Overview

Work roles that use an individuals' lived experience of mental health difficulties are increasingly being funded within the National Health Service (NHS) due, in part, to their presence within the Five Year Forward View for Mental Health (2014) and NHS Long Term Plan (2019). Research focusing on these roles has often focused on the outcomes for services or service users. Increasing consideration is being given to how individuals undertaking these roles have experienced them (Ibrahim et al., 2019; Kemp & Henderson, 2012; Otte et al., 2020; Tate et al., 2021). Despite this, research within this area is not extensive.

This thesis consists of two papers both of which have been prepared for submission in the British Journal of Clinical Psychology, though the word count has been exceeded due to the requirements of the thesis (appendix 1). The first chapter is a systematic literature review which aimed to answer the following research question: 'How do mental health professionals perceive and value Peer Support Workers?'. Nine papers were identified through systematic searches. These were quality appraised and thematic synthesis was used to identify five analytic themes: 'the value inherent in the uniqueness of the PSW role', The benefits mental health services gain from employing PSW', 'The factors required for successful implementation', 'The essence of PSW brings concern', and 'Mental health professionals conscious and unconscious biases'.

The second chapter is a piece of original empirical research that utilised a grounded theory methodology with interviews being conducted with eleven individuals who participate in roles that utilise their lived experience of mental health difficulties within a mental health setting (LX roles). This paper explored the impact of participating in these roles on individuals emotional, social, and professional identity. A theoretical model was developed to represent the findings and highlighted the importance of individuals feeling valued and unvalued and the factors that impact upon this. The following themes were identified: -

‘valued’, ‘feeling unvalued’, ‘emotional rollercoaster’, ‘the only way is up’, ‘future goals’, ‘motivations for doing the roles’, ‘power’, ‘service and organisational culture’, ‘relationships’, and ‘development of critical appraisal’.

Both papers illustrated and highlighted the importance of ensuring that LX roles are implemented appropriately with the requisite support structures. When this did not occur, LX roles were perceived to be tokenistic, and stigma and discrimination were apparent with participants recounting being harmed by the roles. When LX roles were appropriately embedded within team’s mental health professionals ascribed value to the roles. Individuals undertaking them reported an increased sense of confidence and felt motivated to continue participating in them.

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Chapter one

Mental Health Professionals Perceptions of Peer Support Workers: A Systematic Review

Abstract

Peer Support Worker (PSW) roles are increasingly being developed and funded within mental health services. This systematic review considers how mental health professionals and services perceive and value PSWs. Nine research studies were identified through systematically searching four databases, hand searching Google Scholar and forward citation chaining in April 2021. These studies were quality appraised by two independent reviewers before being thematically synthesised. Five analytic themes were identified: 'the value inherent in the uniqueness of the PSW role', The benefits mental health services gain from employing PSW', 'The factors required for successful implementation', 'The essence of PSW brings concern', and 'Mental health professionals conscious and unconscious biases'. Overall, mental health professionals tended to perceive and in turn value PSWs positively, this was not universal with some holding discriminatory and stigmatising beliefs and attitudes towards PSWs; this appeared to be mediated by the impact of successfully implementing PSW roles. Therefore, services need to pay consideration to this process whilst also being aware that mental health professionals may hold discriminatory attitudes toward PSWs and actively work towards reducing this ensuring that the roles are positively perceived and valued.

Introduction

Peer support has been seen to occur throughout history when service users come together to provide informal support to one another, eventually leading to the development of campaigning groups and user-led organisations (Faulkner & Basset, 2012). This resulted in the development of 'Peer-Developed Peer Support' which is "led by people using mental health services" (Stamou, 2014, p.1; Penney, 2018). The roots of which belong in the aforementioned campaigning groups. In turn, peer support's ideologies are based on political and human rights activism which were influenced by the human and civil rights movements from the 1960's (Penney, 2018).

Twenty years ago, in America peer and carer led self-help groups, organisations and services greatly exceed (by more than double) the number of traditional mental health organisations e.g., psychiatric hospitals and community services (Goldstrom et al., 2006). This expansion within the United States, suggests considerable appetite for this type of service provision, but the growth of paid PSW roles within existing mental health services in the United Kingdom has not occurred at the same rate (Repper & Carter, 2011). An increasing focus on the recovery model, as well as the emphasis on the roles within the Five Year Forward View for Mental Health (2014) and NHS Long Term Plan (2019) has assisted somewhat with the growth of the peer workforce, and aspirations of several thousand new roles with ringfenced funding available as a result of the latter.

As a result of the predicted expansion in roles ‘The Competence Framework for Mental Health Peer Support Workers’ was developed to outline the core skills required for PSWs (Health Education England, 2020). This may go some way to developing a more formal agreement of what a PSW is, or even consensus as to the job title with Peer Mentor, Peer Specialist amongst others being used (Repper and Carter, 2011). This is important to help to protect PSWs by providing some clarity over what the role entails. However, it is important to recognise widespread criticism of how the framework was developed, with concerns being raised about limited involvement from the wider service user community. As such, service user groups such as the National Survivor User Network (NSUN) believe that the framework is in turn co-opting peer support from its grassroots focus on equal relationships, by professionalising the role with its focus on more psychological interventions (NSUN, 2020; Recovery in the Bin, 2020).

The growth in employment of PSWs in existing mental health services has led to reviews and meta-analyses being conducted to look at the impact on service users working with a PSW. These reviews have found that whilst peer support is less likely to impact on clinical outcomes, there was a positive effect on measures of recovery, hope and empowerment (Lloyd-Evans et al., 2014; White, 2020). With peer support operating under the recovery model, it is perhaps not unsurprising to consider that the factors that show a positive impact partly concord with the CHIME framework which outlines 13 characteristics e.g., hope, optimism and empowerment associated with an individual's recovery journey (Leamy et al., 2011).

In relation to how different stakeholders view PSWs, consideration must be given to the ongoing concerns around formalising Peer Support. These consider whether the essence of peer support may be lost in this formalisation process due to it so often relying on the natural establishment of good relationships (Faulkner & Basset, 2010; Lawton-Smith, 2013). However, research has found that service users perceive PSWs favourably and, by extension, PSWs facilitate increased trust and improved perceptions of mental health services (Rosenberg & Argentzell, 2018).

PSWs have described a range of experiences relating to how they find the roles but frequently, the challenges experienced when working with registered professionals is highlighted (Kemp & Henderson, 2012; Otte et al., 2020). Some studies look at a number of different stakeholders' views including PSWs and Non-Peer Professionals. These found individuals describing the impact of a lack of role clarity and how it impacted understanding of the roles (Cabral et al., 2014). Others described the process needed for PSWs to navigate their way through existing hierarchies in order for PSWs to become valued members of the wider professional team (Berry et al., 2011; Ehrlich, 2019).

Therefore, the viewpoint of mental health professionals is important to consider in order to understand more about how they perceive PSWs. At times it has been suggested that mental health professionals may have a less favourable view of PSWs and this is perhaps one of the reasons that the peer support workforce has not grown as quickly. This in turn may be as a result of some of the issues inherently present such as stigma (Repper & Carter, 2011). Having a clearer understanding of the views of mental health professionals will allow consideration to be given to some of the challenges PSWs face whilst undertaking this work and consider how best to establish these roles effectively in order to adequately support all involved.

Aims

This systematic review aims to identify and critically appraise qualitative research in order to explore in depth personal qualitative accounts that consider how mental health professionals view PSWs and address the question, "How do mental health professionals perceive and value Peer Support Workers?"

Method

Search strategy

Systematic searches of the literature were conducted in April 2021. When developing the search strategy input from a specialist librarian was sought. The following databases were searched PSYCHINFO, MEDLINE, CINAHL and SCOPUS. No exclusions were made on date of publication. The SPIDER tool developed by Cooke et al, (2012) was used to help develop the search strategy which was as follows:

Sample – Mental health professionals and Mental Health services

Phenomenon of Interest – Mental health peer support in adults

Design – Questionnaires, surveys, interviews, focus groups, case studies (qualitative)

Evaluation – Perception & value

Research Type – Qualitative or mixed methods (with a significant qualitative component).

The key concepts were identified as follows: ‘Mental Health Professionals and Services’, ‘Perceive’, and ‘Peer Work’. Thesaurus were searched to get the full search strategy which is outlined in Table 1

Table 1

Search strategy used

	Concept 1	**Concept 2**	**Concept 3**
Key concepts	Mental health professionals and services	Perceive	Peer work
	Mental health service	Perceive*	Peer Provider*
	Psychiatric services	Perception	Peer Support
	Mental health care	Recogni*	Peer Supporter*
	Community mental health	View	Peer specialist*
	services	Understand	Peer work
	CMHT	Understood	Peer Worker*
	Psychiatric hospital	Acknowledge*	Consumer provider*
	Psychiatric department	Comprehend	Consumer survivor*
	Mental health professional	Value*	Prosumers
	Psychiatry professional		PSW
	Psychiatric nursing		Peer Support Workers
	CPN		Peer Mentor*
	Occupational therapist		
	Social worker		
	Psychiatrist		
	Psychologist		

Forward citation chaining and hand searching of Google Scholar was utilised to identify additional publications. The PROSPERO database was searched to identify existing reviews and to ensure that no similar review was planned. Zotero software was used to import the articles, remove duplicates, and was used to aid the screening process.

Inclusion and exclusion criteria

The studies were screened using the inclusion and exclusion criteria outlined in Table 2.

Table 2

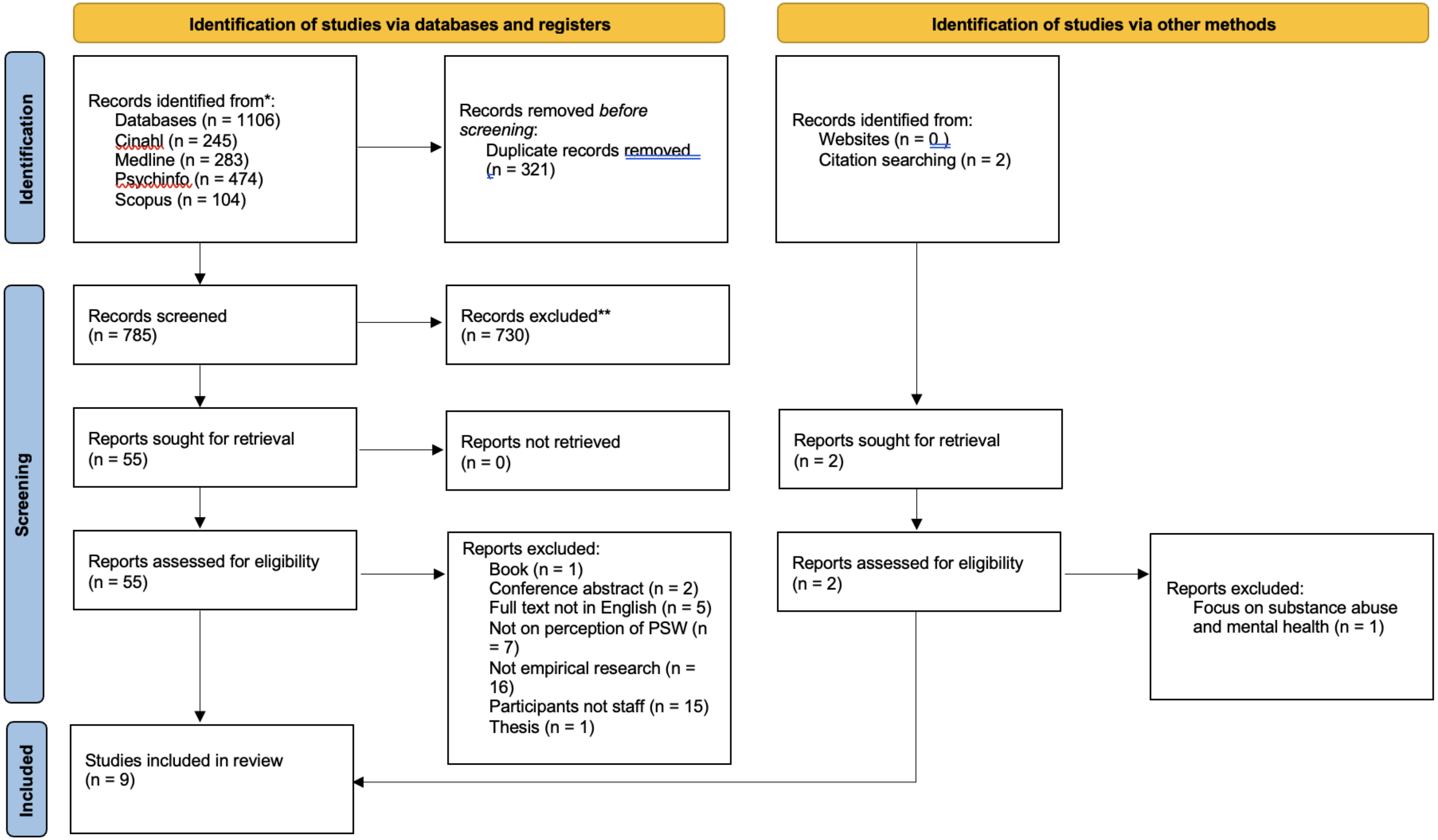
Inclusion and Exclusion Criteria

The inclusion criteria	**The exclusion criteria**
Research published in peer review journals.	Quantitative research only.
Research that was published in English.	Studies focusing on non-mental health peer support, informal peer support or on peer support focused on under 18's.
Qualitative or mixed method papers (with a substantive amount of qualitative data).	Studies that focus on dual diagnosis.
Research that focused on mental health professionals' views of PSWs.	Studies that focus on settings that are not explicitly mental health services.
	Non peer reviewed articles.
	Studies that focus on veterans' health care.

Screening and selection

The search yielded 1106 articles, following the removal of duplicates, 785 articles remained. Whilst all of the titles and abstracts were screened by researcher (CH), to ensure transparency 50 of these papers were chosen at random and the abstract and title was screened by the primary supervisor. Once the full text papers (n = 55) had been reviewed against the inclusion and exclusion criteria, discussion took place with the study team regarding three papers where it was unclear, with consensus reached. It was therefore agreed that nine papers would be included. Figure 1 is the Prisma flow diagram outlining this process (Page et al., 2021)

Figure 1 - *Prisma flow diagram*



Quality assessment

The Critical Appraisal Skills Programme (CASP, 2018) tool for qualitative research was used to appraise the quality of the studies. (See appendix 2). The CASP was chosen as it is frequently used to appraise qualitative health research and focuses on whether the research methodology is appropriate and in turn if the findings are well presented and meaningful (Long et al., 2020; Spencer et al., 2012).

No papers were excluded on quality grounds as it was deemed important to not restrict possible insights on this basis. Quality assessment was used to consider how the study's quality may impact on the findings and this is discussed in the results section. Quality appraisal was done independently by two researchers (CH and SN). They then met to come to a consensus and resolve any disagreements that arose. Table 3 gives an overview of each study's performance on the CASP.

Table 3

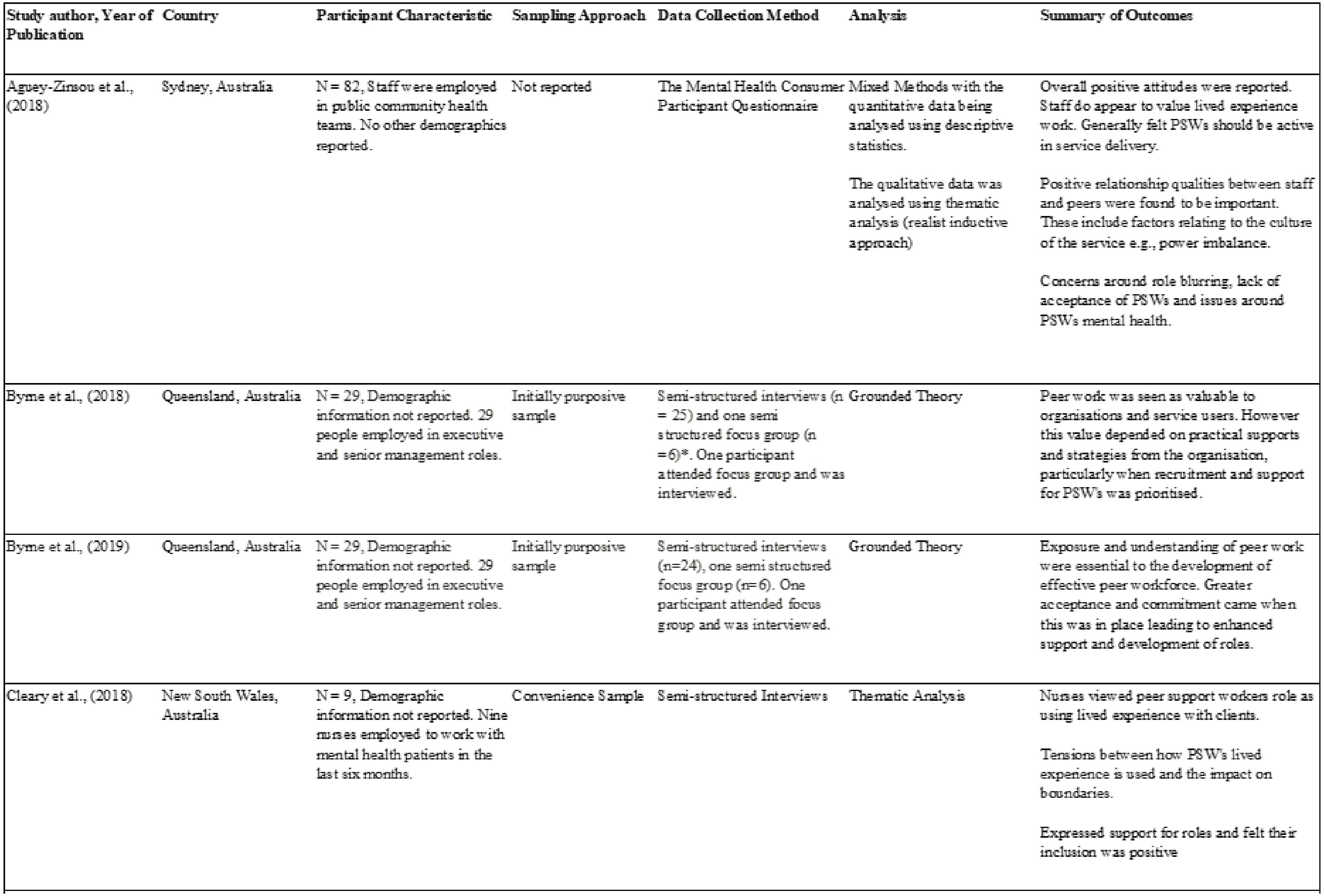
How the studies performed on the Critical Appraisal Skills Programme

Paper title	**Aims of research**	**Methodology appropriate**	**Research design appropriate**	**Recruitment strategy**	**Data collection**	**Relationship**	**Ethical issues**	**Data analysis**	**Statement of findings**	**Value of research**
Aguey-Zinsou et al., (2018)	yes	yes	yes	yes	yes	no	yes	yes	yes	yes
Byrne et al., (2018)	yes	yes	yes	yes	yes	no	yes	yes	yes	yes
Byrne et al., (2019)	yes	yes	yes	yes	yes	no	yes	yes	yes	yes
Cleary et al., (2018)	yes	yes	yes	yes	yes	no	can't tell	yes	yes	yes
Collins et al., (2016)	yes	yes	yes	yes	yes	yes	no	yes	yes	yes
Kilpatrick et al., (2017)	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Korsbek et al., (2021)	yes	yes	yes	yes	yes	yes	no	yes	yes	yes
Moore & Zeeman, (2020)	yes	yes	yes	yes	yes	yes	can't tell	yes	yes	yes
Waynor & Pratt, (2012)	yes	yes	yes	yes	yes	no	can't tell	yes	yes	yes

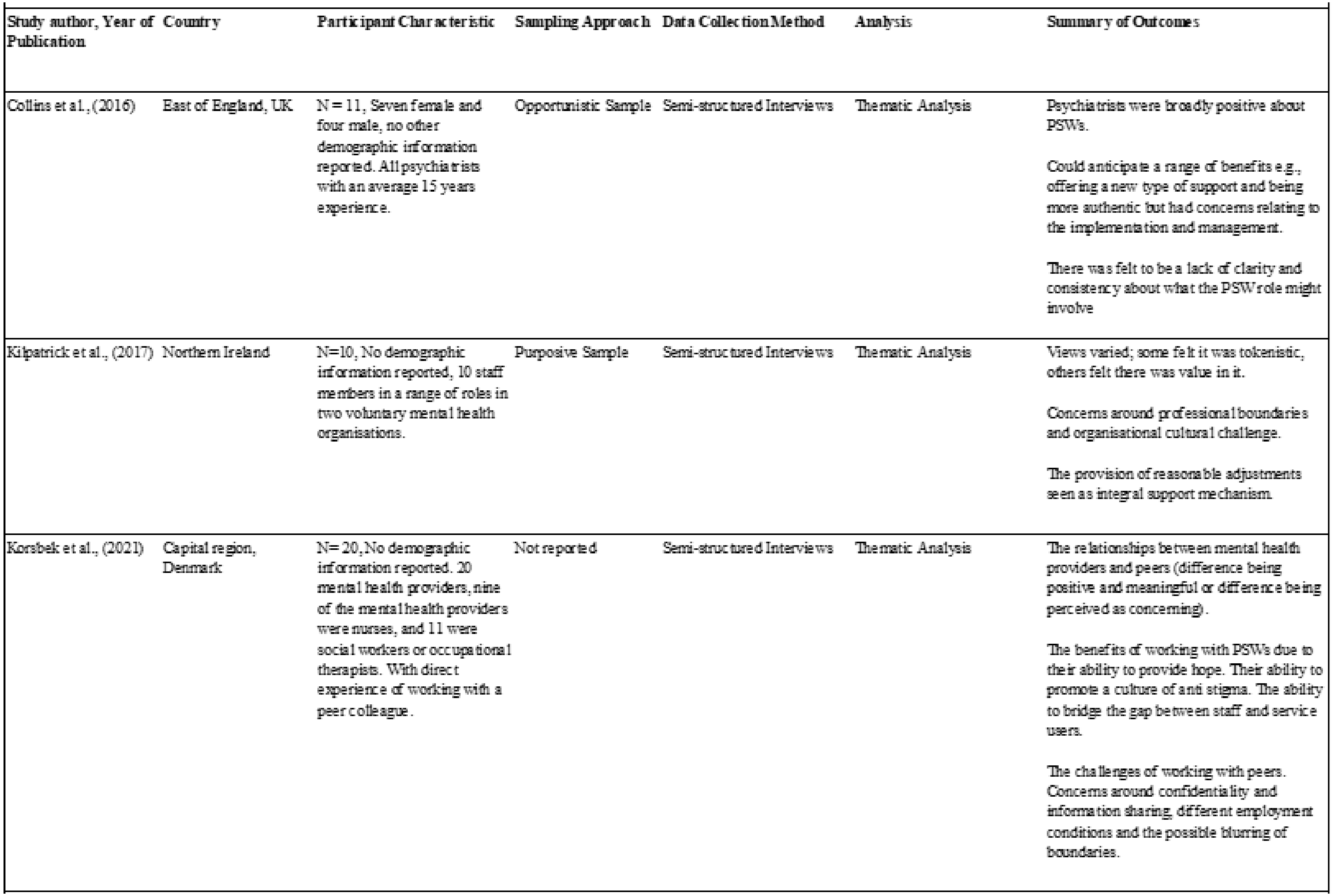
Data extraction

Data was extracted for each study using a spreadsheet that incorporated demographic, methodological and outcome related data (Table 4). Two studies (Byrne et al., 2018; Byrne et al., 2019) reported data that appeared to come from the same study but answered a different question. An email was sent to the author to check that this was the case, but a reply was not received in time. As these papers answered different questions, both papers were included in the analysis. A total of nine studies were analysed, with the results summarised in Table 4:

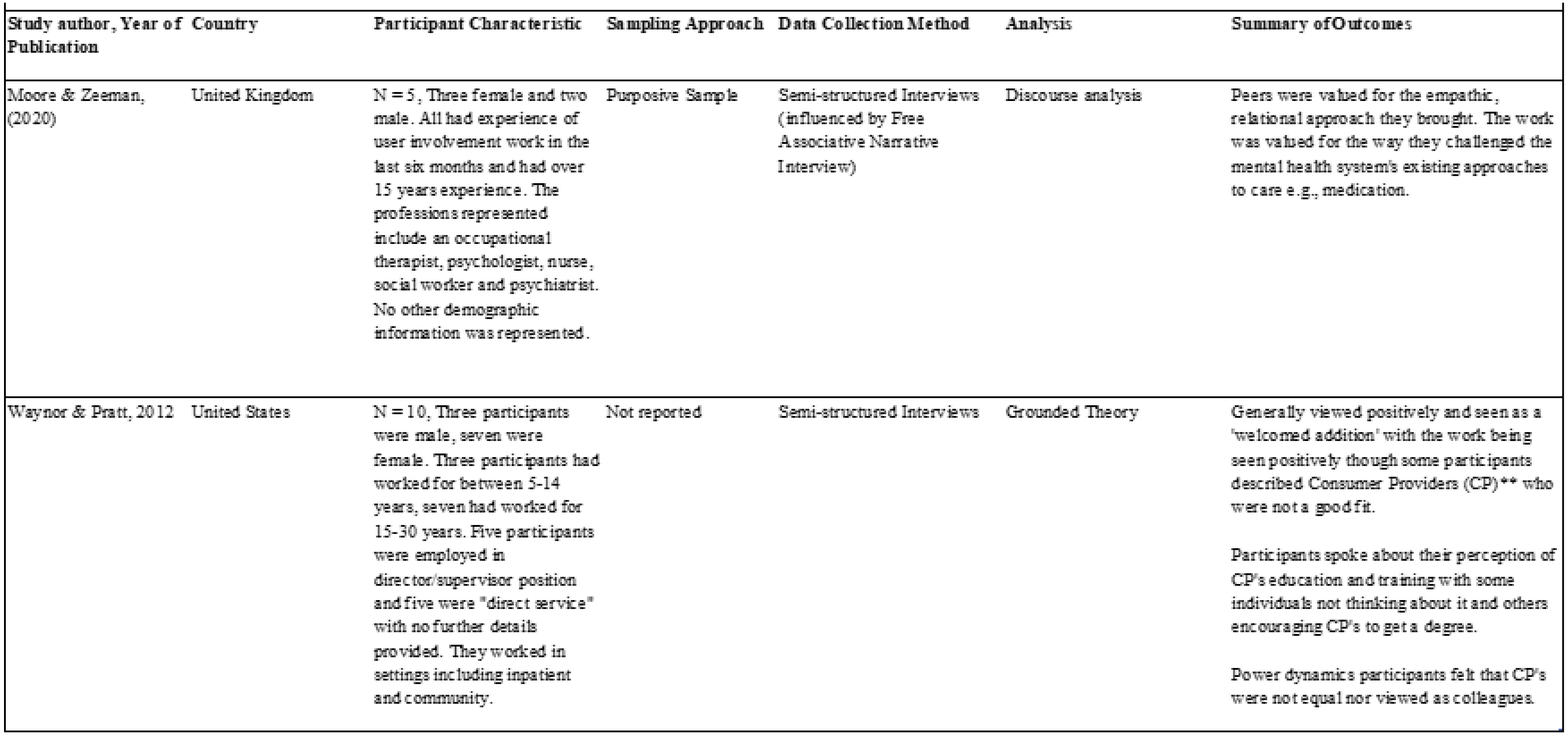
Table 4 - Data extracted from the nine studies



Study author, Year of Publication	Country	Participant Characteristic	Sampling Approach	Data Collection Method	Analysis	Summary of Outcomes
Aguey-Zinsou et al., (2018)	Sydney, Australia	N = 82, Staff were employed in public community health teams. No other demographics reported.	Not reported	The Mental Health Consumer Participant Questionnaire	Mixed Methods with the quantitative data being analysed using descriptive statistics. The qualitative data was analysed using thematic analysis (realist inductive approach)	Overall positive attitudes were reported. Staff do appear to value lived experience work. Generally felt PSWs should be active in service delivery. Positive relationship qualities between staff and peers were found to be important. These include factors relating to the culture of the service e.g., power imbalance. Concerns around role blurring, lack of acceptance of PSWs and issues around PSWs mental health.
Byrne et al., (2018)	Queensland, Australia	N = 29, Demographic information not reported. 29 people employed in executive and senior management roles.	Initially purposive sample	Semi-structured interviews (n = 25) and one semi structured focus group (n =6)*. One participant attended focus group and was interviewed.	Grounded Theory	Peer work was seen as valuable to organisations and service users. However this value depended on practical supports and strategies from the organisation, particularly when recruitment and support for PSW's was prioritised.
Byrne et al., (2019)	Queensland, Australia	N = 29, Demographic information not reported. 29 people employed in executive and senior management roles.	Initially purposive sample	Semi-structured interviews (n=24), one semi structured focus group (n=6). One participant attended focus group and was interviewed.	Grounded Theory	Exposure and understanding of peer work were essential to the development of effective peer workforce. Greater acceptance and commitment came when this was in place leading to enhanced support and development of roles.
Cleary et al., (2018)	New South Wales, Australia	N = 9, Demographic information not reported. Nine nurses employed to work with mental health patients in the last six months.	Convenience Sample	Semi-structured Interviews	Thematic Analysis	Nurses viewed peer support workers role as using lived experience with clients. Tensions between how PSW's lived experience is used and the impact on boundaries. Expressed support for roles and felt their inclusion was positive



Study author, Year of Publication	Country	Participant Characteristic	Sampling Approach	Data Collection Method	Analysis	Summary of Outcomes
Collins et al., (2016)	East of England, UK	N = 11, Seven female and four male, no other demographic information reported. All psychiatrists with an average 15 years experience.	Opportunistic Sample	Semi-structured Interviews	Thematic Analysis	Psychiatrists were broadly positive about PSWs. Could anticipate a range of benefits e.g., offering a new type of support and being more authentic but had concerns relating to the implementation and management. There was felt to be a lack of clarity and consistency about what the PSW role might involve
Kilpatrick et al., (2017)	Northern Ireland	N=10, No demographic information reported, 10 staff members in a range of roles in two voluntary mental health organisations.	Purposive Sample	Semi-structured Interviews	Thematic Analysis	Views varied; some felt it was tokenistic, others felt there was value in it. Concerns around professional boundaries and organisational cultural challenge. The provision of reasonable adjustments seen as integral support mechanism.
Korsbek et al., (2021)	Capital region, Denmark	N= 20, No demographic information reported. 20 mental health providers, nine of the mental health providers were nurses, and 11 were social workers or occupational therapists. With direct experience of working with a peer colleague.	Not reported	Semi-structured Interviews	Thematic Analysis	The relationships between mental health providers and peers (difference being positive and meaningful or difference being perceived as concerning). The benefits of working with PSWs due to their ability to provide hope. Their ability to promote a culture of anti stigma. The ability to bridge the gap between staff and service users. The challenges of working with peers. Concerns around confidentiality and information sharing, different employment conditions and the possible blurring of boundaries.



Study author, Year of Publication	Country	Participant Characteristic	Sampling Approach	Data Collection Method	Analysis	Summary of Outcomes
Moore & Zeeman, (2020)	United Kingdom	N = 5, Three female and two male. All had experience of user involvement work in the last six months and had over 15 years experience. The professions represented include an occupational therapist, psychologist, nurse, social worker and psychiatrist. No other demographic information was represented.	Purposive Sample	Semi-structured Interviews (influenced by Free Associative Narrative Interview)	Discourse analysis	Peers were valued for the empathic, relational approach they brought. The work was valued for the way they challenged the mental health system's existing approaches to care e.g., medication.
Waynor & Pratt, 2012	United States	N = 10, Three participants were male, seven were female. Three participants had worked for between 5-14 years, seven had worked for 15-30 years. Five participants were employed in director/supervisor position and five were "direct service" with no further details provided. They worked in settings including inpatient and community.	Not reported	Semi-structured Interviews	Grounded Theory	Generally viewed positively and seen as a 'welcomed addition' with the work being seen positively though some participants described Consumer Providers (CP)** who were not a good fit. Participants spoke about their perception of CP's education and training with some individuals not thinking about it and others encouraging CP's to get a degree. Power dynamics participants felt that CP's were not equal nor viewed as colleagues.

*Byrne et al., (2018) whilst the numbers do not add up to 29 this is how it is reported in the study.

** Waynor & Pratt, (2012) used the terminology Consumer Providers (CP).

Results Synthesis

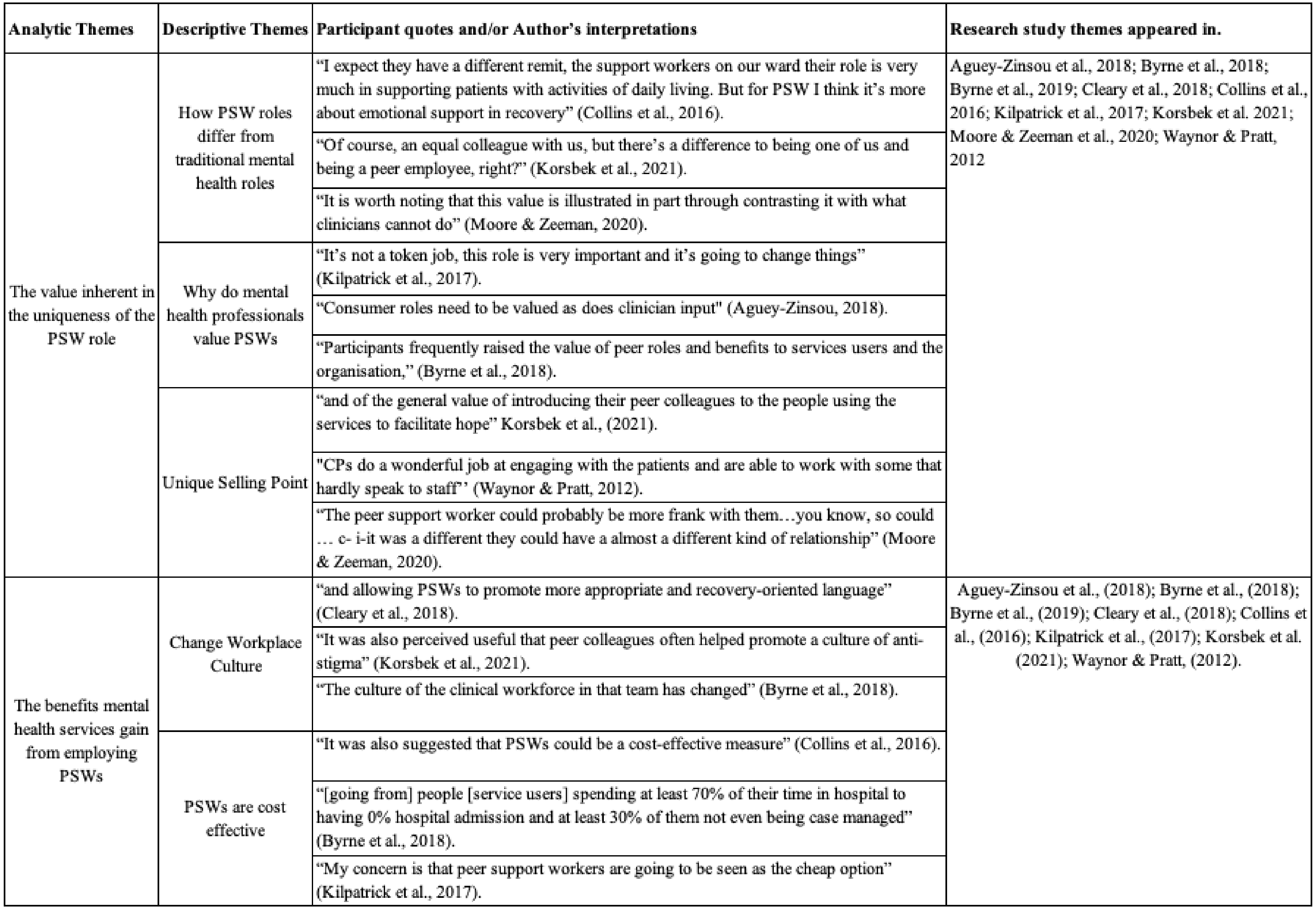
Thematic synthesis was chosen in order to generate higher order themes and key concepts that go beyond the data reported in the individual studies. The data utilised from the majority of original studies, was the entirety of the section marked ‘results’ or ‘findings’. However, Cleary et al., (2018) considered nurses’ views on the nursing role and peer support role, so only the section on peer support was extracted. Aguey-Zinsou et al., (2018) employed a mixed methods approach and thus only the qualitative findings were extracted.

Thematic synthesis incorporates a three-stage approach with the first stage employing a line-by-line approach. The second stage resulted in the development of descriptive themes before the third stage where analytic themes are developed (Thomas & Harden, 2008). The entirety of the analysis was conducted by CH using QSR NVIVO 12 (2018) and was discussed with the wider research team.

Results

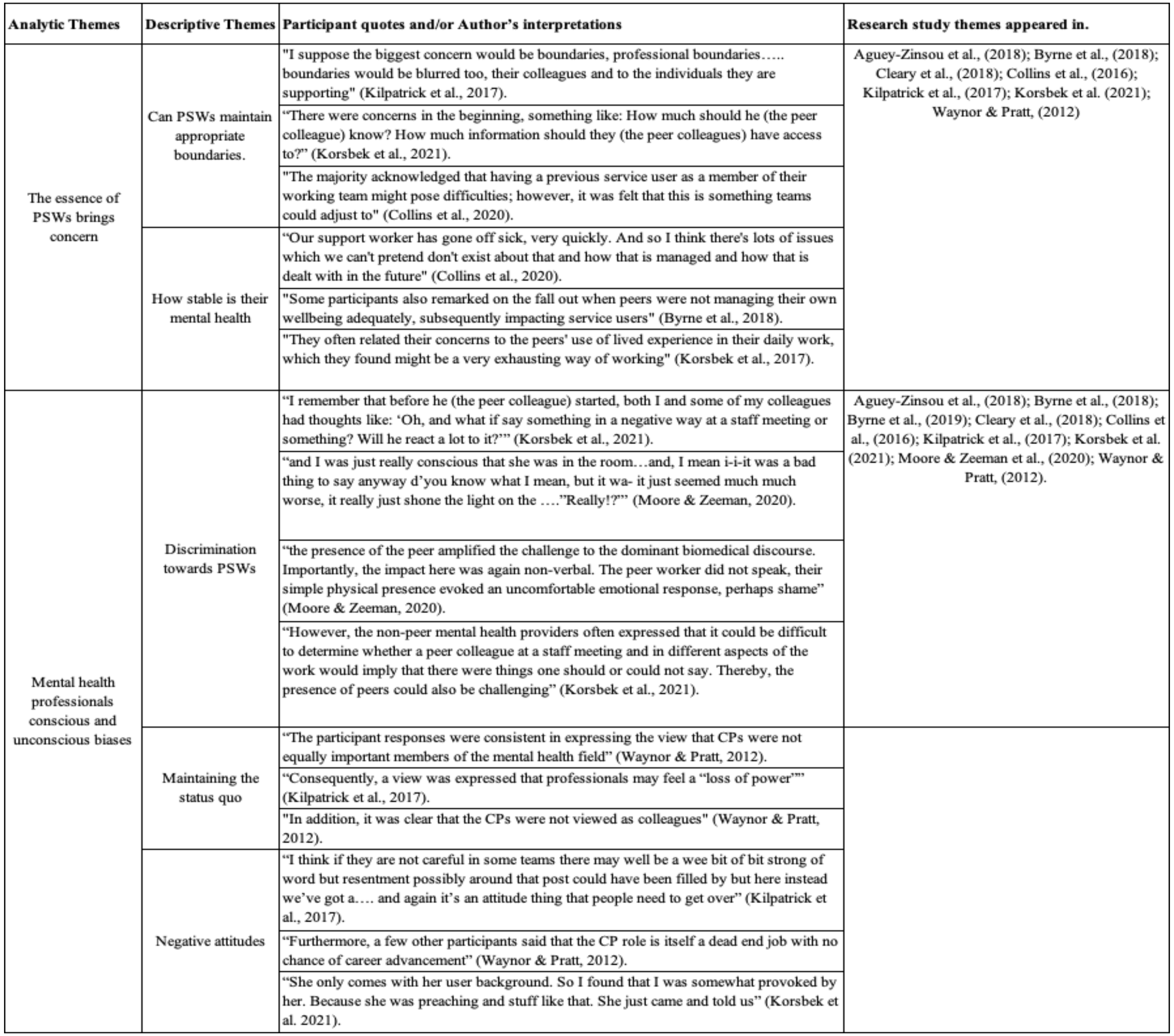
The synthesis identified five analytic themes and 15 descriptive themes that outlined how mental health professionals perceived and valued PSWs. These were as follows:-‘the value inherent in the uniqueness of the PSW role’ (‘How PSW roles differ from traditional mental health roles’, ‘why do mental health professionals value PSWs’, ‘unique selling point’). ‘The benefits mental health services gain from employing PSWs’ (‘PSWs are cost effective’, ‘change workplace culture’). ‘The factors required for successful implementation’ (‘exposure to PSW’, ‘implementing the roles’, ‘how can services support the roles’, ‘the scope of the roles’). ‘The essence of PSWs brings concern’ (‘can PSWs maintain appropriate boundaries’, ‘how stable is their mental health’). ‘Mental health professionals conscious and unconscious biases’ (‘maintaining the status quo’, ‘negative attitudes’, ‘discrimination towards PSWs’). Table 5 provides illustrative quotes and the distribution of the themes across the nine studies.

Table 5 – A selection of Participant quotes and Author interpretations that comprise the Analytic and descriptive themes



Analytic Themes	**Descriptive Themes**	**Participant quotes and/or Author's interpretations**	**Research study themes appeared in.**
The value inherent in the uniqueness of the PSW role	How PSW roles differ from traditional mental health roles	"I expect they have a different remit, the support workers on our ward their role is very much in supporting patients with activities of daily living. But for PSW I think it's more about emotional support in recovery" (Collins et al., 2016).	Aguey-Zinsou et al., 2018; Byrne et al., 2018; Byrne et al., 2019; Cleary et al., 2018; Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al. 2021; Moore & Zeeman et al., 2020; Waynor & Pratt, 2012
		"Of course, an equal colleague with us, but there's a difference to being one of us and being a peer employee, right?" (Korsbek et al., 2021).	
		"It is worth noting that this value is illustrated in part through contrasting it with what clinicians cannot do" (Moore & Zeeman, 2020).	
	Why do mental health professionals value PSWs	"It's not a token job, this role is very important and it's going to change things" (Kilpatrick et al., 2017).	
		"Consumer roles need to be valued as does clinician input" (Aguey-Zinsou, 2018).	
		"Participants frequently raised the value of peer roles and benefits to services users and the organisation," (Byrne et al., 2018).	
	Unique Selling Point	"and of the general value of introducing their peer colleagues to the people using the services to facilitate hope" Korsbek et al., (2021).	
		"CPs do a wonderful job at engaging with the patients and are able to work with some that hardly speak to staff"' (Waynor & Pratt, 2012).	
		"The peer support worker could probably be more frank with them…you know, so could … c- i-it was a different they could have a almost a different kind of relationship" (Moore & Zeeman, 2020).	
The benefits mental health services gain from employing PSWs	Change Workplace Culture	"and allowing PSWs to promote more appropriate and recovery-oriented language" (Cleary et al., 2018).	Aguey-Zinsou et al., (2018); Byrne et al., (2018); Byrne et al., (2019); Cleary et al., (2018); Collins et al., (2016); Kilpatrick et al., (2017); Korsbek et al. (2021); Waynor & Pratt, (2012).
		"It was also perceived useful that peer colleagues often helped promote a culture of anti-stigma" (Korsbek et al., 2021).	
		"The culture of the clinical workforce in that team has changed" (Byrne et al., 2018).	
	PSWs are cost effective	"It was also suggested that PSWs could be a cost-effective measure" (Collins et al., 2016).	
		"[going from] people [service users] spending at least 70% of their time in hospital to having 0% hospital admission and at least 30% of them not even being case managed" (Byrne et al., 2018).	
		"My concern is that peer support workers are going to be seen as the cheap option" (Kilpatrick et al., 2017).	

Analytic Themes	**Descriptive Themes**	**Participant quotes and/or Author's interpretations**	**Research study themes appeared in.**
The factors required for successful implementation	Exposure to PSW's	"So when we get our PSW, if that goes really well I think we'll be begging for another one, you know it depends how that experience goes is the truth... if it's a disaster it will just dissolve as one of those ideas..." (Collins et al., 2016).	Aguey-Zinsou et al., (2018); Byrne et al., (2018); Byrne et al., (2019); Collins et al., (2016); Kilpatrick et al., (2017); Korsbek et al. (2021); Moore & Zeeman et al., (2020); Waynor & Pratt, (2012)
		"the interaction between peer worker and service user must be witnessed, as opposed to read about, to truly appreciate its value" (Moore & Zeeman, 2020).	
	How can services support the roles?	"Reasonable adjustments are big one I think depending on if you are not actually addressing them appropriately, if you don't have the flex in the system to meet the individuals needs" (Kilpatrick et al., 2017).	
		"...it was certainly something that you know it was needed, to have a consumer [peer manager] managing consumers [peer workers]" (Byrne et al., 2019).	
		"Strategies that need to be put into place by the mental health service to support the peer worker role were also identified. These included: clear processes and roles, and systemic support" (Aguey-Zinsou et al., 2018).	
	Implementing the roles	"When peers were seen to be 'imposed' upon management or the team, it adversely affected the acceptance of peers within the workplace" (Byrne et al., 2019).	
		"There's quite a big gap in the thinking I think possibly because teams are constantly at the moment, and have been over the past few years, in flux and understaffed anyway and so it doesn't give anyone the space to sort of think about that" (Collins et al., 2016).	
		"I think it was very much 'we're getting this money t o do this, it's gonna be great to have this fresh idea' . . . rushed like a bull out a gate—just get people in positions and not actually think about whether they're right for that position" (Byrne et al., 2018)	
	The scope of the roles	"Like I say it's very new and I think probably the challenge is working out what the role of PSWs is going to be within the teams" (Collins et al., 2016).	
		"However, we had to figure out how we would use her (the peer colleague) and what her job assignments could be. There was no clear job description" (Korsbek et al., 2021).	
		"Participants expressed concern that PSWs were engaging in a role that may be perceived as tokenistic" (Kilpatrick et al., 2017).	



Analytic Themes	Descriptive Themes	Participant quotes and/or Author's interpretations	Research study themes appeared in.
The essence of PSWs brings concern	Can PSWs maintain appropriate boundaries.	"I suppose the biggest concern would be boundaries, professional boundaries….. boundaries would be blurred too, their colleagues and to the individuals they are supporting" (Kilpatrick et al., 2017).	Aguey-Zinsou et al., (2018); Byrne et al., (2018); Cleary et al., (2018); Collins et al., (2016); Kilpatrick et al., (2017); Korsbek et al. (2021); Waynor & Pratt, (2012)
		"There were concerns in the beginning, something like: How much should he (the peer colleague) know? How much information should they (the peer colleagues) have access to?" (Korsbek et al., 2021).	
		"The majority acknowledged that having a previous service user as a member of their working team might pose difficulties; however, it was felt that this is something teams could adjust to" (Collins et al., 2020).	
	How stable is their mental health	"Our support worker has gone off sick, very quickly. And so I think there's lots of issues which we can't pretend don't exist about that and how that is managed and how that is dealt with in the future" (Collins et al., 2020).	
		"Some participants also remarked on the fall out when peers were not managing their own wellbeing adequately, subsequently impacting service users" (Byrne et al., 2018).	
		"They often related their concerns to the peers' use of lived experience in their daily work, which they found might be a very exhausting way of working" (Korsbek et al., 2017).	
Mental health professionals conscious and unconscious biases	Discrimination towards PSWs	"I remember that before he (the peer colleague) started, both I and some of my colleagues had thoughts like: 'Oh, and what if say something in a negative way at a staff meeting or something? Will he react a lot to it?'" (Korsbek et al., 2021).	Aguey-Zinsou et al., (2018); Byrne et al., (2018); Byrne et al., (2019); Cleary et al., (2018); Collins et al., (2016); Kilpatrick et al., (2017); Korsbek et al. (2021); Moore & Zeeman et al., (2020); Waynor & Pratt, (2012).
		"and I was just really conscious that she was in the room…and, I mean i-i-it was a bad thing to say anyway d'you know what I mean, but it wa- it just seemed much much worse, it really just shone the light on the ….”Really!?”' (Moore & Zeeman, 2020).	
		"the presence of the peer amplified the challenge to the dominant biomedical discourse. Importantly, the impact here was again non-verbal. The peer worker did not speak, their simple physical presence evoked an uncomfortable emotional response, perhaps shame" (Moore & Zeeman, 2020).	
		"However, the non-peer mental health providers often expressed that it could be difficult to determine whether a peer colleague at a staff meeting and in different aspects of the work would imply that there were things one should or could not say. Thereby, the presence of peers could also be challenging" (Korsbek et al., 2021).	
	Maintaining the status quo	"The participant responses were consistent in expressing the view that CPs were not equally important members of the mental health field" (Waynor & Pratt, 2012).	
		"Consequently, a view was expressed that professionals may feel a "loss of power"" (Kilpatrick et al., 2017).	
		"In addition, it was clear that the CPs were not viewed as colleagues" (Waynor & Pratt, 2012).	
	Negative attitudes	"I think if they are not careful in some teams there may well be a wee bit of bit strong of word but resentment possibly around that post could have been filled by but here instead we've got a…. and again it's an attitude thing that people need to get over" (Kilpatrick et al., 2017).	
		"Furthermore, a few other participants said that the CP role is itself a dead end job with no chance of career advancement" (Waynor & Pratt, 2012).	
		"She only comes with her user background. So I found that I was somewhat provoked by her. Because she was preaching and stuff like that. She just came and told us" (Korsbek et al. 2021).	

Quality

Overall, the studies quality appeared to be of a relatively high standard. All the studies reported clear research aims, sampling strategy and provided information on how the data was analysed. However, there were two methodological areas that studies did not report on, and these were relationship to the research and ethical issues. Five studies did not discuss the researcher's relationship to the research (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Byrne et al., 2019; Cleary et al., 2018; Waynor & Pratt, 2012). This means that it is impossible to know if the researchers considered their own role and took steps to reduce implicit bias. Five studies had limited to no reporting of how they maintained ethical standards. Three studies (Collins et al., 2016; Korsbek et al., 2021; Waynor & Pratt, 2012) did not outline that they had received ethical approval whilst two studies (Cleary et al., 2018; Moore & Zeeman, 2020; Waynor & Pratt, 2012) did provide this information. Out of these five studies only one (Waynor & Pratt, 2012) described gaining informed consent from participants and how they considered participants confidentiality.

It is important to note that the CASP does not incorporate appraisal of theory within the tool. However, each paper was reviewed in terms of its theory, and it was noted that across the studies there was limited information provided around the theory used. There was also a lack of information provided around the epistemological stance taken. As such this needs to be taken into consideration when reviewing the results.

The value inherent in the uniqueness of the PSW role

This theme reflected how the participants conceptualised the roles, by considering what made them stand out and in turn the benefits that they felt this brought.

How PSW roles differ from traditional mental health roles

The studies' participants outlined how they felt the role of PSWs differed from traditional roles (Korsbek et al., 2021; Moore & Zeeman, 2020; Waynor & Pratt, 2012). They described that PSWs had more time to focus on client-identified needs which were regarded as being more emotional, care and comfort based (Collins et al., 2016; Korsbek et al., 2021; Moore & Zeeman, 2020). Participants described the importance of the PSW role being distinct from other mental health professionals' roles; this is in order to protect the value that they felt occurred due to the contrast between the roles (Korsbek et al., 2021; Moore & Zeeman et al., 2020).

Why do mental health professionals value PSWs

All of the studies reported the value and benefit they felt that PSWs brought both to the service and to the service users they worked with (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Byrne et al., 2019; Cleary et al., 2018; Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al., 2021; Moore & Zeeman et al., 2020; Waynor & Pratt, 2012). This appeared to occur when the relationship was founded on equality and collaboration where both roles were equally valued (Aguey-Zinsou et al., 2018; Kilpatrick et al., 2017; Korsbek et al., 2021). Some participants outlined how they felt the roles were integral to the team. This seemed to be particularly true when PSWs were integrated within the wider clinical team, and in turn PSWs were seen as colleagues (Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al., 2021).

Unique Selling Point

Participants outlined how the roles bridged a gap between traditional mental health services and service users, which may help facilitate relationships and reduce the power imbalance to promote change (Byrne et al., 2019; Byrne et al., 2018; Korsbek, 2021; Waynor & Pratt, 2012). Participants described how they felt that PSWs brought something 'special and different' to their work which was identified as being unique (Collins et al., 2016; Byrne et al., 2018; Korsbek et al., 2021; Moore & Zeeman, 2020).

This appeared to be highlighted in the way that PSWs worked; some participants spoke about the relationships with service users being more equitable which had a different quality to it (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Moore & Zeeman, 2020). Participants highlighted how PSWs seemed to be particularly able to engage service users and built rapport possibly due to the credibility their lived experience provides (Byrne et al., 2018; Cleary et al., 2018; Korsbek, 2021; Waynor & Pratt, 2012). This resulted in participants suggesting that PSWs were able to have difficult conversations in a more effective way than would be possible with those in traditional roles (Byrne et al., 2018; Collins et al., 2016; Moore & Zeeman, 2020). This meant that PSWs were able to inspire hope and show that ‘meaningful lives’ were possible (Byrne et al., 2018; Korsbek et al., 2021; Collins et al., 2016).

Participants spoke about how the PSWs brought their own lived experience which was particularly important in their work with clients (Korsbek, 2021; Moore & Zeeman, 2020). However, participants described how lived experience was not enough for individuals to fulfil the role (Kilpatrick et al., 2017). Thus, there needs to be a focus on more than just someone having lived experience due to the importance of the ‘whole person’ (Byrne et al., 2018).

The benefits mental health services gain from employing PSW

Participants outlined how they felt services benefited from the roles. This seemed to tie in with organisations financially benefiting and improving workplace culture.

PSWs are cost effective

A number of participants outlined how PSWs could be ‘cost effective’ for services (Collins et al., 2016; Waynor & Pratt 2012). However, it was highlighted that this may mean that they are at risk of being exploited so the importance of sufficient funding was outlined (Collins et al., 2016; Kilpatrick et al., 2017). Services were seen to benefit from a reduction in service use by service users who had engaged with PSWs such as a reduction in hospital admissions (Aguey-Zinsou et al., 2012; Byrne et al., 2018; Byrne et al., 2019).

Change workplace culture

The presence of PSWs was seen to be a conduit in which to alter team dynamics and changing how mental health was viewed by reducing stigma (Aguey-Zinsou et al., 2012; Byrne et al., 2018; Collins et al., 2016; Korsbek et al., 2021). Some participants felt that PSWs being open about their mental health difficulties may enable positive change as it is not just PSWs who have lived experience (Byrne et al., 2018; Byrne et al., 2019; Collins et al., 2016; Waynor & Pratt, 2012). Participants described how they felt that the role of PSWs brought positive change to the culture of the workplace and organisation (Byrne et al., 2018; Byrne et al., 2019; Kilpatrick et al., 2017). However, this came with an expectation that peers will challenge them to use and promote more respectful, recovery-focused language (Byrne et al., 2018; Cleary et al., 2018; Korsbek et al., 2021).

The factors required for successful implementation

The importance of the wider employment support structures was outlined. This appeared to mediate the relationship between participants holding positive or negative views of PSWs.

Exposure to PSWs

Exposure to PSW roles experienced by participants at the time of participating in the study varied. This seemed to be key in terms of influencing the attitudes held by participants as those who had exposure seemed to hold more favourable viewpoints and held the belief that these roles would be welcomed and in turn expanded as one could see the value (Byrne et al., 2019; Collins et al., 2016; Moore & Zeeman, 2020; Korsbek et al., 2021). However, where there was less exposure more discriminatory views appeared to be held. This seemed to restrict the growth in PSW roles partly because participants felt that they could not see the value that the roles would bring and it was thus outside their conscious awareness (Byrne et al., 2019; Collins et al., 2016; Moore & Zeeman, 2020).

Implementing the roles

Careful implementation of the roles was described as important to ensure their success. Some participants outlined challenges around not having enough time or space to consider issues that may arise. As a result, there was a concern that implementation may inadvertently be rushed which had led to difficulties with workforce retention (Byrne et al., 2018; Collins et al., 2020). Suggestions to help with this included sharing learning around how to develop the roles (Byrne et al., 2018; Byrne et al., 2019).

Some participants outlined the need to prepare teams for the roles being implemented (Byrne et al., 2019). Management support is key with participants outlining how important it is for the roles to have supporters (especially those who do not experience mental health difficulties) to champion the roles (Byrne et al., 2019).

How can services support the roles?

Participants talked about difficulties encountered within the roles including that PSWs often seemed to have different employment situations including the fact that many PSWs did not work full time (Kilpatrick et al., 2017; Korsbek, 2021). However, when an organisation was flexible and supportive it was deemed that the employment of PSWs should be no different to any employee (Byrne et al., 2018; Kilpatrick et al., 2017). However, despite this, participants talked about the importance of support structures such as supervision and the requirement for reasonable adjustments (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Byrne et al., 2019; Collins et al., 2020; Kilpatrick et al., 2017). The importance of tailored support was also raised, and consideration given to support from others who have lived experience both in terms of supervision and management structures (Byrne et al., 2018; Byrne et al., 2019).

The scope of the roles

Participants talked about how the roles lacked clarity, with a lack of job description (Collins et al., 2020; Kilpatrick et al., 2017; Korsbek, 2021). This created uncertainty due to teams needing to understand the roles to ensure that PSWs are not overloaded, or their role is tokenistic or co-opted by the demands of the service (Collins et al., 2020; Kilpatrick et al., 2017; Korsbek, 2021).

Participants outlined the scope of the role with it being thought that PSWs could voice views that had previously been unvoiced (Moore & Zeeman, 2020). In turn this, they believed meant that PSWs would be able to share what they have learnt from their experiences both with service users and services to create change both directly and indirectly (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Collins et al., 2020; Kilpatrick et al., 2017; Waynor & Pratt, 2012).

The essence of PSW brings concern

Whilst PSWs, mental health difficulties were seen as an asset by some participants. Other participants expressed concern about how their mental health difficulties may impact upon their ability to do their work appropriately.

Can PSWs maintain appropriate boundaries

Participants spoke about how they were worried about whether appropriate boundaries could be maintained by PSWs (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Cleary et al., 2018; Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al., 2021). This may be due to the fact that PSWs would share their personal experiences, and this contrasted with the clear boundaries held by mental health professionals (Korsbek et al., 2021). Despite the focus of PSW roles being on sharing one’s lived experience a tension existed as there were explicit concerns that PSWs would over share, and the focus would be on them as opposed to the service user they were working with. As such participants outlined the importance of PSWs receiving appropriate training, support mechanisms and to ensure that they were clear of their roles (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Cleary et al., 2018; Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al., 2021; Waynor & Pratt, 2012).

In addition, there were concerns by professionals about working with PSWs where they had used services, although there was a perception that this may be overcome as the roles became established (Aguey-Zinsou et al., 2018; Collins et al., 2016). The duplicity of roles also led to concerns around confidentiality and information sharing especially at the beginning when the roles were being implemented (Korsbek et al., 2021).

How stable is PSWs' mental health?

Some participants expressed concern around the stability of PSWs' mental health (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Cleary et al., 2018; Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al., 2021; Waynor & Pratt, 2012). This led to participants believing that PSWs needed to have some level of stability before starting the roles as when PSWs did not have stability this negatively impacted upon service users (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Cleary et al., 2018; Collins et al., 2016). Participants also believed that the roles could lead to PSWs becoming unwell due to the role being triggering or stressful (Byrne et al., 2018; Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al., 2021).

Mental health professionals conscious and unconscious biases

Despite many participants perceiving PSWs favourably this was not true for all participants, as either they or their colleagues held discriminatory and/or stigmatising views about their PSW colleagues. This did seem to be moderated by the 'exposure' that participants had to PSWs.

Maintaining the status quo

Some participants outlined that they felt PSWs were colleagues. Others described a ‘them and us’ attitude explaining that they did not perceive PSWs as colleagues or had concerns about how they would integrate into the team (Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al., Waynor & Pratt, 2012). This was conceptualised in terms of a power imbalance rooted in the hierarchy that traditionally exists between services and service users; some expressed a desire to address this, but it was noted that this may result in mental health professionals losing some of their previously held power (Aguey-Zinsou et al., 2018; Byrne et al., 2019; Kilpatrick et al., 2017; Waynor & Pratt, 2012).

Part of the reason for this imbalance seemed to be due to the fact that PSWs did not work to the traditional or dominant mental health models. This created a conflict with some professionals putting less value on PSWs’ work due to the lack of clinical knowledge (Cleary et al., 2018; Collins et al., 2016; Kilpatrick et al., 2017; Korsbek et al., 2021; Moore & Zeeman, 2020; Waynor & Pratt, 2012). In turn this meant that some participants felt that this created an unequal playing field with professional experience being elevated; this disconnect could occur due to the difference in focus with participants describing working to an evidence base as opposed to sharing their personal experience (Cleary et al., 2018; Collins et al., 2016; Kilpatrick et al., 2017; Moore & Zeeman, 2020; Waynor & Pratt, 2012).

Negative attitudes

Some participants outlined experiencing both good and bad experiences with PSWs (Byrne et al., 2018; Korsbek et al., 2021; Waynor & Pratt). Others described how the introduction of PSWs could be seen as threatening with concerns that rather than adding to the workforce skillset, PSWs would instead take their jobs (Byrne et al., 2018; Kilpatrick et al., 2017; Korsbek et al., 2021). As such some participants questioned what additional value PSWs brought suggesting that if mental health professionals were more open about their lived experience it would negate the need for PSWs in part as they were unsure how the roles differed, as they felt that they and/or their service already focused on the recovery model (Collins et al., 2016; Korsbek et al., 2021).

Several participants explained how they felt some PSWs were employed in roles that were tokenistic, but others queried whether employing someone on the basis of their lived experience of mental health difficulties may be tokenistic (Aguey-Zinsou et al., 2018; Byrne et al., 2018; Kilpatrick et al., 2017). This may explain why some participants held demeaning views about the PSW role and a belief that those undertaking the role would be unable to build a career from it (Waynor & Pratt, 2012).

Discrimination towards PSWs'

Participants outlined how they expected to be challenged by PSWs when they heard discriminatory or disrespectful language or practice (Byrne et al., 2018; Kilpatrick et al., 2017; Korsbek et al., 2021; Moore & Zeeman, 2020). Whilst some participants seemed to be aware that PSWs would encounter 'negative' situations or microaggressions, other participants went further describing how stigma was 'ingrained' and professional's attitudes could be 'discriminatory' or prejudiced (Byrne et al., 2018; Byrne et al., 2019; Kilpatrick et al., 2017; Korsbek et al., 2021; Moore & Zeeman, 2020; Waynor & Pratt, 2012). However, some participants outlined how simply the presence of PSWs was 'challenging'. This was in part due to the fact that encountering people in these roles brought to their awareness the fact that they may hold stigmatising or discriminatory attitudes (Korsbek et al., 2021; Moore & Zeeman, 2020).

Discussion

Qualitative data from nine empirical research papers were synthesised using thematic synthesis. The original studies had 205 (179 distinct) participants and looked at how mental health professionals perceive and value PSWs. The search terms did not specify a date range.

However, all of the studies identified through the searches and incorporated within the syntheses were published within the last ten years; with the exception of one, all were published within the previous five years. This review thus provides an overview of mental health professional's views from this time frame which ties in with the growth of formal peer support roles, though it is important to note that the studies cover a global perspective. Five analytical themes were identified: -'the value inherent in the uniqueness of the PSW role', 'The benefits mental health services gain from employing PSW', 'The factors required for successful implementation', 'The essence of PSW brings concern', and 'Mental health professionals conscious and unconscious biases'.

The synthesis suggests that all the studies reported the value of PSWs in terms of both the uniqueness of the roles and the benefits to services. This was not a universal opinion amongst participants, with the implementation process seeming to mediate between whether individuals had positive or negatives views of PSWs. This highlights that the roles needed to be properly implemented with appropriate whole system support including funding, in order to reduce both the concerns around PSWs' mental health and, the discrimination that PSWs can and do face.

The findings of the synthesis concur with previous research and reviews which suggests that the value of PSWs' work with service users' concords with the key tenets and values of peer support including - hope, empathy, empowerment, and engagement (Lloyd-Evans et al., 2014; White, 2020). The importance mental health professionals placed on having PSW roles as distinct entities to allow them to focus on these tenets and values to enhance the multi-disciplinary team was highlighted. However, concerns were raised about the fact that at times this could be difficult to focus on as there was a perceived lack of clarity about the role of a PSW and the importance of clear job descriptions. This links to previous research that highlights the ambiguity to both mental health professionals and PSWs that is inherent within peer support job roles and titles (Cabral et al., 2014; Repper and Carter, 2011). This may be addressed in England by developments such as the ‘The Competence Framework for Mental Health Peer Support Workers’ (Health Education England, 2020).

Whilst not explicitly linking to the research question the synthesis highlighted the importance of the roles being implemented appropriately as it seemingly acts as a mediator to PSWs being perceived positively or negatively by mental health professionals. Suggestions include proper recruitment; support structures and thought being given to preparing the team and services for the introduction of PSWs. The importance of these jobs being implemented carefully has been highlighted in previous research (Faulkner & Basset, 2010; Lawton-Smith, 2013) and the development of initiatives such as ‘Implementing Recovery through Organisational Change’ (IMROC) within the United Kingdom has strived to ease some of these difficulties.

The synthesis illustrated the importance of the moderating role of ‘exposure’ to PSWs in terms of the stigma and discrimination they face and in turn how they are perceived and valued by mental health professionals. This concords with the ‘intergroup contact theory’ that posits that exposure to different groups reduces discrimination (Alport 1954; Pettigrew & Tropp, 2006). Thus, through highlighting and sharing the value that PSWs will bring to a team and addressing and acknowledging potentially unfounded fears such as, PSWs will have a higher rate of sick leave, a resultant reduction of prejudice for mental health professionals should be seen (Brown & Paterson, 2016; Byrne et al., 2018).

Research frequently suggests that PSWs encounter discrimination and microaggressions in work (Byrne et al., 2016; Firmin et al., 2019). This was also described in the synthesis with participants expressing that they or their colleagues held stigmatising, prejudicial or discriminatory attitudes towards PSWs. Some participants expected PSWs to challenge this and spoke of the role of the PSW in policing language and challenging professionals when disrespectful or inappropriate discussions were held. In turn it was felt that this would lead to a better workplace culture. However, thought was frequently not given by participants to how PSWs would feel facing regular discrimination and microaggressions and the increased likelihood of psychological consequences or traumatic discrimination as a result (Nadal, 2018). As such, it is important that all mental health professionals endeavour to create this change to ensure that it is not just down to the minority to do the work to educate the majority.

Research suggests that stigmatising attitudes towards individuals with mental health difficulties are not uncommon amongst mental health professionals (Kopera et al., 2015; Lauber et al., 2006; Rao et al., 2009). It is perhaps unsurprising therefore that some participants expressed concerns around employing individuals with mental health difficulties; this may explain how just the PSW's physical presence could lead some individuals to feel uncomfortable or shame, in part because it highlighted either their or their team's conscious or unconscious prejudice towards individuals with mental health difficulties. This seems to correlate with research that focuses on racism. Critical race theory discusses constructs such as 'white guilt' or 'white shame' which highlight the emotions that White individuals have surrounding racism (Hunter, 2010; Steele, 1990). This can in turn lead to the development of strategies to deal with the emotions but in turn these can escalate into externalising blame on to the individual who has brought the discomfort (Grzanka et al., 2019). Whilst these concepts address a very different type of discrimination (racism) they may partly explain why both PSWs and mental health practitioners who have lived experience of mental health difficulties, face discrimination, marginalisation, and encounter stigma from their colleagues.

Traditional models of mental health were ascribed power by some participants who appeared to hold 'learnt knowledge' in higher regard then 'experiential knowledge'. This is likely to tie in with the current hierarchal approach within the NHS where doctors are often seen to be at the top (Morgan & Ogbonna, 2008). As services slowly move away from this and adopt new ways of working as outlined in the NHS long term plan (2019), where the power lies will naturally shift creating a threat to the professionals who have previously held the power. This concords with Friere's concept of 'critical pedagogy' which describes changing where the power lies in education and as such reducing and/or removing the traditional teacher learner hierarchy (Friere, 2004). As such, mental health services could consider these ideas with service users being encouraged to freely discuss their concerns with their mental health team leading to both parties benefiting and learning (DasGupta et al., 2006). This in turn may reduce the risk of co-opting peer support by professionalising the role through elevating 'learnt knowledge' (NSUN, 2020; Recovery in the Bin, 2020). Whilst reducing the need for PSWs to navigate their way through existing hierarchies in order to be seen as valued members of the wider professional team (Berry et al., 2011; Ehrlich, 2019).

However, there is still a hesitancy to share power with arguments around mental health professionals also having lived experience being used (Byrne & Wykes, 2020). This was observed in some studies with some participants discussing whether PSW roles would be needed if mental health professionals were open about their own mental health difficulties. This concords with research around mental health professionals sharing and disclosing their own lived experience (King et al., 2020). Recently the 'sharing lived experience framework' has been developed to assist mental health professionals in deciding whether and how to share personal information with service users (Dunlop et al., 2021). However, the majority or participants described the importance of the PSW role being distinct and how their value and uniqueness was based on more than them sharing their lived experience it is important that this is borne in mind and in turn the roles do not become conflated.

Clinical implications

This review found that whilst mental health professionals typically valued the existence of PSW roles this was not a universal feeling, with professionals also recounting and reporting prejudicial beliefs and discriminatory experiences. As such when implementing the roles, it is key that this is considered. Whilst there were suggestions around sharing best practice, finding supporters and allies, and preparing teams the discrimination was likely to be symptomatic of wider workplace issues. Thus, organisational and team culture should be considered with thought given to implementing more respectful discourses around individuals with mental health difficulties. This could be introduced by empowering individual professional to challenge their colleague’s language in a way that feels safe and respectful for all involved. This could be through the introduction of training focusing on reducing mental health professional’s conscious and unconscious stigma towards individuals with mental health difficulties, or through reflective practice groups.

Exposure to PSWs appears to moderate some of the fears that participants held. Learning from services that employ PSWs should be widely spread in various ways both informally such as anecdotally within and between mental health services e.g., workshops and mentoring and formally through the dissemination of research e.g., service evaluations. This should be done in conjunction with ensuring that peer support values are established and disseminated to services and professionals.

When implementing the PSW role, it is likely to be helpful for services to establish clarity around the scope of the role, including considering what factors beyond lived experience of mental health difficulties are needed within a PSW. It is key that this is undertaken collaboratively and that it does not become a one-size-fits-all approach to ensure that PSW roles retain their inherent flexibility. Some participants described the roles as tokenistic, and thought should also be given to collaboratively avoid this.

Strengths and limitations

This review is the first to comprehensively review how mental health professionals perceive and value PSWs. As such it provides an additional perspective to developing research looking at how differing stakeholders view PSWs. Whilst, one reviewer (CH) went through all of the papers, to reduce the impact of bias an additional reviewer (SB) went through 50 randomly selected papers to ensure that there were no discrepancies. In addition, two reviewers (CH & SN) independently quality appraised the studies. Where there were discrepancies the wider research team was consulted, and discussions were held to ensure agreement.

However, caution needs to be employed when interpreting the results as they are unlikely to be generalisable as only nine papers were identified which came from a number of different countries. Consideration therefore needs to be given to the fact that each country will have its own context that individual mental health services are situated within. In addition, the studies participants were from a range of different professional backgrounds and as such the roles held by individual professional varied.

The systematic review focused only on peer reviewed research due to the rigour of the peer review process. It is important to consider by excluding grey literature from the review, whether smaller scale projects e.g., service evaluations are missing. In turn it is important to consider whether through the focus on peer reviewed articles we are elevating learnt knowledge over experiential knowledge as much of the information referenced within this review from service users is contained within ‘blogs’ and other grey literature. This may mean that the findings would differ had we considered a range of sources including social media.

The quality assessment found that over half the papers (n= 5) did not discuss the relationship that the research team had with the research. It is therefore important to consider whether the studies may have had biased results due to this not being explicitly made clear. One study (Moore & Zeeman, 2020) described using a service user group as part of the analysis and one study (Korsbek et al., 2021) outlined that all bar one of the research team had mental health issues. Which influenced their interest in the research, this was also true of this systematic review. All of the research team had worked with experts by experiences in a range of roles. Two of the research team (CH and MB) had previously worked as a PSW and MB currently works as Head of Professions for lived experience in an NHS trust. Consideration was paid to this throughout analysis, but it is important to consider the impact that this experiential lens will have had on the analysis and in turn the way that this will influence the relationship to the studies.

Future research

This review highlights a number of areas where further research could be warranted. The review highlighted the importance of the implementation process in ensuring mental health professionals perceive PSWs as a valuable addition to services. The results found that this was inextricably linked with the 'exposure' that mental health professionals had previously had to PSW's. Therefore, research that looks specifically at mental health professionals' 'exposure' to PSWs and whether this does in fact moderate the perception that mental health professionals have about PSWs. In order to consider suggestions for how services can reduce discrimination faced by PSWs and in turn help with the process of implementing PSW roles.

Additionally, across the studies some mental health professionals held stigmatising and discriminating viewpoints. As such it is important that research looks at discrimination encountered by PSWs from mental health professionals, and in turn identify both what factors are at play and how to reduce this. In turn, specific focus could be given to how the presence of PSWs brings about a feeling of discomfort in mental health professionals. This could also be developed as a basis to look at the stigma that is experienced by mental health professionals who also experience mental health difficulties.

Conclusion

This systematic review looked at nine papers that focused on how mental health professionals perceived and valued PSWs. Thematic synthesis was conducted to identify five analytic themes which were comprised of 15 descriptive themes. Overall, PSWs were found to be a valuable addition to the team bringing a unique perspective that was perceived as beneficial. However, some participants held discriminatory attitudes and had concerns about PSWs' mental health and the ability for appropriate boundaries to be maintained. This highlighted the importance for consideration to be given when PSW roles are being implemented as this appeared to mediate mental health professionals' views of the roles. However, this should not stop the PSW roles being developed as 'exposure' to PSWs appeared to moderate this process by reducing the stigma and discriminatory views held by staff.

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Chapter two: Empirical Paper

The Impact that Participating in Roles that Directly Utilise Lived Experience of Mental Health Difficulties Has on Identity: A Grounded Theory Study

Abstract

The number and type of roles that utilise an individual's lived experience of mental health difficulties within a mental health context (LX roles) have been increasing in the UK. Research has traditionally focused on the impact to services and/or service users. More recently the focus has shifted to the impact on the individual undertaking the LX role. This study aimed to understand the emotional, social, and professional impact that participating in an LX role within a mental health context has on that individual's identity. Semi-structured interviews were conducted with 11 individuals currently participating in a range of LX roles in different settings. A social constructivist grounded theory methodology was utilised. A theoretical model incorporating 10 categories was subsequently developed to understand how LX roles impact individual's identity. Participants described the impact that the roles had on their identity in terms of feeling valued and/or unvalued and the 'emotional rollercoaster' that accompanied these dynamic concepts. This process was facilitated by a number of factors that pertained to the 'organisational and service culture', 'power', and 'relationships'. 'The development of critical appraisal' impacted upon whether the roles were experienced as tokenistic or more genuine co-production and this in turn could impact on individuals 'motivations for doing LX roles'. This research highlights the importance of LX roles being implemented appropriately to ensure that individuals undertaking them feel supported, valued and in turn they experience a positive impact upon their identity.

Keywords: Lived experience roles, mental health difficulties, identity, grounded theory

Introduction

Lived Experience Roles

Roles that directly use an individual's lived experience of mental health difficulties (LX roles) date back to at least the late 1700's with Pussin and Pinel at the Bicêtre asylum (Shuster et al., 2011). Historically, integration of LX roles into statutory mental health service provision in the UK has been slow. As a result of significant support for this type of work within the NHS Long Term Plan more roles have started arising, both within National Health Service (NHS) and NHS-commissioned organisations (NHS England, 2019). Despite this there is limited consensus as to how best to refer to these LX roles, or what they should entail (Repper & Carter, 2011). This research focuses on any LX role that specifically utilises an individual's lived experience of mental health difficulties within a mental health context. These LX roles include but are not limited to: peer support workers, peer trainers, peer researchers, lived experience practitioners, and service user involvement.

Seminal documents such as the NHS Five Year Forward View (2014) and the NHS Long Term Plan (2019), as well as the historic groundwork laid by organisations such as 'Implementing Recovery through Organisational Change' (IMROC) have all played significant parts in ensuring the recent increase in peer roles within the NHS (Millar et al., 2016). More recently 'The Competence Framework for Mental Health Peer Support Workers (PSWs)' was developed to outline the core skills required for PSW (Health Education England, 2020). In part this framework aimed to professionalise the role of PSWs. However, this was not without criticism due in part to how it was developed with limited involvement from the wider service user community (NSUN, 2020; Recovery in the Bin, 2020.). Subsequently, the lived experience workforce, whose roots are firmly embedded within mental health activism and grassroots of the survivor community, have been met by NHS culture, with requirements of standardisation, professionalisation and uniformity to all roles (Voronka, 2017).

Arnstein's (1969) '*Ladder of Citizen Participation'* groups several layers of involvement under the heading 'degrees of tokenism' which occurs when involvement is happening but there is no requirement for action to be taken. Widespread criticism of NHS-based LX roles, and subsequent professionalisation, 'standardisation' and concurrent 'co-option' of them is expressed within research and via social media within the survivor and service user community (Recovery in the Bin n.d.). As such, barriers to engaging with these NHS LX roles, by nature of their low banding, inconsistent presence, and apparent lack of power to create meaningful change, are often seen as tokenistic and they can be experienced as being disempowering by those participating in them (Madden & Speed, 2017; Ocloo & Matthews, 2016; Recovery in the Bin, 2017).

This has meant that historically research on service user involvement has focused on either the impact to services or the impact (directly or indirectly) to the recipients of services (Omeni et al., 2014). Research is now starting to look at the effect that LX roles have on the individual undertaking them and how services and the system can facilitate and hinder this process. The process of engaging with these roles is facilitated through organisational culture including staff having a favourable attitude towards LX roles, such roles being part of a team, and individuals within the roles feeling pride in their work. However, barriers to engaging within the role include limited career progression, appropriate levels of pay/funding and insufficient supervision (Adams, 2020; Ibrahim et al., 2019; Tate et al., 2021).

Identity

Identity is a diverse area of research that means it can be defined in a number of ways (Alberts & Durrheim, 2018). Individuals hold a multitude of identities, so this research uses a broad conceptualisation of identity as "the traits and characteristics, social relations, roles, and social group memberships that define who one is" (Oyersman et al., 2012, P69). Identities are perceived by some to not be static but instead change over time due to life circumstances changing how we perceive ourselves (Burke et al., 2006).

Some individuals with mental health difficulties report a loss of identity and sense of self due in part to losing previously held identities (Wisdom et al., 2018). As a result, the development of an 'illness identity' may occur; this is when an individual's identity, incorporates their personal understanding of their mental health difficulties (Yanos et al., 2010). This has been suggested as a factor that can influence individuals' recovery from mental health difficulties (Yanos et al., 2010; Yanos et al., 2020). However, interpersonal changes also occur, as the notion of 'master status' illustrates. This describes how others (in particular mental health professionals) view individuals with mental health difficulties solely through this lens (Deegan, 2001).

Social identity theory posits that identity is a fluid state that changes depending on which groups an individual currently aligns with (Tajfel, 1974). The resultant impact of being viewed through the 'master status' lens means that individuals experiencing mental health difficulties are more likely to encounter stigma and prejudice from others (Nascimento, 2015). This combined with the fact that mental health difficulties are frequently linked to social isolation, will have an impact on one's perception of self and their identity (Elisha et al., 2006; Linz, 2013). As such, the role that long-established mental health communities (as well as informal meeting places for individuals including day centres) play in reducing isolation and in turn on individual's identity formation must be considered. These services have been directly impacted through the impact of austerity, which combined with neoliberal ideologies resulted in the rise in focus on 'recovery' (Cummins, 2018; Lavalette, 2017), with its focus on reducing dependency on services due to the individual taking increased responsibility for their own mental health (Cummins, 2018; Esposito & Perez, 2014;

Lavalette, 2017; McWade, 2016). In some instances, this has resulted in these informal spaces being ‘replaced’ by more formalised spaces such as recovery colleges and professionalised peer support services (Gilburt et al., 2014; NSUN, 2019).

As some service users transition to participating in LX roles, they will in turn increase the amount of time they spend in services in an LX role, as opposed to in services receiving the service itself. As such, they will change and develop as exposure to the etiquette, expected standards of behaviour and language of the employees of the service become hallmarks of their day-to-day interactions (Repper, 2013). It is probable that this will lead to the formation of a professional identity, defined as “the attitudes, values, knowledge, beliefs and skills shared with others within a professional group” (Adams et al, 2006. P. 56).

Identifying as belonging to a ‘professional’ group is likely to impact individuals in a number of ways. When considering the more personal impact that these LX roles have, the importance of factors like sense of purpose was described as inspiring individuals and in turn had a resultant impact on the individual’s personal life (Tate et al., 2021). However, factors such as self-care, burnout and growth were also seen to influence an individual’s identity and focus on self-development (Debyser et al., 2018; Tate et al., 2021). More recently it has been suggested that these LX roles may lead to a process of growth or even post traumatic growth especially if the LX role facilitates healing for the individual participating in the role (Debyser et al., 2018; Flood et al., 2018).

Despite this, individuals undertaking LX roles can find themselves caught in a personally challenging place due to the impact of holding both a service provider and service user identity (Byrne et al., 2019). Transitioning fluidly in and out of these identities as required can be personally challenging due to individuals struggling to comprehend and support the idea of two identities co-existing; the binaries of ‘vulnerable service user’ and ‘resilient lived experience worker’ for example, are easier to comprehend and assume than a blurred, more human existence which at times includes aspects of both (Debyser et al., 2018; Voronka, 2017). This focus from others led Ball (2017) to describe this experience as “though at times it felt deeply personal, it wasn’t really about me but what I represented…” (P19).

However, despite these challenges, research has found evidence of the process of identity change. This occurred within individuals who perceived their identity had changed from being defined through being a service user (‘illness identity’), to one that was more aligned with that of a peer researcher or peer worker (‘professional identity’), (Debyser et al., 2019; Hutchinson and Lovell, 2013). This may suggest that participating in these roles allows individuals an opportunity to develop or change their sense of social, professional, and emotional identity (Clarke et al., 2012; Horrocks & Callahan, 2006; Tajfel, 1974).

Current Study

Research exploring how LX roles impacts those undertaking them, is in its infancy. The focus has tended to be on one specific role such as peer support. This approach is at odds with the fact that many individuals participating in LX roles do a variety of roles simultaneously. It is important to therefore consider a broader context by incorporating and linking a wide range of LX roles and thinking about the impact that these have on an individual’s identity.

The current research has the following aims:

- To understand how individuals conceptualise and understand the emotional, social, and professional impact that participating in an LX role has on that individual’s identity.
- To gain an understanding of how an individual’s identity develops and changes over time whilst participating in these roles.
- To develop an explanatory model focused on the impact lived experience roles have on identity over time.

Method

Design

A qualitative, social constructivist grounded theory (Charmaz 2006, 2008) approach was adopted. This ensured that an in-depth understanding of individuals' experiences of participating within LX roles was developed. Due to the limited existing research and theory within this area, grounded theory was chosen as it allows for the development of theory (Urquhart, 2013). Social constructivist grounded theory focuses on how individuals construct realities rather than assuming that there is an objective reality (Charmaz, 2006). As a result, the approach does not assume the researcher is a blank slate (Mills et al., 2006). Instead, it allows the transparent consideration of what the researcher, and wider research team, brings with them during the research process both in terms of what is discussed by participants at interview and subsequently when the data is interpreted and analysed (Charmaz, 2006).

Ethics

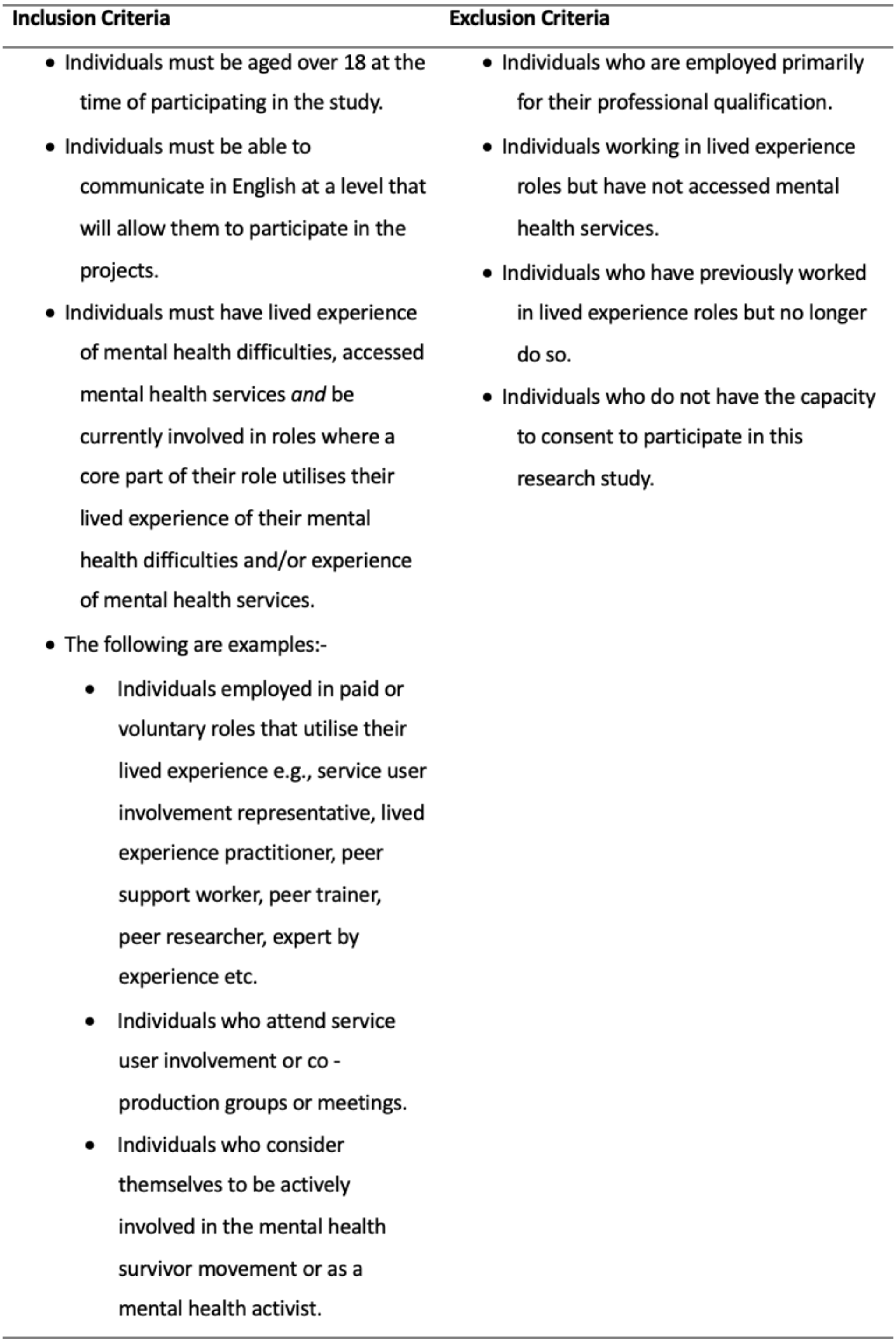
Ethical approval was granted by the University of Liverpool Ethics Committee in August 2020 (see appendix 3).

Recruitment, Screening and Sampling

The study advertisement (appendix 4) was posted with a request to share it, on a study-specific Twitter account, the Researcher's personal Facebook page, the National Survivor User Network weekly newsletter, and emailed to members of the British Psychological Society's, Group of Trainers in Clinical Psychology, Expert by Experience email list. This was completed in early August 2020. Due to the volume of interest, no further recruitment drives took place, and recruitment closed in September 2020. The advertisement contained a study-specific email address which individuals were requested to contact the Researcher via. In total 74 individuals came forward, with 39 individuals being eligible to be a participant.

This process was informed by the inclusion and exclusion criteria (see Table 1) and is outlined in Figure 1.

Table 1 -*Inclusion and exclusion criteria for the participants*

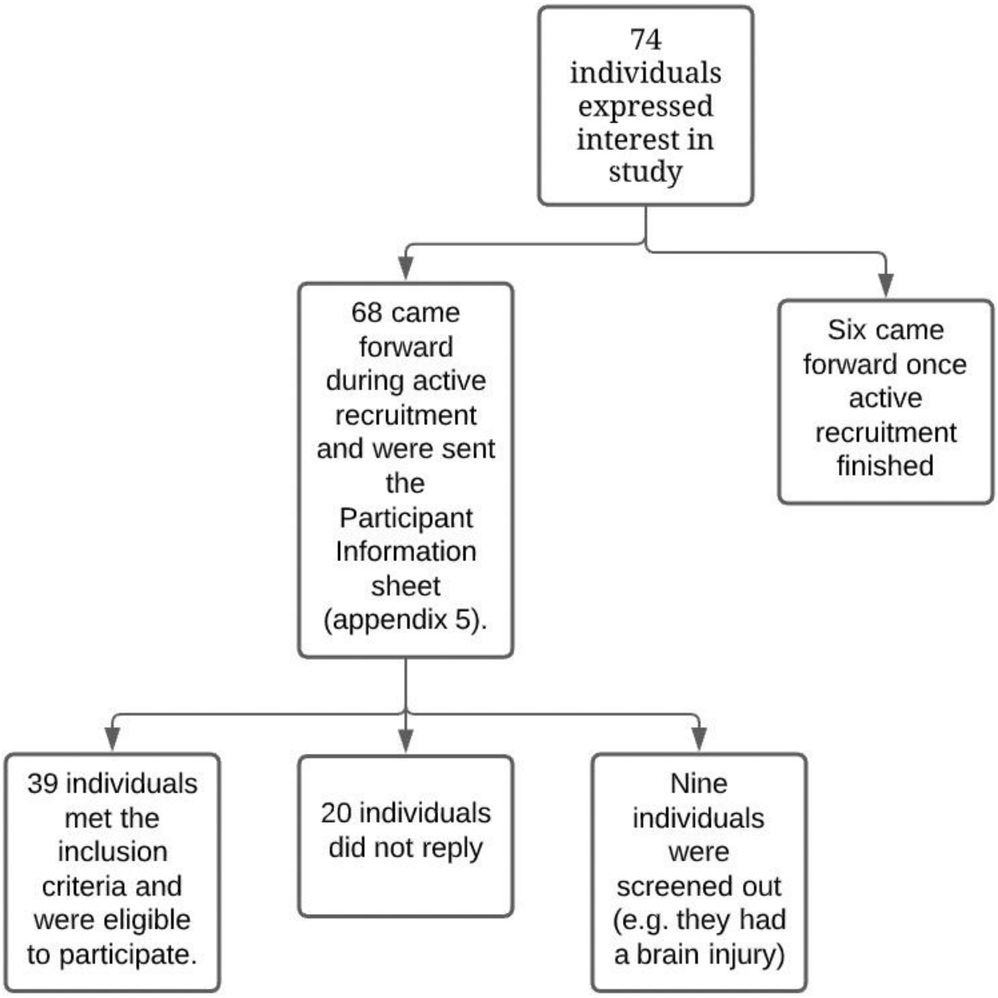


Inclusion Criteria	**Exclusion Criteria**

• Individuals must be aged over 18 at the time of participating in the study.
• Individuals must be able to communicate in English at a level that will allow them to participate in the projects.
• Individuals must have lived experience of mental health difficulties, accessed mental health services *and* be currently involved in roles where a core part of their role utilises their lived experience of their mental health difficulties and/or experience of mental health services.
• The following are examples:-
  • Individuals employed in paid or voluntary roles that utilise their lived experience e.g., service user involvement representative, lived experience practitioner, peer support worker, peer trainer, peer researcher, expert by experience etc.
  • Individuals who attend service user involvement or co - production groups or meetings.
  • Individuals who consider themselves to be actively involved in the mental health survivor movement or as a mental health activist.
	• Individuals who are employed primarily for their professional qualification.
	• Individuals working in lived experience roles but have not accessed mental health services.
	• Individuals who have previously worked in lived experience roles but no longer do so.
	• Individuals who do not have the capacity to consent to participate in this research study.

Figure 1

Flow Chart outlining the participant screening process



Individuals interested in participating spoke with the Researcher on one occasion between August and October 2020 (appendix 6). This enabled the Researcher to screen participants with the inclusion/exclusion criteria, ask questions to aid with theoretical sampling and answer any questions. Participants were informed that due to the number of potential participants, theoretical sampling would be used and those who were not interviewed would be informed when the study concluded which would be in Spring 2021. All individuals were then emailed the consent form to complete and return to the Researcher (appendix 7).

The process for sampling participant is outlined in Table 2. This study looked at a range of LX roles across differing settings to gain a broad perspective of how individuals undertaking these roles find them. It is important to note that the majority of individuals who came forward to be a participant, participated in a range of roles, in a range of settings. This therefore needed to be considered when using theoretical sampling to ensure that participants accurately reflected the range of LX roles. As such whilst convenience sampling was used initially, with the first five individuals that were screened being interviewed. The subsequent six interviews employed theoretical sampling to ensure that recruitment was representative of the range of LX roles and settings available. Whilst being directed by the existing data, to expand upon the initial themes and address gaps within the emerging data set (Ligita et al., 2019). Sampling stopped once categories reached 'conceptual depth' (Nelson, 2016). At this point theoretical sufficiency was deemed to have been achieved (Saunders, 2017). Charmaz (2008) explains that it is more important to "collect sufficient data to discern and document how research participants construct their lives and worlds" (P. 403).

Table 2

Participant sampling process

	Sampling process
Step one	Screening phone calls identified 39 individuals eligible to be participants
Step two	Convenience sampling – first five individuals screened.
Step three	Theoretical sampling – identified most participants worked in the NHS. Sought individuals working in other settings e.g., charities.
Step four	Theoretical sampling – difference noticed within those working within salaried employment. Identified individuals undertaking full times LX roles.

Participants

A total of 13 individuals who were all currently participating in LX roles within a mental health context were approached to be interviewed between September 2020 and April 2021. Due to personal constraints two individuals who were approached in March 2021 to review the model were unable to participate within the required time frame for data collection. A total of 11 participants were interviewed; six male and five female participants, with a range of ages (the mode age range is 40-44, n=3) and ethnicities (the mode ethnicity is white British - n=6). Participant's demographic information is presented in Table 3.

To ensure anonymity, information that could directly identify individuals has not been included. This is due to the small number of people participating in LX roles and in turn some participants being one of the only individuals undertaking that role in the country or in their NHS Trust. The majority of participants undertook a number of different LX roles such as peer support and user involvement as opposed to just one LX role. Participants worked in a wide range of services and settings including the NHS, Academia, and charities. Renumeration differed; some participated in these roles voluntarily or were given vouchers, whilst others were paid a service user hourly or consultancy rate, or a salary commensurate with the NHS Agenda for Change system. The length of time the participants had been involved in these roles varied with the minimum of time being one and a half years and the maximum length of time being 18 years.

Table 3

Participant's demographic information

* Participant 5 gave their age with this range.

Participant number	Age	Gender	Ethnicity	Saw the study advertised
1	45-49	Female	White European	Twitter
2	45-49	Male	White British	Twitter
3	50-54	Female	White British	Twitter
4	40-44	Female	Asian British	Informed by a colleague
5	35-44*	Male	Indian Asian & White mixed	Twitter
6	30-34	Male	White	NSUN/Twitter
7	35-39	Female	White British	NSUN
8	40-44	Male	White British	Twitter
9	35-39	Female	White British	Twitter
10	70-74	Male	White British	NSUN
11	40-44	Female	Asian Bangladeshi	NSUN

Interview Procedures

Prior to the interviews taking place the Researcher contacted participants via email to see if they still consented to participate. Interviews were conducted over Zoom or Microsoft Teams. Before the interview started, participants were given the opportunity to ask questions and were verbally asked if they still consented to participate. Interviews lasted on average one hour (range 39– 75 mins), with a semi-structured interview schedule (appendix 8) being used to guide the interview. This ensured the Researcher was able to maintain a flexible, curious stance during this process. The interview schedule was amended with the input of the supervisory team over the course of the interviews as per the requirement of grounded theory methodology to ensure that emerging codes could be explored further (Charmaz, 2014). At the end of the interview participants were given the opportunity to ask questions; a debrief form (appendix 9) and £15 voucher were sent to participants via email. A distress protocol was developed (appendix 10) but was not needed.

Reflexivity

In line with social constructivist grounded theory the Researcher considered their positioning throughout the research process (Charmaz, 2006, 2008). To ensure that a reflexive stance was maintained the Researcher wrote a reflexive statement at the start of this process which has been incorporated into the thesis and a personal reflective journal was kept throughout. The Researcher ensured that they commented in the post-interview story summaries (appendix 11) and memos (appendix 12) when there was an overlap of personal experience or they felt that a participant might be directing a comment at themselves e.g., registered professionals increasingly having lived experience. Supervision with the entire supervisory team was used to ensure a balance was found between the Researcher's clinical psychology, LX roles and service user identities in order to accurately represent the participant's experiences.

The Researcher was clear with all participants that this research was being conducted as part of their Doctorate in Clinical Psychology degree. However, they also had prior experience of working in LX roles which they were open about on social media. As such, whilst they did not directly disclose this to any individuals some but not all participants were aware of this. As a result, the perception of the Researcher by participants varied. Some individuals explained that they came forward to participate in the research as they saw the Researcher as a fellow as a result of their background as a peer worker. However, others saw the Researcher as a trainee clinical psychologist with/without lived experience of mental health difficulties. This is expanded further in the discussion.

Analysis

Soon after the interviews were completed, the Researcher wrote a story summary outlining how they had found the interview, key themes that they had noted from the interview and questions that had arisen. Each interview was transcribed with the Researcher transcribing the first interview; subsequent interviews were transcribed by a University of Liverpool approved transcriber. Prior to analysis, the Researcher listened to the audio recording with the transcript to ensure accuracy. The transcript was then re-read on several occasions.

Interviews were analysed by the Researcher using QSR's (2018) NVivo12 (Appendix 13). Interviews occurred concurrently to the coding and analysis to ensure that all the codes and strands were considered as the theory and model was developed. The coding followed Charmaz's (2006) approach with the first step being 'initial coding' with data analysed on a line-by-line basis. Subsequently, focused coding identified core categories. Finally, theoretical coding occurred where codes were related to each other and used to develop the theory. To ensure the validity of the developing theory the research team met regularly throughout this process and discussed what was constructed to develop and hone the model.

Following interview eight, focused coding did not result in any further new codes and interviews nine and 10 were used to refine thinking around the developing theory. Following interview 10 the model was developed. Interview 11 was spent continuing to refine thinking before a draft model was shown (appendix 14) and discussed with the participant to see what sense they made of the theory and model.

Expert by Experience Involvement

The research team was designed to be as inclusive and coproduced as possible, all involved had professional experience within this field. One supervisor has experience of drawing upon her lived experience in her clinical role. Another worked in a range of LX roles and is now in a senior lived experience leadership and management role within the NHS. To ensure that the voices of individuals with mental health difficulties were at the heart of the study, the study was designed with input from two survivor activists; they were unable to commit to the whole project as a supervisor but were kept updated through the project.

This meant that throughout the research process, both a psychological and lived experience lens were utilised. The different positions held by the supervisory team ensured that in-depth discussions took place that would not have occurred had the research group been professionally homogenous. This was particularly noticeable during data collection and analysis. The multitude of perspectives meant that changes to the interview schedule and the resultant understanding of the data was far richer than if only one lens was held.

Consideration from the different lenses was given to the inherent power that was held. This was illustrated through discussions held around ensuring that the study was done ethically, stopping when sufficiency was reached. This was done whilst acknowledging that there were more individuals wanting to be participants than could feasibly be interviewed.

Results

Following interview ten the theoretical categories were developed (see Table 4) and a draft model was developed; this was shown to Participant eleven for comments. Following this, changes to the model were made in discussion with the study team (see Figure 2)

Table 4

The theoretical categories and focused codes developed

Theoretical Categories	**Focused Coding**
Feeling Valued	Increasing Confidence Personal Growth View of self
Feeling Unvalued	Emotionally draining Questioning values Putting self-down
Emotional Rollercoaster	Rollercoaster
The only way is up	Low point Poor Prognosis Distress leading to involvement
Motivations for doing LX roles	Improving services Changing perceptions Connecting with service users Assists recovery Contributing to society Nourish
The role of Power	Where and how is power situated Holding power Whose voice is heard Putting others down
Organisational and Service Culture	Organisation factors Pay Sharing personal stories or experiences Support structures Training needs Covid impact How the role is viewed Being held back Stigma and discrimination Inclusivity Tokenism
Changing Relationships	Connection with others No Man's land Relational difficulties Master Identity From service user to colleague Unicorn
Development of critical appraisal	Time in role Autonomy Critical Engagement Relating with LX peers
Future goals	Career pathway New challenges Restricted by circumstances

Changing career

The Model

Participants expanded far beyond the focus of the prepared interview questions. This led to a rich insight into the multitude of experiences individuals undertaking LX roles encountered and their associated impact.

Brief overview of the Model

Figure 1 represents a dynamic model that conceptualises the emotional, social, and professional impact on the identity of individuals who participate in LX roles within a mental health context. The identity of the participants appeared to be impacted through the core categories of ‘feeling valued’ and ‘feeling unvalued’. Participants moved between these positions through the theoretical category of ‘emotional rollercoaster’. This is the process which explains the emotional impact undertaking LX roles had on individuals; these experiences and encounters led them to feel both ‘feeling valued’ and/or ‘feeling unvalued’. These are not fixed positions; rather participants could occupy these states dynamically depending upon how their experiences and understandings within the role changed over time. These were impacted by the following contextual and interpersonal factors which were interconnected, and both facilitated and hindered this process:- ‘changing relationships’, ‘organisational and service culture’, and ‘the role of power’.

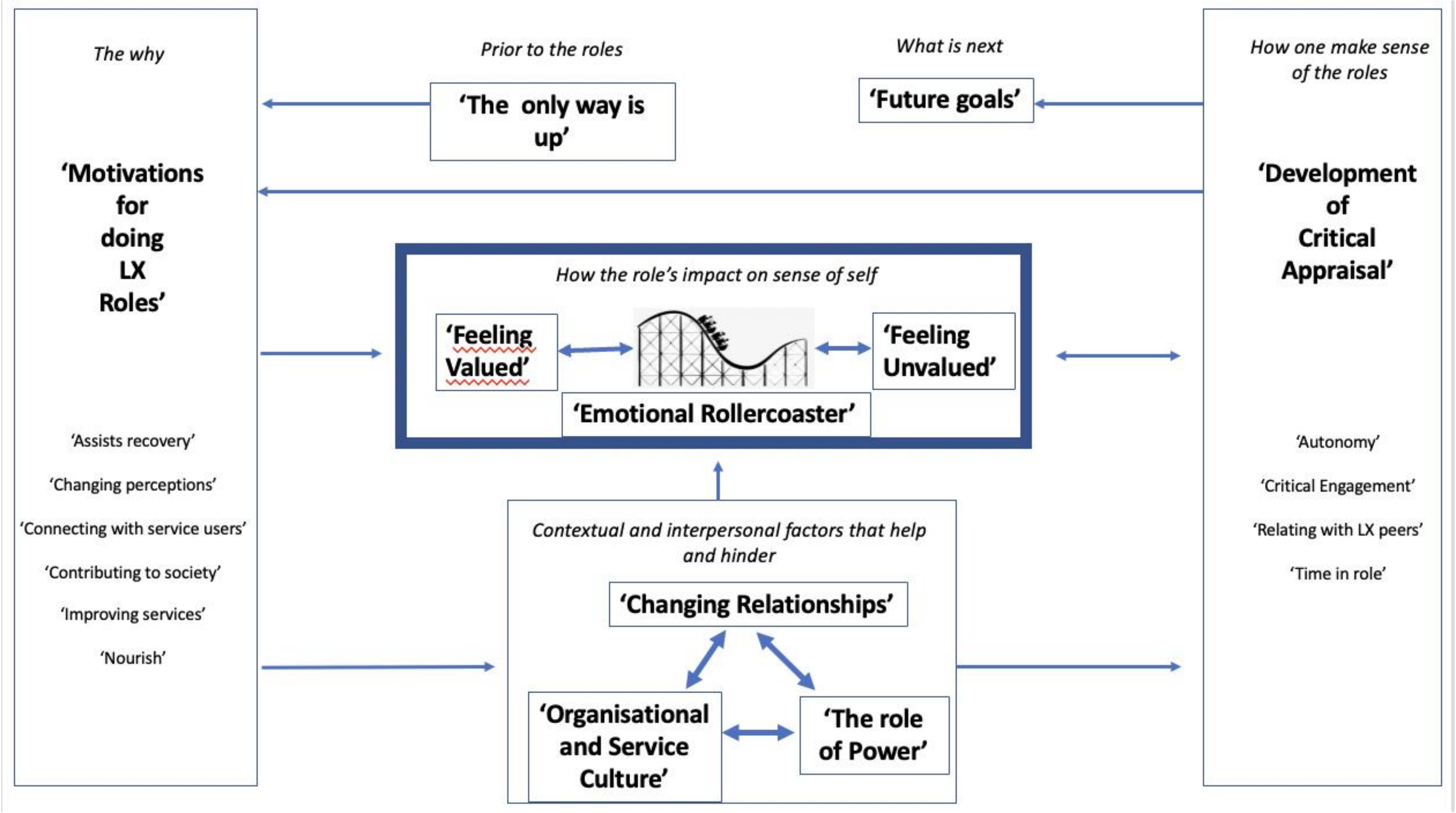
Participants spoke about two intrapersonal factors that both explained why they undertook LX roles (‘motivations for doing LX roles’) and how they made sense of them (‘development of critical appraisal’). Participants’ ‘motivations for doing LX roles’ appeared crucial for inspiring and allowing individuals to continue with their involvement. The ‘development of critical appraisal’ allows an individual to appraise the roles and their understanding of them with a more critical lens. This developed through a number of interlinking factors; key amongst these was associating with others who are undertaking LX roles and in turn going through a similar process as well as being exposed to broader discourse such as ‘mad studies’ and activism.

Lastly to provide context, the experiences individuals had prior to starting the roles (‘The ‘only way is up’) was considered. If prior to participating in LX roles individuals had experienced a loss of sense of self due to the impact of their mental health difficulties, it is likely that they would feel an enhanced sense of value on beginning the roles than if they undertook LX roles as a planned career move. Due to the inclusion criteria, all participants were still participating in LX roles. However, participants described a variety of options about their ‘future goals’; some wanted to climb the LX roles career pathway, whilst others spoke of the inherent challenges within these roles and the toll it had taken on them.

The aforementioned categories are dynamic and interlink as the following example illustrates. If an individual is motivated to undertake the roles by the prospect of creating change due to their prior experience of mental health services, then they are likely to feel ‘feeling valued’ if this is facilitated by the service and they have the power to influence this process. However, if the service has a tokenistic approach to these roles and change is not possible, participants will likely ‘feel unvalued’ and in turn unmotivated. However, the ‘development of critical appraisal’ appeared to allow some participants to change their motivations from directly impacting small service changes to instead creating wider systemic changes and indeed aspiring to change the functions of LX roles. As such, the individual’s internal reference continued to evolve which would have a direct impact on their ‘future goals’.

Each of these codes will be described with participants’ quotes given to provide more detail below.

Figure 2 – Grounded theory model on how individual's identity is impacted through participating in LX roles



Feeling Valued

Participants spoke about how organisations, services or registered professionals could leave them feeling valued. However, the theoretical category of 'feeling valued', primarily covers the positive impact on participants' identity and/or sense of self.

Increasing Confidence

Participants universally commented on the positive impact to their confidence since becoming involved with LX roles.

> "I think initially, I had very, low self-confidence, low self-esteem, low self-worth, and these roles have, (pause) have definitely given me, a lot of self-belief and, feel like I'm doing something that I'm good at, that I've not felt in a long time" (P8).

This increase in confidence was apparent to participants not only in an 'employment' setting but also in their personal lives.

Participants explained that their increase in confidence was noticeable to those around them including their family, friends, and colleagues.

> "I've got a very big head now, it's terrible! (…). Even my sister says, oh go away, you're terrible now, you used to be so nice and lovely, and you walk in the room and it's all confident sort of head up high and whatever!" (P2).

This increased confidence for some participants aligned with their changing sense of identity "but I think having that, that sense of identity that, that's come from doing volunteering has given me the confidence to go on to do these sorts of things as well" (P4).

Personal Growth

A number of participants spoke about how they had personally grown since participating in LX roles. P6 described this process as "a heck of a journey it's been unbelievable" leading him to reflect "my whole identity changed, (…) I've got the identity that I had kind of before back. But I think it's only, it's almost like an improved version…".

In addition, participants explained how they have personally developed through learning new skills, developing more interpersonal skills or understanding more about their strengths. As P9 explains "it's given me a lot of, opportunities for, for growth for networking for learning new stuff."

View of self

Participants described how their view of themselves had changed. This comprised of intrapersonal changes due to the participant's need to integrate one's mental health difficulties into their identity at work and as such this carried on into their personal life.

> "I think I'm less ashamed now of my mental health history and like I probably ten years ago would've never ever envisaged that I'd have, a social media account that, even mentioned my mental health let alone be like, my identity as it's who I am on there". (P9)

Others described interpersonal changes with many saying that they believed others viewed them differently and this impacted on how they viewed themselves. Participants gave examples of how this occurred e.g., seeing that family members were proud of them and what they had achieved, or hearing colleagues' views on themselves as P7 illustrates:

> "I never really thought of myself as somebody that was particularly a people person, or particularly caring person, erm, and kind of other people sort of reflecting that back to me I was like, ok maybe I am, yeah it makes you feel good about yourself".

Feeling unvalued

Participants did not describe the experience of participating in LX roles as being inherently likely to trigger mental health difficulties. However, the challenges associated with 'feeling unvalued' appeared to occur according to participants when the external factors did not align with participants 'feeling valued'.

Emotionally draining

Participants described the impact and toll that participating in LX roles had on both themselves and their mental health. They described how at times they had experienced LX roles as being "triggering" (P2 & P4), "overwhelming" (P1), "hell on earth" (P6). Some participant described how they felt that this was in part attributed to the additional challenges caused through centring and working directly with their mental health difficulties. P8 explained "the distress and the kind of trauma and the re-traumatising nature of lived experience (roles) (…) I was exhausted and erm ended up as an in-patient again".

The impact of LX roles on participants' mental health was not always felt to be considered by others. Instead, it was perceived as a continuation of their previous mental health difficulties:

> "I don't think, people make the link, between the impact of the role on my mental health, and, they just see it as just a continuation of, oh well you've always had episodes of being unwell." (P9)

Questioning values

Participants spoke about how at times they were expected to undertake activities that went against their values and/or left them feeling conflicted. P6 described a moral dilemma that occurred "having to be involved in restraining and stuff because that was, you know part of the peer support role in the Trust I work in (…) that was really upsetting a lot of the time".

Other participants described a feeling of conflict in relation to their concerns of harm being done to themselves and others undertaking the LX roles and their desire to not be part of this. P9 illustrates this dilemma

> "I had no idea when I started this work, that I would lose colleagues to suicide (…) but the last four funerals I've been to have been people who've done, involvement

> work, (…) I guess it's hard not to think that you're part of something that's potentially doing people harm".

Putting self-down

At times participants appeared to struggle to believe in themselves and this led to self-doubt with participants trying to mimic a level of comprehension that they did not believe they had. This could be seen when they compared themselves to others "I view professionals as people who are educated within mental health. Whereas I am not educated in mental health I just have my lived experience (…) so, for me I think, seeing myself as a kind of professional is actually quite hard" (P5).

Emotional Rollercoaster

Rollercoaster

Participants described participating in LX roles as akin to being on a "rollercoaster". This appeared to be how participants assimilated their experiences by focusing on the resultant emotional impact and in turn represents the dynamic nature of the model. "I wouldn't do it if it was all frustrating, there are some rewards in there, you know," (P3),

Participants described the varied emotional impact that they experienced through undertaking LX roles. These were often relayed as a broad overview that could be experienced as both positives and negatives or high and lows. On occasions participants linked to more specific occasions:

> "so, it's very much up and down. Sometimes I'll leave a meeting being like, that was great, I'm so glad I did that, that's really positive. And other times, I mean I've got a bit kind of (laugh), don't know what the word is, jaded I suppose." (P7).

‘The Only Way Is Up’

Individuals’ prior life experiences provide important contextual information to consider how participants conceptualised their sense of self and identity development when undertaking the roles.

Low point

Participants described what life was like prior to becoming involved with these roles. This often consisted of inpatient admissions and/or suicide attempts and/or periods out of work. This was demonstrated by P9 “and yet I’ve been very deep in the system, so probably had like 40 admissions in my 20’s”.

The challenges inherent in comparing themselves to others were outlined due to what they perceived others to have that they did not, which then expanded into how this left them feeling. P3 described the experience of being in hospital following an overdose “I was jealous of her (…) of somebody dying because they’re getting an end to their suffering (…) and mine was just pain and suffering till I died”.

Poor Prognosis

A number of participants described how mental health professionals had explained to them that due to their mental health difficulties they would not be able to accomplish much in the future. P3 recounted “The Psychiatrist had told me that I’d always be ill, I’d always be medicated, and I’d never work again, and I believed that because he had the answer to my problems”. This appeared to restrict participants’ ambitions, leading to a sense of hopelessness as both they and their families believed that their future would be limited. “for all intents and purposes, we kind of felt, my, career if you like, was over”.

Distress leading to involvement

Individuals’ experience of mental health difficulties often led to them discovering LX roles due to chance e.g., involvement workers being present on inpatient wards. For others it occurred as they were looking for support with their own mental health difficulties in less traditional mental health settings such as art groups or to give themselves access to meaningful activities as following an inpatient admission P6 explained “I kind of started volunteering at the ward as well on occasions (…) just to keep busy and stuff.”

Motivation for doing LX roles

Participants described a wide range of both intrinsic and extrinsic motivators that appeared to change and develop over the time that they had been undertaking LX roles. These were powerful enough to ensure that participants continued participating in LX roles even when an individual felt unvalued.

Improving services

Participants described how important changing and improving mental health services was to them “my main passion (…) is to try and make services better” (P2). Concurrent to this was a desire to also positively impact upon mental health professionals’ practice. Both indirectly “something that you say might go on to change the way that somebody works” (P4) and directly “He (a psychologist) was like well how about we do some co-produced training, on psychosis so we can help some of the staff understand this and maybe practice this moving forward and I thought oh this is brilliant” (P6).

This motivation frequently arose from their personal experience of receiving support from mental health services. Some participants outlined how they may need mental health care in the future, providing a direct motivator for individuals who were either still under secondary services or as is outlined by P3 “because I might be back in there one day, and I want it to be in a better place than when I left it”. Participants described a range of personal experiences of mental health services; a real desire to change services for others was apparent when the experience had not been positive “I know how frustrating it can be. You know, when services aren’t what they should be or when things aren’t available” (P7). In contrast when participants reported positive experience this appeared to be linked to a desire to repay services for the support received "I feel like I'm giving something back to services that I've received so much from" (P8).

Changing perceptions

Stigma and discrimination were widely reported amongst participants, and it is perhaps unsurprising that participants "do it to kind of challenge stigma" (P6). Stigma is perceived in varied ways by different communities and thus it is important that this is not viewed through a homogenous lens as P4 explains "being BAME, mental health is very stigmatised and you know is very, very hush-hush in the Asian communities, so for me it's something I'm quite passionate about".

This desire to change perceptions was particularly seen when participants saw their mental health difficulties as an "asset". This meant that they were able to help others get a greater level of understanding. P7 illustrates this by describing an encounter following the showing of a video she appeared in, "she was crying, and she just said, thank you for sharing that because, my son's going through something similar, and I just didn't get it".

Connecting with service users

Many participants spoke about the importance of working (directly or indirectly) with service users. Inspiring hope was a key motivator, perhaps unsurprisingly due to the contrast with the registered professionals' views. "the main thing I wanna do is inspire hope" (P6). However, other participants spoke about helping others being linked to their personal values such as caring for other or as P9 explains "it felt like, a sort of natural fit of (…) still holding on to that, desire that I had as, as an 18-year-old, to, be a Doctor and to help people and make a difference". Finally, individuals described the extrinsic reward that occurred through providing support to individuals "someone, tells you how much it means to them, then, you know, it makes you feel really good." (P7).

Assists recovery

Participants ascribed the positive impact that the roles had on their mental health through factors such as having a routine. Participants could demonstrate the improvement in their mental health since starting to participate in LX roles "I've been working in the NHS since 2016 (…) never had any sickness because of my mental health, which, just feels amazing" (P6).

Other participants described the importance of creating something positive out of their experience of mental health difficulties which they had often experienced as adverse. P4 explained "I think the main thing was the idea that using my lived experience which for me hasn't been great, but if I can turn it into something positive (…) then at least something good can come out of everything I've been through really"

Contributing to society

Participants compared how life had changed since involvement in LX roles. Many explained they felt more connected to wider society. "my ability to kind of take part in society in some way or have something to contribute, umm, changed the way I think about myself" (P1). However, the LX roles also gave participants a "status" which they could use to respond to others as P4 described "being able to say I'm a volunteer is better than just saying I don't work".

Nourish

Participants described the enjoyment that they got from participating in LX roles. Many found the experience "mentally stimulating", personally rewarding, or something that they were proud of. This seemed in part to be due to being connected with others who shared similar values or life experience to you; "I've enjoyed being part of something, I've enjoyed working as a group, you know being part of a team" (P4). This was vital in sustaining individuals because "it can be empowering and wonderful" (P2).

The role of power

Mental health difficulties are often associated with a sense of powerlessness. Participants described how LX roles bring about a change in positioning of power for all relevant stakeholders; as such this requires staff and services to be willing to embrace this in order for those undertaking LX roles to feel valued.

Where and how is power situated

Participants described services were lived and learnt experience were perceived as equal. However, typically participants described learnt experience as being elevated above lived experience as outlined by P9

> "led equally by, a professional and someone with lived experience who had, equal voice, equal say in the decision making, equal pay (…) we were not even invited to the meetings that decided the recovery strategy, yet so much of it was around co-production and around equality" (P9).

This illustrates the power differentials that can exist especially when there is unequal pay or disparity in meeting attendance. This lack of equality could be seen when participants described staff as tone policing them or expecting them to agree with a set opinion. As highlighted by P2

> "professionals, who find that service users should be seen and not heard as such or seen and be in their little place and in their little box and if you actually did go along and say I disagree with that, they get a bit umpty".

The way power was considered in relation to service users who participants encountered in a professional capacity seemed to be dependent on who they viewed the power against. P10 described an absence of power in relation to registered professionals explaining "some of the service users that I see, don't want to see me, because I've got no power which is true". Yet others discussed the inherent hierarchies that are built into LX roles through working in mental health services due to their job title, having an NHS staff card, having access to confidential information and in turn enhanced knowledge of services. “I almost feel like the badge gives me a hierarchy or a status over someone which, doesn’t always sit comfortably with me because I feel like my role as a lived experience worker is to break down those hierarchical barriers and kind of make even playing fields” (P6).

Holding power

Participants described how having power made them feel. P3 explained “I am just a nobody, I’ve been an invisible service user all my life with no identity and no purpose and suddenly people are listening, people are taking on board what I’m saying and they’re responding to it, and I find that incredible”.

The power held by individuals differed due to the LX roles undertaken. Some had a level of seniority over others undertaking LX roles. This gave them access to decision makers and in turn the power inherent within this. “since I’ve come into this role, I’ve found myself in a lot more meetings with perhaps more senior management than I would have in my other roles”. This contrasts with participants who did not have access to key individuals and experienced resultant challenges as P3 explains “getting to the right people is the main challenge, you know, because you can speak to so-and so, but they might not pass it on or it might not get to where it needs to be, it’s like with the lived experience voice”.

Whose voice is heard

Participants reflected on how they felt it was often the same people undertaking LX roles. As such participants raised concern about this and explained that “I don’t want it to just be The (Name) Show, I want it to be everybody’s show” (P3). This seemed to result in participants actively trying to ensure that a range of different individuals’ voices were heard e.g., not staying in an LX role (e.g. ‘patient governor’) for a long period of time or trying to promote and empower those who are traditionally marginalised.

Other participants reflected on how the diversity (or lack of it) within the profession could lead to a resulting power discrepancy between those undertaking LX roles and the wider mental health professional community. This seemed in part to be due to how mental health professionals perceived individual LX workers; if they appeared to fit the mould of a mental health professional through the unspoken markers of belonging e.g., accent or appearance. Participants felt that they were given more credence. P9 explains “I dunno, I think I can pass as one of them, so they listen to me (laugh). As a white middle class, degree educated female, I think that I had more of a chance of, being heard (…) I can do the polite NHS speak”. This contrasted with other participants’ experiences who described having to work harder to achieve recognition due to their race or their class. As P11 expresses “Cos sometimes I think class is a thing, I'm, not White, middle class, then I think sometimes I have to, fight things more, which I do extra, to get things that other people might get”.

Putting others down

Some participants appeared to unconsciously lift themselves up by putting others down. This seemed to be due to the limited number of LX roles, leading to comparisons being made. P5 outlines this “I think the issue is that obviously I’m the pioneer (…) I’m pretty much leaps and bounds ahead of a lot of people”. For others it felt connected to a deeper point, that as they had been able to get themselves out of their ‘low point’ others should be able to experience the same benefit if they tried hard enough. Which P10 explains “I just wish, more people would get involved. It’s very easy when you’ve got mental health issues to sit on your backside and, feel ill. For me the cure was to get and do things and help people and feel better about myself”.

Organisational and Service Culture

Participants worked in a wide range of settings and services. Despite the organisations and services having their own unique culture and set of values, a large overlap of experiences was reported by participants.

Organisational factors

Participants frequently spoke about challenges they had experienced through being one of the ‘first’ service users in posts which contrasted with the perspective of individuals who had been participating in the roles for longer. P11 explained that “when I first started, five to ten years ago, it was very, I don't know if, the cultures probably changed a bit, they're seeing more lived experience, there's more paid lived experience and there's higher band, banded roles”.

Participants outlined a number of systemic factors that they found particularly difficult that reflected the politics and challenges inherent within large organisations. These include things such as the impact of limited funding or the length of time it took to enact simple changes. This resulted in participants suggesting that this was what they found the most difficult - “it was working with colleagues and the system, which was more emotionally draining, and I think more frustrating” (P6).

A number of participants described a lack of role clarity amongst organisation, services, and the wider staff team. This led to differing expectations and/or resulted in services not making the best use of LX roles. At times this led to a lack of structure around what was expected, and participants described being given a broad remit which was not always practical. P1 explained “I think the added struggle is around the lack of understanding of the roles, how to get the most out of the roles, I think they don’t understand quite how to make the roles work for them”.

Pay

Organisations differed in the remuneration offered some services offered no remuneration, whilst other services offered vouchers, and a few offered meaningful involvement rates. This appeared to be for a number of reasons including the possible impact on eligibility for benefits.

Participants explained the importance of being paid equitably to other mental health professionals. Frustration was expressed at being offered less than minimum wage. When LX roles where not remunerated appropriately, many participants expressed that they did not readily want to participate in them or described how this left them feeling unvalued.

Participants did express the importance of it not being a 'one size fits all approach' and this seemed to concord with the personal circumstance of individuals. How participants felt about the pay and remuneration situation also appeared to change in conjunction with the process of 'developing critical appraisal'. On beginning to participate in LX roles P5 recounted how he experienced being offered vouchers when he begun the roles. "it almost became quite nice to actually be valued (…) even if it was a voucher and even if it was 20 quid to tell you the truth, I was very grateful for, the money." Yet other participants contrasted there pay in comparison to what mental health professionals who they attended meetings and/or worked closely with were paid

> "I would be sat being told how lucky we are to be in this boardroom where everyone's paid, you know, five, six times what we are, and I just don't know how they can continue to say that lived experience is valuable when there's such a disparity in the pay." (P9)

Sharing personal stories or experiences

The majority of participants explained that it was often a direct expectation that they shared their personal story or experiences. Whilst happy to share in certain circumstances for example in order to build rapport with a service user, or to make/prove a point, many reported that they found it emotionally difficult - "it's very draining (…) you get to the point sometimes where you think to yourself oh god really have, I really got to tell them about that then" (P2). This was particularly pertinent for those who were undertaking LX roles in a more ad hoc manner were limited to no support was available.

Despite how this was often a key part of participant's jobs this process of sharing one's experiences was described by a number of participants as "traumatic" with P7 explaining "you shouldn't be encouraged or pressed into, sharing really personal stuff in a room full of strangers, it's not fair and it can be quite damaging to people". The perception participants held around 'feeling valued' in regard to sharing their personal stories/experience changed as participants appeared to develop 'critical appraisal' and in turn their viewpoint seemed to change as illustrated by P9,

> "I think, very much early on in my career I was wheeled out a lot to sort of, tell my story and as someone who'd not had any power or status (…) going on stage and being clapped at by 100 people, like I loved it, so, continued to do it and not paying any attention, to the fact that I was like, absolutely dissociating every time I read it" (P9).

Support structures

The support structures in place for LX roles varied as those that were done on a more ad hoc basis had limited to no supervision in contrast with permanent or more senior LX roles. P6 explained "I mean when I first started as a peer support worker I kind of felt I had a bit too much supervision, I think I had like three different supervisions and I was like pfft, this is hardcore.".

Despite this disparity all participants highlighted how important and necessary support and supervision is and many described how what they were offered was limited especially when compared to the wider staff team as P2 explained “you wouldn’t let a member of your staff let’s say, do a piece of work and you wouldn’t put in the adequate support you know like briefings and debriefings (…) even clinicians get triggered for certain things”.

Many participants highlighted that they would appreciate lived experience supervision for a number of reasons including the fact that they would have a direct understanding of some of the challenges. P8 expressed this as “we need people who have, been through this and can empathise with us”.

Training needs

Participants described how there was limited training available. What was available often did not meet individual’s needs; due to the level it was aimed at or the timing of when it was offered. Available training was frequently not lived experience specific. “I definitely think that training would be good, certainly sort of earlier on or even later on, they tend to assume that you’ve had your induction and that’s it” (P7). As a result, some participants described having to find and in turn often fund appropriate training themselves.

Covid impact

A number of participants spoke about how at the start of the COVID-19 pandemic all involvement stopped contrary to guidance issued by the NHS (2020). Participants expressed how they felt that this demonstrated the value that was placed on LX roles as other meetings continued albeit online. P2 explained that “a lot of organisations seem to have stopped their involvement with people with lived experience because all of a sudden this COVID pandemic has come in (…) you never heard anything from anyone (…) I had them a lot of the time say, well we didn’t really wanna worry (…) and I go back very quickly to say but I needed you at this time”.

How the role is viewed

How LX roles were perceived between and within organisations, services and individual staff members seemed to vary considerably. Participants talked about how often involvement was pushed by certain staff members which contrasted with staff or services who did not understand or see the value that the roles could bring “the biggest challenge is trying to persuade people that I’m actually doing something useful” (P11).

This was particularly challenging for participants when these two viewpoints mixed. P7 illustrates this conundrum as “you’re there because someone’s boss has told them they have to, you know, involve service users. Not because they want you to be or they actually value what you say” (P7).

Being held back

Participants spoke of the differences between individual teams with some teams really wanting them to fulfil their potential; however, many reported the opposite experience. This appeared to be for a number of reasons with some participants explaining they felt it suited the service for them to not grow or develop due to what it would mean for them. P1explains “your ability to relate to the clients you are working with is really important and it’s an almost feeling of wanting to keep you in your, in that box and not grow and change”.

Other participants spoke about being held back from undertaking specific activities or roles as they were not in their remit. P10 described his service “did not give me the freedom, to do what I know I can do like running the little courses, they said oh no you need more senior people to do that (…) I dunno they don’t want people taking their jobs (laughing)”.

Stigma and discrimination

Participants reported receiving or hearing negative views from others; a significant number of participants also reported encountering stigma and discrimination from the wider staff team. This occurred both directly as P7 explains “I’ve been treated, so badly in meetings

(…) really patronising comments when people assume that you are a bit of an idiot”. Indirectly P9 linked her experience to those that she had encountered as a patient “but erm, I would say on a day-to-day basis, face sort of, microaggressions, and, silencing, gaslighting, and a lot of the same, relational struggles that I had as a patient.”.

Inclusivity

Participants identified the inequalities inherent within involvement work. Some participants commented on this in relation to COVID commenting on digital exclusion and the impact of poverty. P3 explained that “Covid has made the disparities and the inequality a lot bigger for people like myself who are classed as Black, Asian, Minority Ethnic”.

Whilst others spoke about the importance of LX roles being available across services and ensuring that individuals undertaking the roles reflected the diversity of the local community as opposed to “it’s not just white middle aged, people who are Peer Support Workers, you know everybody has got a chance of Peer Support working. It’s a big piece of work that needs doing.” (P3)

Tokenism

Participants felt that the roles were seen as something that had to be undertaken by services as opposed to there being a genuine commitment to them. This resulted in participants feeling like the roles were a tick box exercise as P8 explained “a lot of the time it does feel very tokenistic”. This was particularly apparent when participants felt lived experience was not as valued as learnt experience. Participants described times when their ideas were not considered or listened to and how frustrating this felt to them as it was the opposite of genuine coproduction.

Changing Relationships

Participants described how key the relationships that they had formed through participating in LX roles were. At the same time many participants also described relational conflict with others or a sense of isolation due to being between two distinct social groups.

Connection with others

One of things that participants really valued about LX roles was an increasing sense of connection with others. This was particularly apparent through the descriptions of meeting new people (both with and without mental health difficulties). P8 explained that “my social world has, erm increased exponentially and for the better really”. The negative impact of COVID-19 was described as it impacted this aspect of the roles “it’s a shame, I do really miss that social side of things, you know, just meeting with people and mixing with people”.

No Man’s land

Participants also described how “lonely” (P3) the roles could be. This was due to participants questioning where they belonged as they felt like they were no longer part of the service user community but also were not part of the wider mental health professional community. This process of being in between the two distinct groups was described as “we’re in a bit of a no-man’s land” (P8).

Some participants described how they felt the roles were interpreted by other service users. For some there was a feeling that service users may be ‘jealous’ of their new position within mental health services. Others talked about how some service users believe “we’ve kind of sold out” (P8). This created an internal challenge for some participants who agreed with some of these perceptions “people from the survivor movement or certain groups don’t agree with peer support in the NHS because they feel it’s at risk of being co-opted or professionalised, which I 100% agree with if I’m honest” (P6).

Relational difficulties

Participants described a range of relational difficulties they had encountered both with mental health professionals, their peers undertaking LX roles and the wider service user community.

Some described how LX roles themselves can be set up to create conflict with a focus on LX professionals being pitted against mental health professionals. P7 described "going to lots of meeting and arguing with lots of people about lived experience involvement". However, other participants spoke about how the roles went deeper than this and "it's not always about bashing the Trusts or NHS or bashing a psychiatrist or bashing this person or that one." (P2).

Participants also reported interactions with individual staff that proved to be challenging or negative

> "there's been times where I just kind of have come up against clinicians or certain people who I just think, yeah, you're really awkward and difficult to work with and you're just not kind of getting it or you're just being really kind of obnoxious" (P6).

These conflicts were also reported amongst those undertaking these roles with P4 describing a situation which "ended up with some quite, sort of personal attacks (which led to) the group sort of splintered as a result of that".

Master Identity

This code correlates with the notion of 'master status' (Deegan, 2001), as participants described the reduction of their identity to their mental health diagnosis "no matter how much you do, you'll never prove to them, you can be, like I say a trustee of an organisation, do something like leadership, you're still seen as a service user." (P11). This resulted in some participants changing how they interacted with their colleagues due to concerns over how they would be viewed by others "without almost giving them further ammunition. Like I'm always conscious of, of showing any emotion in a meeting because I feel like that’s what they’re expecting from me and they’ll put it down to, how they perceive, my previous diagnosis” (P9).

From service user to colleague

Participants often worked in the Trusts where they had accessed services, ultimately working alongside mental health professionals or in services which they had been under or an inpatient in. Some participants described the challenges, others talked about the positive relationships that could develop “I think one of the experiences for example was on one of the clinical psychologists who worked at the residential unit (…) lived in the same area as me (…) our children ended up going to the same childminder and there were times when my son stayed over at her house and then we would go off and work together”. (P1).

Unicorn

A number of participants described how certain staff perceived them as “a bit of a unicorn or a bit of a miracle or different in some way a bit special” (P1). This could also be seen through the concept of ‘role model’ being ascribed to participants. Some explained that professionals involved in their care were proud of them which appeared to have bolstered individuals’ sense of value as they had defied their care teams’ expectations - “I mean my care team (…) often comment on the fact that I’m doing a PhD (…) I guess they didn’t think I had it in me” (P8).

Development of critical appraisal

The ‘development of critical appraisal’ impacts upon individuals’ perception of LX roles. This is a linear developmental process as individuals cannot revert back to their previous stance due to the development of self-awareness and reflexivity. This process occurs through spending time with others participating in LX roles in addition to engaging in broader critical discourse combined with how much autonomy they held and the length of time they had worked in the roles for.

The 'development of critical appraisal' could be seen as paradoxical as whilst it often occurred due to a process of personal and professional growth, it frequently led individuals to question the LX roles which were directly responsible for bringing about this growth.

Time in role

The length of time individuals spent in LX roles seemed to naturally correlate with being offered more opportunities; participants explained how they had begun to develop a reputation amongst services and colleagues. P1 describes how this manifests as "people know that you have developed some expertise in particular areas, so I think that changes how people see you as maybe more of an expert".

However, some participants questioned whether the length of times they spent in LX roles should be limited. With queries around whether it should be seen as a step towards recovery or linked to the severity of their mental health this led some to question

> "when does my lived experience come to an end in my role (…) when does it expire? Because obviously I still struggle with my mental health and these things will be ongoing forever, but I haven't used a secondary mental health service for some time" (P6).

Autonomy

Participants who held roles that were more 'senior' typically had more autonomy, power, and the ability to influence on some level, the culture of the organisation they worked within. However, they were also less likely to currently be impacted by pay discrepancies, lack of support, and supervision, and had more say in what if anything they shared about their experiences. Despite this, participants were not immune from these experiences as they had often progressed in LX roles, as illustrated by P6 who started “at an entry level role and I’ve slowly worked up”.

Critical Engagement

Critical engagement with the roles seemed key in helping people make sense of LX roles and in turn question and challenge them. Participants reported attending “mad studies”, engaging with “Mad Covid” events, being active on “social media” including “Twitter” and one participant was completing a “Masters in Mental Health and Social Inclusion”. These were credited with helping participants connect to some of the more critical discourses.

Participants spoke about their desire to have their attitudes challenged by those who were external to the LX roles.

> “I just feel, if I was supervised from someone outside, it would always help me hold that kind of activist in me almost. I almost feel like sometimes, I become too chilled out and too, too tamed or too sterilised” (P6).

Some participants explained how this tied into the inherent challenge of trying to stay authentic to oneself and one’s values, whilst working in an organisation where these can easily become subsumed into the wider systemic structures.

> “the dissonance between trying to be authentic and represent what you know (…) but being so outnumbered and feeling like it’s impossible to have your voice, heard (…) just that constant tension of like, am I now the enemy? Am I like one of the bad guys? Have I lost my way? Have I lost what I was trying to do?” (P9)

Relating with LX peers

Participants described a number of ways that they connected with their peers who also undertook LX roles. This allowed them to build informal support networks that were highly valued as P8 explained “that made a big emotional difference, just to be able to meet with the others and share what we were finding difficult and things like that". These spaces allowed for participant to share ideas, network and provide informal support to one another.

Future goals

Whilst all participants were actively involved in LX roles, they discussed their futures throughout the interviews and were also explicitly asked about this at the end. There was no single consensus amongst participants but instead a wide range of options were discussed.

Career pathway

Participants described how opportunities had snowballed for participating in LX roles. A few participants described not knowing what they would do next or waiting to see where the journey would take them. The majority of participants described the lack of career pathway for LX roles. This appeared to partially be due to a number of participants being one of “the first” to hold a specific role. The lack of career progression meant that for a period of time P6 “moved out to a non-lived experience role which I really regretted doing, if I’m honest”. Subsequently a LX career pathway in his NHS trust was established, and he returned.

Participants were unequivocal about the importance of the career pathway needing to “have the same credibility and knowledge as all the kind of clinical professions have” (P6). A number of participants expressed a desire for a wide range of roles to be developed. Though issued caution due to the importance of the implementation process “we’ve got to get the process right. I don’t want loads of people starting and not being able to fulfil the roles for whatever reason or the Trust letting them down” (P3).

New challenges

Participants gave ideas of what they would like to do next within the LX roles such as focusing on embedding and developing change within their current service or working with new services as P2 explained “I’d love to do some work with crisis care”.

Other participants expressed desire to become more senior within the lived experience profession. This seemed to entail a desire for some participants to “work my way up, the career path” (P8), or to become a Director. This seemed to be connected to their belief that seniority may in turn allow them to “have a significant, influence in changing the culture” of their trust (P9).

Restricted by circumstances

It is important that consideration is given to the fact that not everyone was in a position to drastically change or increase the amount of time they spent participating in LX roles. This was for different reasons including it being related to their health “I struggle a lot with my health (…) it’s really unlikely that I’d be able to go back to work again anyway.” (P4). Others linked it to the importance of needing to financially support their family

> “I need to go out and work and provide for my family. (…) I’m not going to be able to be one of those pioneers to really push through and say no, forget your job, I can do better on my own” (P5).

Changing career

Some participants did feel conflicted about staying within LX roles. One participant expressed a desire to undertake further professional therapy training. Other participants questioned if undertaking LX roles was appropriate for them. P6 shared his uncertainty of,

> “if I want to, be in a lived experience role in the NHS forever (…) the more I’ve got into my master’s the more I am questioning my identity, and where my knowledge or my kind of professional learned knowledge sits.”

This concords with P9 describing “there’s part of me that desperately wants to get out and leave tomorrow”. This seemed to predominately be due to factors that link with the code unvalued but also internal factors as outlined by P11 “Because I always see myself as more than lived experience.”

Discussion

The current study aimed to develop an understanding of the professional, social, and emotional impact participating in LX roles in a mental health context has upon an individual's identity. Eleven individuals took part in a semi-structured interview that focused on the process, personal impact, and resultant changes that they had observed as a result of participating in LX roles. Interviews were conducted and analysed using social constructivist grounded theory (Charmaz, 2006) leading to the development of a theoretical framework and model outlining the key processes involved in individual's identity change. Participants assimilated the experiences they encountered whilst undertaking LX roles. The process of identity change occurred through the dynamic concept of 'feeling valued' or 'feeling unvalued'. This was facilitated and hindered by three interlinking factors ('organisational and service culture', 'changing relationships', and 'the role of power'). This occurred in conjunction with individuals' 'motivations for doing LX roles' and the 'development of critical appraisal'. Consideration was paid to participants' prior life experience ('the only way is up') and their 'future goals' as these provided contextual information.

Despite the research questions focusing on identity participants described at length the impact that participating in LX roles had on them and this led to a number of implications for future implementation. Focus was paid to the impact of 'service and organisational culture' on individuals linking to previous research which outlines the importance of workplace culture and the impact that this can have on individuals undertaking LX roles (Ibrahim et al., 2019; Tate et al., 2021). This may align with the increasing professionalization of these roles since the publication of policies such as the NHS Five Year Forward View (2014), and the NHS Long Term Plan (2019). As a result, individuals may be seen as pioneers in these roles due to the limited number of LX roles in existence in the U.K. As such, increasing the number of roles available and in turn co-producing a career pathway may in turn reduce some of the challenges encountered by participants. It is therefore unsurprising that in spite of positive experiences a wide range of challenges were reported. These challenges e.g., remuneration and lack of supervision and support were vitally important to participants and often led them to question how valued LX roles were.

The concept of ‘value’ has been discussed in previous research but has typically focused on the value these roles bring to services, recipients of services or how services and staff value the roles (Ibrahim et al., 2019; Moore & Zeeman, 2020). In contrast with previous studies the current study identified the importance of individuals feeling valued and how this linked with participants’ overall changing view of self and identity. Research suggests that mental health difficulties align with individuals being devalued due to stigma and this has a resultant impact upon one’s identity (Hinshaw, 2005; Thoits, 2011). As such, this may explain why participants placed such importance on being valued especially on initially participating in LX roles. In turn, this may explain why some participants struggled with how to position the roles on beginning to develop critical appraisal due to the paradoxical nature that occurs through beginning to question whether the entity that has allowed you to grow is also causing you harm.

Participants credited LX roles for their changing view of self. This concords with previous research which reports that through participating within LX roles individuals are likely to move from an ‘illness identity’ (the only way is up) to having a more ‘professional identity’ which is accompanied by increased confidence and personal growth (Debyser et al., 2018; Faulkner and Basset, 2012; Yanos et al., 2010). This changing view of self may also be explained in the current study by participants describing how they valued having a sense of purpose, the importance of being able to contribute to society and a sense of belonging with several participants describing the significance of having an NHS badge. Research has found being valued by others has an important link to identity both in terms of societal perceptions (what you do), and personal perceptions (who you are) (Hine et al., 2019; Steeman et al. 2013). As such, it appears individuals may be undergoing a process of identity change in the eyes of wider society as a resultant impact on how they view themselves. This is likely to correlate with holding a devalued and stigmatised identity (prior to starting the roles) through to being seen to contributing and valued through the act of participating in the roles.

One of the aspects that participants particularly valued was the expansion of their social group. This is likely to result in a process of interpersonal change as outlined by social identity theory (Tajfel, 1974). This change maybe especially likely due to the changing perception of registered professionals from that of caregiver to colleague. However, the current study and previous research highlight relational difficulties occurring in part due to the challenges of holding a service provider and service user identity (Ball, 2017; Debyser et al., 2018; Korsbek et al., 2021; Voronka, 2017). This is illustrated through participants' description of 'no man's land' where they do not belong fully to either the service user community or the mental health professional community. As such, one might consider that participants have found themselves in the out group due to the outgroup derogation that can occur (Branscombe & Wann, 1994). This is likely to impact on one's self-esteem and may concord with stigma and in turn can impact on how valued one feels (Hinshaw, 2005; Sampasivam et al., 2016).

Those undertaking LX roles report stigma and discrimination in both the current study and previous research (Byrne et al. 2019). As participants described being viewed through the lens of "master status" they are likely to be hindered in fully developing a 'professional identity' by the stigmatising views of others and the difference accorded to individuals in terms of prestige, power, and autonomy (Deegan, 2001; Slay and Smith, 2010). When considered alongside Arnstein's (1969) 'ladder of citizen participation' this was particularly apparent when 'tokenism' or a sense of powerlessness was reported by participants. This contrasts to when participants described being seen as equal and in turn afforded similar levels of power and prestige to other mental health professionals which concords with the FREDA principles and Human Rights Act (1998) highlighting the importance of not discriminating individuals and treating them with respect (Curtice & Exworthy, 2010).

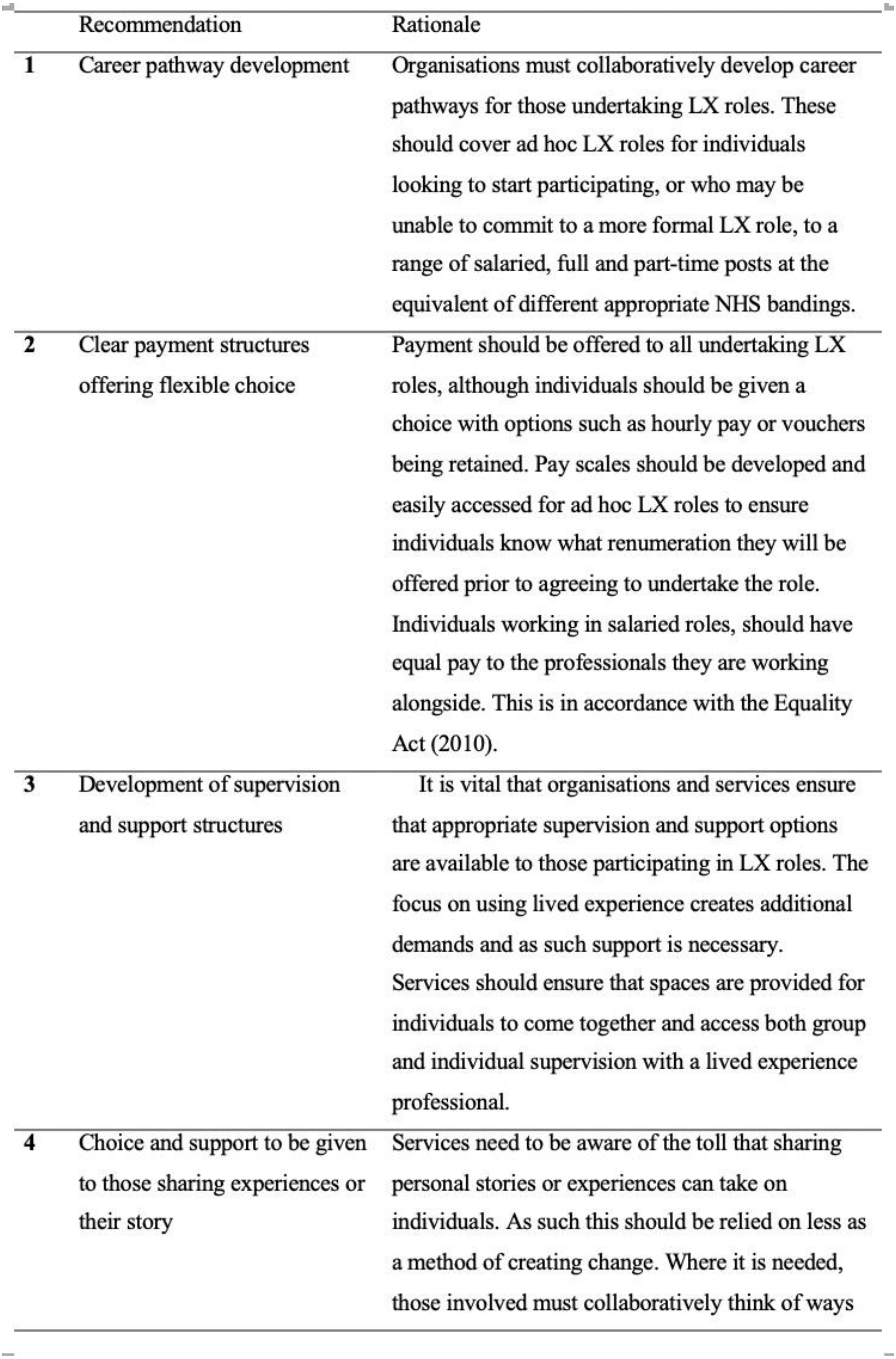
Identity development is impacted by the unique life experiences we face and in turn will be impacted by the emotions that go alongside this (Horrocks & Callahan, 2007). Participants frequently described LX roles as an emotional rollercoaster, and it is important to consider that it is not always the case that positive experiences lead to a positive impact on one's identity and negative experiences lead to a negative impact. Instead, an individual's self-view ties in with feedback that they have received, and the opportunities received in which to challenge it (Stets, 2005). This could be seen through the 'development of critical appraisal' as whilst participants described receiving positive feedback when they also felt undervalued due to e.g., limited pay or remuneration then this is likely to lead them to have a negative experience despite the increasing opportunities. As identity development is dynamic, the roles that people hold will influence how their identity develops. It is important to not presume that the concepts of 'feeling valued' or 'feeling unvalued' and the resultant impacts on self-esteem will eventually lead individual's identity to positively or negatively develop. Instead, some participants reported how LX roles had allowed them to turn their mental health difficulties into something positive. The same is liable to be true with individuals being able to construct positive identities despite negative attributions and oppression leading to them feeling empowered (Elraz, 2018).

Implications

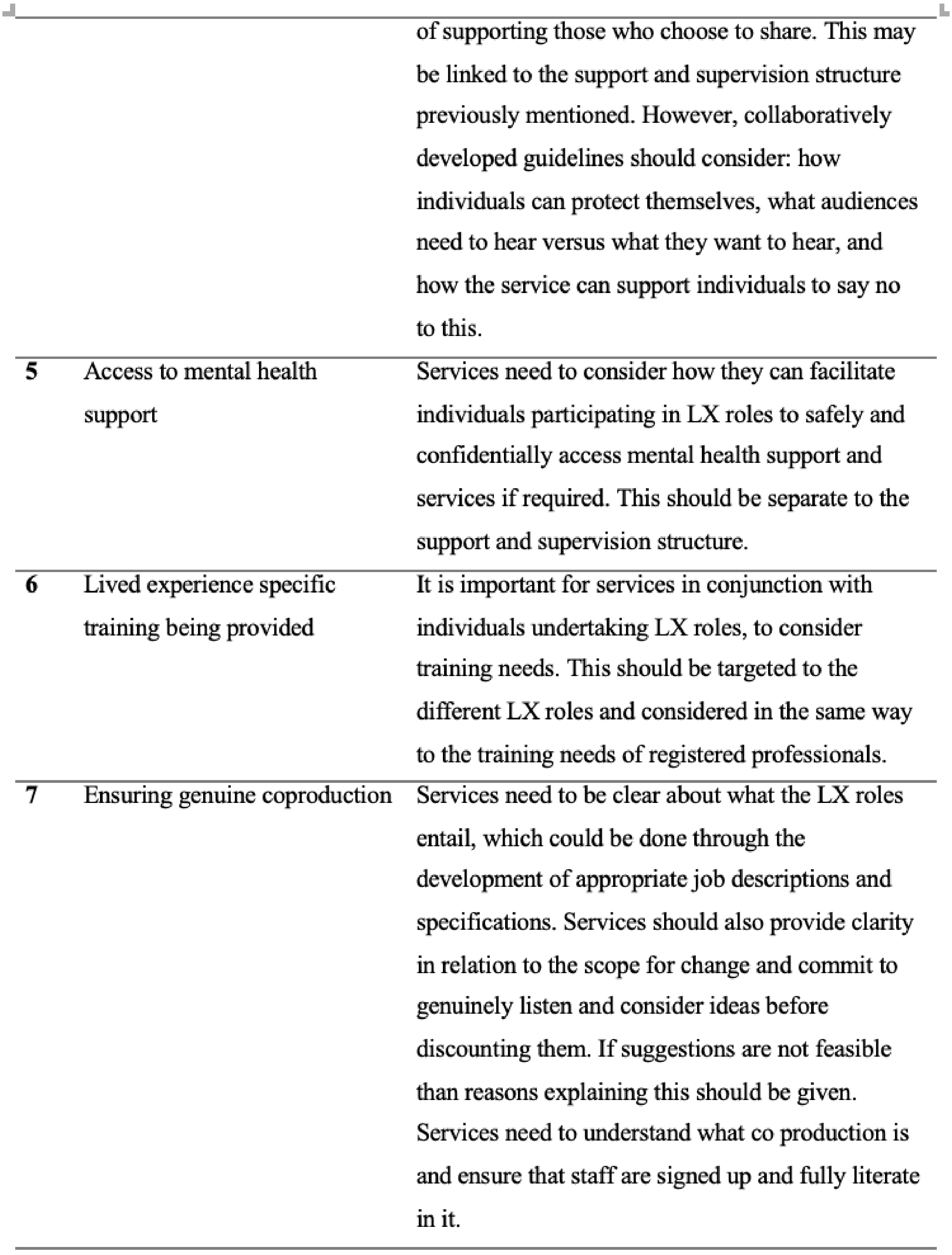
As mental health services, charities and organisations increasingly introduce LX roles, thought must be given to the impact that these roles can have on the individuals undertaking them and in turn their identity development. It is key that awareness is paid to developing, implementing and embedding appropriate support structures that enable individuals to feel valued with the resultant positive impact on confidence, sense of self and potential for growth. The factors that were seen to help and hinder should be considered and these were ‘the service and organisational culture’, ‘the role of power’, and ‘changing relationships’. This will ensure that LX roles and the individuals undertaking them can flourish. Practical recommendations from this study, which links directly to what helps and hinders individuals feeling valued, for those who employ individuals in LX roles in a mental health context are outlined in Table 5.

The ‘development of critical appraisal’ enabled participants to critically reflect upon the LX roles that they were undertaking and in turn consider their positioning in relation to this. This process could not occur without groups of individuals participating in LX roles sharing experiences and in turn developing a shared professional identity that was rooted in the broader historical context that had resulted in the development of LX roles. This process allowed individuals to develop self-awareness and reflexivity and services should therefore encourage this. However, some participants reported how they were actively discouraged by services from meeting with their peers. This seemed particularly contradictory for participants who described a sense of alienation and in turn restricted the possibility of feeling valued.

Table 5 – Recommendations for Services



	Recommendation	Rationale
1	Career pathway development	Organisations must collaboratively develop career pathways for those undertaking LX roles. These should cover ad hoc LX roles for individuals looking to start participating, or who may be unable to commit to a more formal LX role, to a range of salaried, full and part-time posts at the equivalent of different appropriate NHS bandings.
2	Clear payment structures offering flexible choice	Payment should be offered to all undertaking LX roles, although individuals should be given a choice with options such as hourly pay or vouchers being retained. Pay scales should be developed and easily accessed for ad hoc LX roles to ensure individuals know what renumeration they will be offered prior to agreeing to undertake the role. Individuals working in salaried roles, should have equal pay to the professionals they are working alongside. This is in accordance with the Equality Act (2010).
3	Development of supervision and support structures	It is vital that organisations and services ensure that appropriate supervision and support options are available to those participating in LX roles. The focus on using lived experience creates additional demands and as such support is necessary. Services should ensure that spaces are provided for individuals to come together and access both group and individual supervision with a lived experience professional.
4	Choice and support to be given to those sharing experiences or their story	Services need to be aware of the toll that sharing personal stories or experiences can take on individuals. As such this should be relied on less as a method of creating change. Where it is needed, those involved must collaboratively think of ways



		of supporting those who choose to share. This may be linked to the support and supervision structure previously mentioned. However, collaboratively developed guidelines should consider: how individuals can protect themselves, what audiences need to hear versus what they want to hear, and how the service can support individuals to say no to this.
5	Access to mental health support	Services need to consider how they can facilitate individuals participating in LX roles to safely and confidentially access mental health support and services if required. This should be separate to the support and supervision structure.
6	Lived experience specific training being provided	It is important for services in conjunction with individuals undertaking LX roles, to consider training needs. This should be targeted to the different LX roles and considered in the same way to the training needs of registered professionals.
7	Ensuring genuine coproduction	Services need to be clear about what the LX roles entail, which could be done through the development of appropriate job descriptions and specifications. Services should also provide clarity in relation to the scope for change and commit to genuinely listen and consider ideas before discounting them. If suggestions are not feasible than reasons explaining this should be given. Services need to understand what co production is and ensure that staff are signed up and fully literate in it.

The impact of the Researcher

The Researcher is open about their past job roles and lived experience of mental health difficulties, and actively engages in discussions on this in areas such as Twitter and through attending ‘Mad Study’ groups. The personal and professional experience the Researcher has within this area, is therefore likely to have impacted on the research in contrast to if only professional experience was held (Gillard et al., 2010).

Consideration needs to be given to this as some but not all participants were aware of this role duplicity. At least one participant commented on how they had spoken more freely because of this, possibly due to the aforementioned view about the importance of meeting others who are doing or have done these roles. This seemed to correlate with the Researcher’s view that interviews with participants who were aware felt different to those where participants were unaware. It is hard to fully conceptualise this, but it seemed at times a common language was used and whilst the Researcher understood, they found that they had to ask participants to clarify or expand upon what they were saying to ensure that they were not wrongly interpreting the situation during analysis. Participants who did not know about this seemed to provide more contextual information and expand on their points. The possibility of whether different answers would have been given to a different researcher and in turn the possibility of bias that may emerge as a result of this should be considered.

Service user research is increasingly becoming recognised as a valid form of research bringing key insights. However, the Researcher was conducting this research as part of their Doctorate in Clinical Psychology thesis. As a result, they were not fully able to engage and utilise their ‘survivor’ lens in the process. By holding back, their full ‘survivor’ self during the interview and analysis process some of the richness that this ‘lens’ brings to the analysis and commentary is likely to be lost. Attempts to balance this were made through having a supervisory team that ensured that a balance was found between meeting the course’s requirements and ensuring that the lived experience voice was represented.

Limitations and Future Research

The number of individuals who came forward and expressed interest in participating exceeded the number of interviews that it was possible to conduct. As such, whilst full details are unknown at present it has been agreed by the study team that individuals who were not able to be participants will be given the opportunity to feedback on the model at an online event to consider the application of it in service.

Individuals typically held a range of roles, in a range of settings. This was therefore considered when undertaking theoretical sampling. However, consideration needs to be given to the fact that individuals may have been identified to be a participant for holding one role and yet their identity may have been more significantly impacted by another role that they held. To try and control for this, participants were asked at the start of the interview to provide details of all their roles and clarity was sought during the interviews. In addition, the theoretical sampling focused on a range of factors not just the roles held by individual's e.g., including length of time doing the role.

Participants were not asked their demographic details until the interview stage. Therefore, it was not possible to ensure that participants accurately reflected the demographics of those who came forward to participate. One of the criticisms of this field of work is the lack of ethnic diversity (Kalathil, 2008; Rose & Kalathil, 2019), which was also mentioned by a number of participants. As a result, it is important to consider that this model may not accurately reflect the experiences of individuals from ethnic groups that are not covered. Ensuring this is reflected in future research is vital.

This research was conducted during the COVID-19 pandemic. This may have impacted on those who came forward to be a participant as some individuals may have been struggling with the impact of Covid-19 in either their personal or professional lives through being furloughed or having an increased workload. A number of participants described the challenges of these roles going online due to the impact of digital exclusion. This means that with the research relying on remote technology this will have either increased or significantly decreased accessibility for individuals.

This research focused on individuals participating in LX roles within a mental health context and it would be useful for future research to consider both those undertaking LX roles in different context such as physical health. In addition to the experiences of individuals who are no longer participating in LX roles in a mental health context, consideration must be given to the retrospective impact undertaking LX roles had on the individual and whether their reasons for leaving where linked. This may increase understanding about how these roles function in an individual's career trajectory.

Strengths

This is the first study to look at the wide range of roles that use an individual's lived experience of mental health difficulties and consider the impact that they have on the individual and their identity. The findings bring together a new way of understanding how these roles work and consider the impact on the individual and the role that organisations and services play within this. A social constructivist grounded theory approach allowed the Researcher to consider the participant's voice and in turn produce a new model outlining the factors that impact on individuals participating in LX roles.

The number of individuals who came forward (74) to be a possible participant suggests that there was significant interest in the study by those undertaking LX roles. Individuals contacting the Researcher described how important they felt this research topic was to them. However, whilst only 11 individuals were interviewed due to sufficiency being achieved, the use of theoretical sampling mitigates the likelihood that if different individuals were interviewed different data would have arisen. To further mitigate this, P11 was shown a draft version of the model and theoretical codes to get their opinions on the model and they made comments on both the theoretical categories and the model. This feedback was then used to develop the actual model in conjunction with the wider study team.

Conclusion

Individuals participating in LX roles reported that the roles left them feeling both valued and unvalued with a resultant impact on their identity. The study highlights the need for organisations to consider the impact of factors like ‘service and organisational culture’ to ensure that LX roles are not viewed as tokenistic but instead are given appropriate levels of support and individuals undertaking the roles are seen as equal leading to them feeling valued. This impact on the individual’s sense of self and identity, allowing individuals to continue feeling motivated to undertake the roles. This will allow organisations to maximise the benefit from the input of lived experience voices and ultimately improve and increase access to services for people with mental health difficulties.

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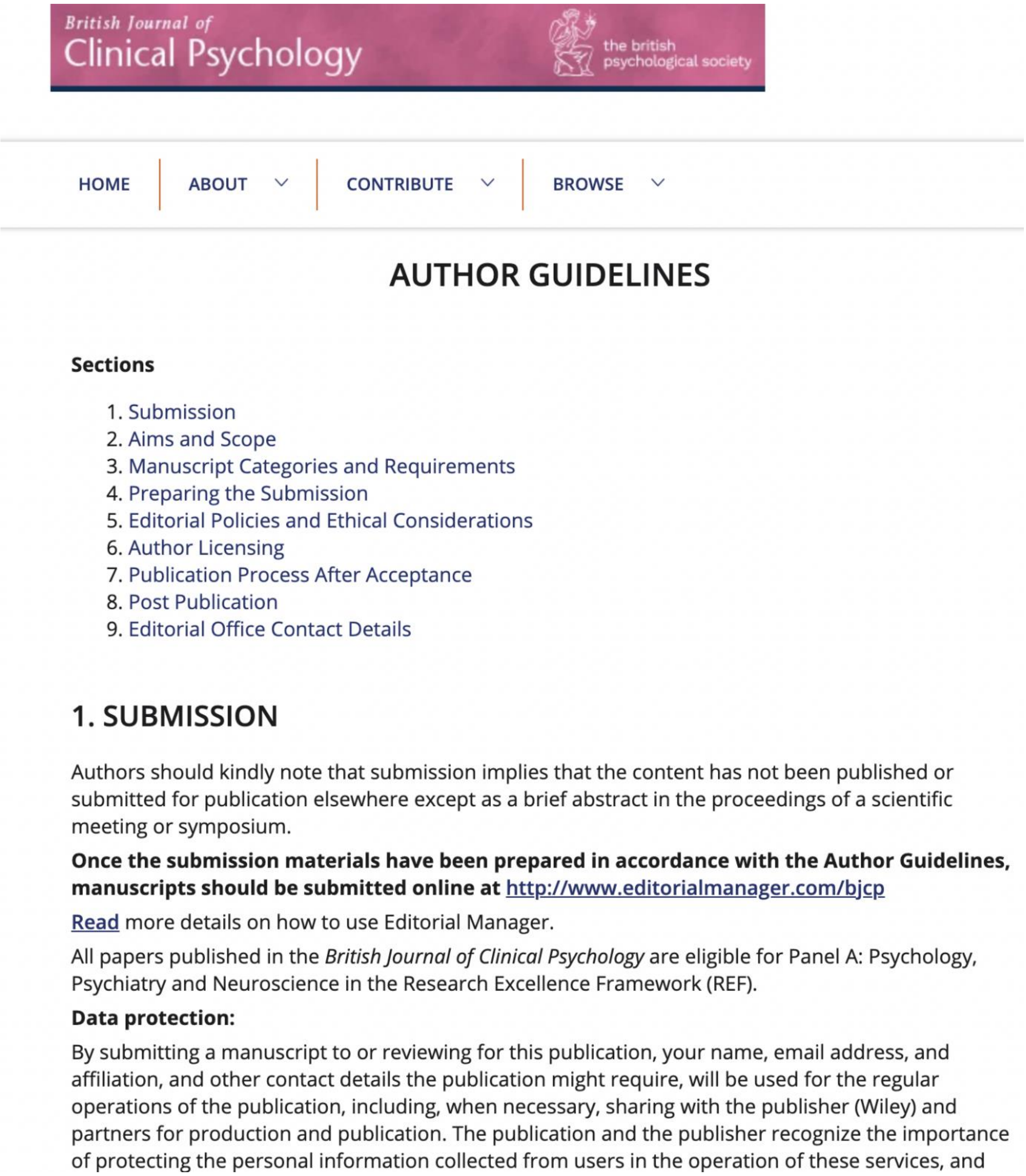
Appendices

Appendix 1. – Author Guidelines for Systematic and Empirical Paper



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Sections

1. Submission
2. Aims and Scope
3. Manuscript Categories and Requirements
4. Preparing the Submission
5. Editorial Policies and Ethical Considerations
6. Author Licensing
7. Publication Process After Acceptance
8. Post Publication
9. Editorial Office Contact Details

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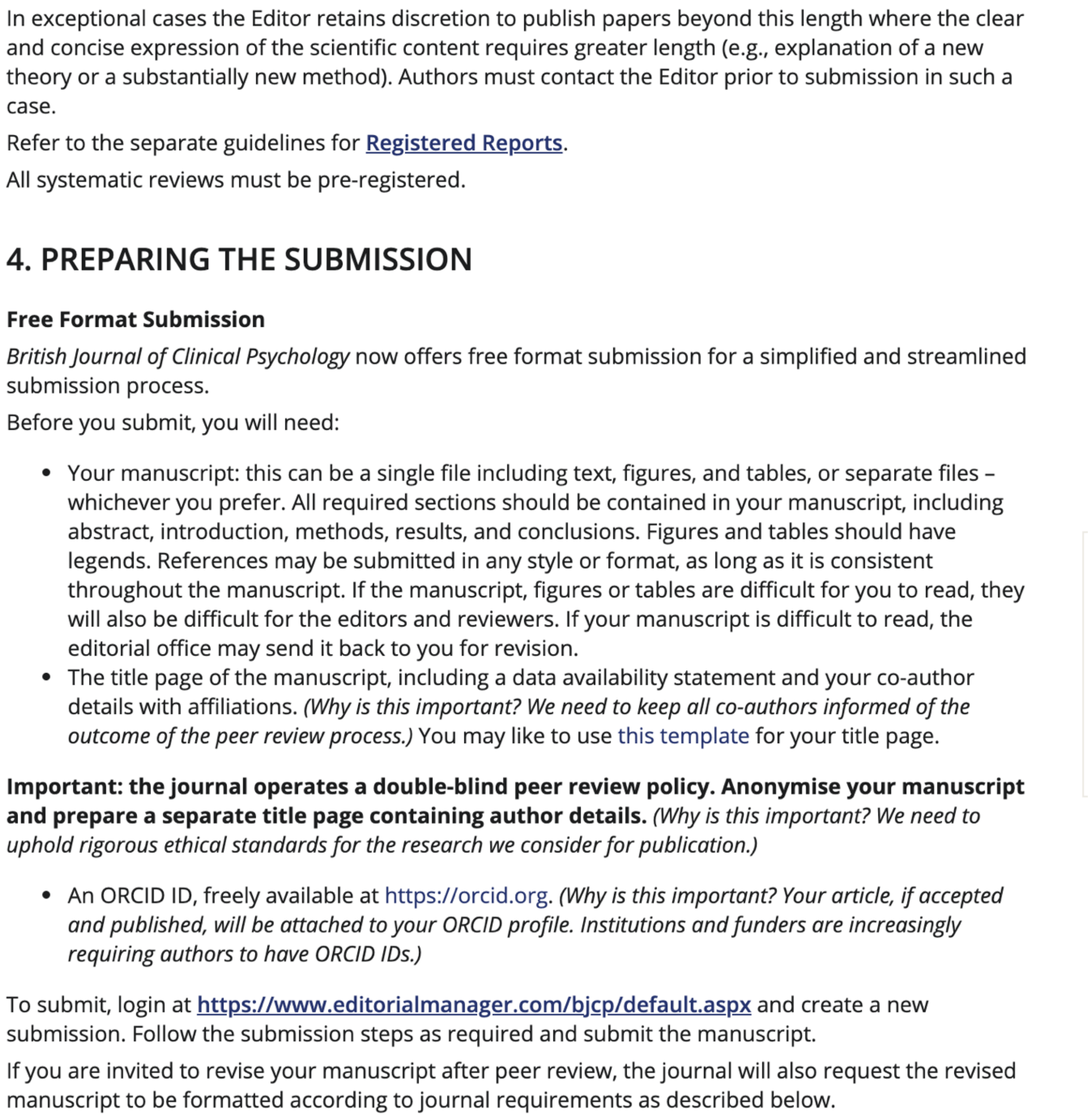
Articles should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Brief reports should not exceed 2000 words and should have no more than one table or figure. Any papers that are over this word limit will be returned to the authors. Appendices are included in the word limit; however online appendices are not included.



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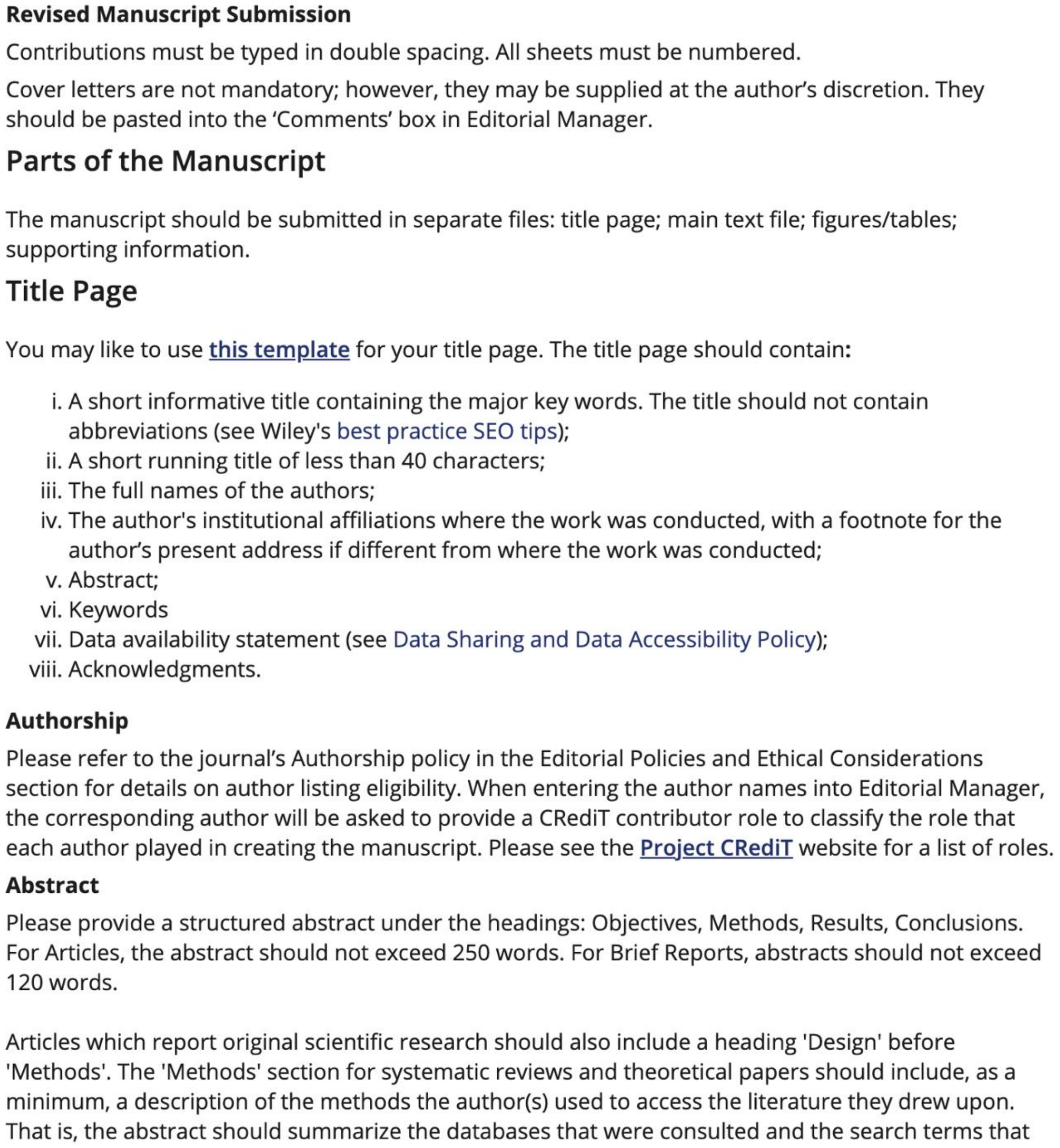

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Please provide a structured abstract under the headings: Objectives, Methods, Results, Conclusions. For Articles, the abstract should not exceed 250 words. For Brief Reports, abstracts should not exceed 120 words.

Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

Keywords

Provide appropriate keywords.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

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All articles must include Practitioner Points – these are 2-4 bullet points, following the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice. (The Practitioner Points should be submitted in a separate file.)

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ii. Main text
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v. Appendices (if relevant)

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

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- The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

References in published papers are formatted according to the Publication Manual of the American Psychological Association (6th edition). However, references may be submitted in any style or format, as long as it is consistent throughout the manuscript.

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Colour figures. Figures submitted in colour may be reproduced in colour online free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white. If an author would prefer to have figures printed in colour in hard copies of the journal, a fee will be charged by the Publisher.

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Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the **APA Publication Manual** published by the American Psychological Association. The following points provide general advice on formatting and style.

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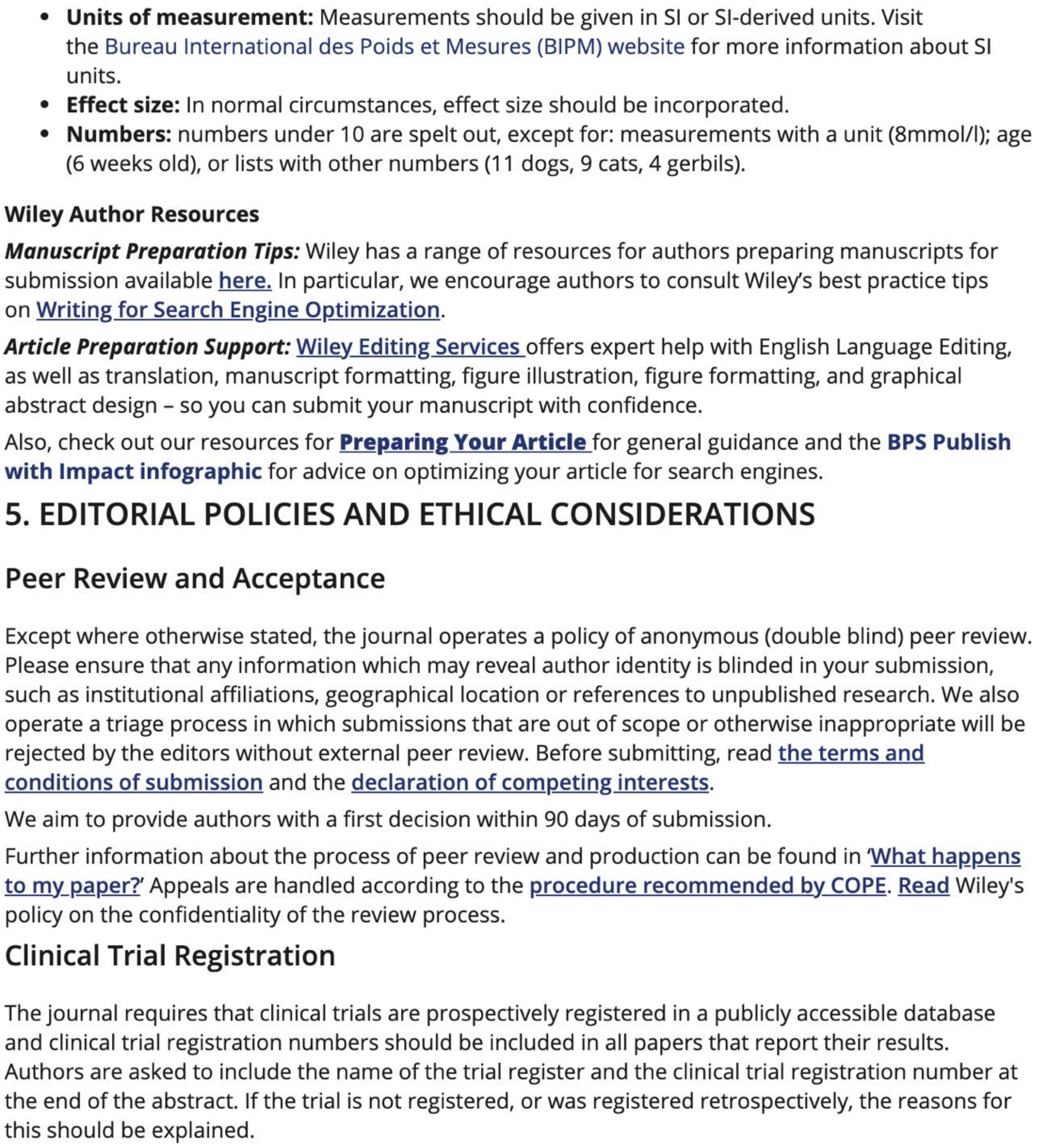
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.



- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.
- **Effect size:** In normal circumstances, effect size should be incorporated.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Wiley Author Resources

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Except where otherwise stated, the journal operates a policy of anonymous (double blind) peer review. Please ensure that any information which may reveal author identity is blinded in your submission, such as institutional affiliations, geographical location or references to unpublished research. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review. Before submitting, read **the terms and conditions of submission** and the **declaration of competing interests**.

We aim to provide authors with a first decision within 90 days of submission.

Further information about the process of peer review and production can be found in '**What happens to my paper?**' Appeals are handled according to the **procedure recommended by COPE**. **Read** Wiley's policy on the confidentiality of the review process.

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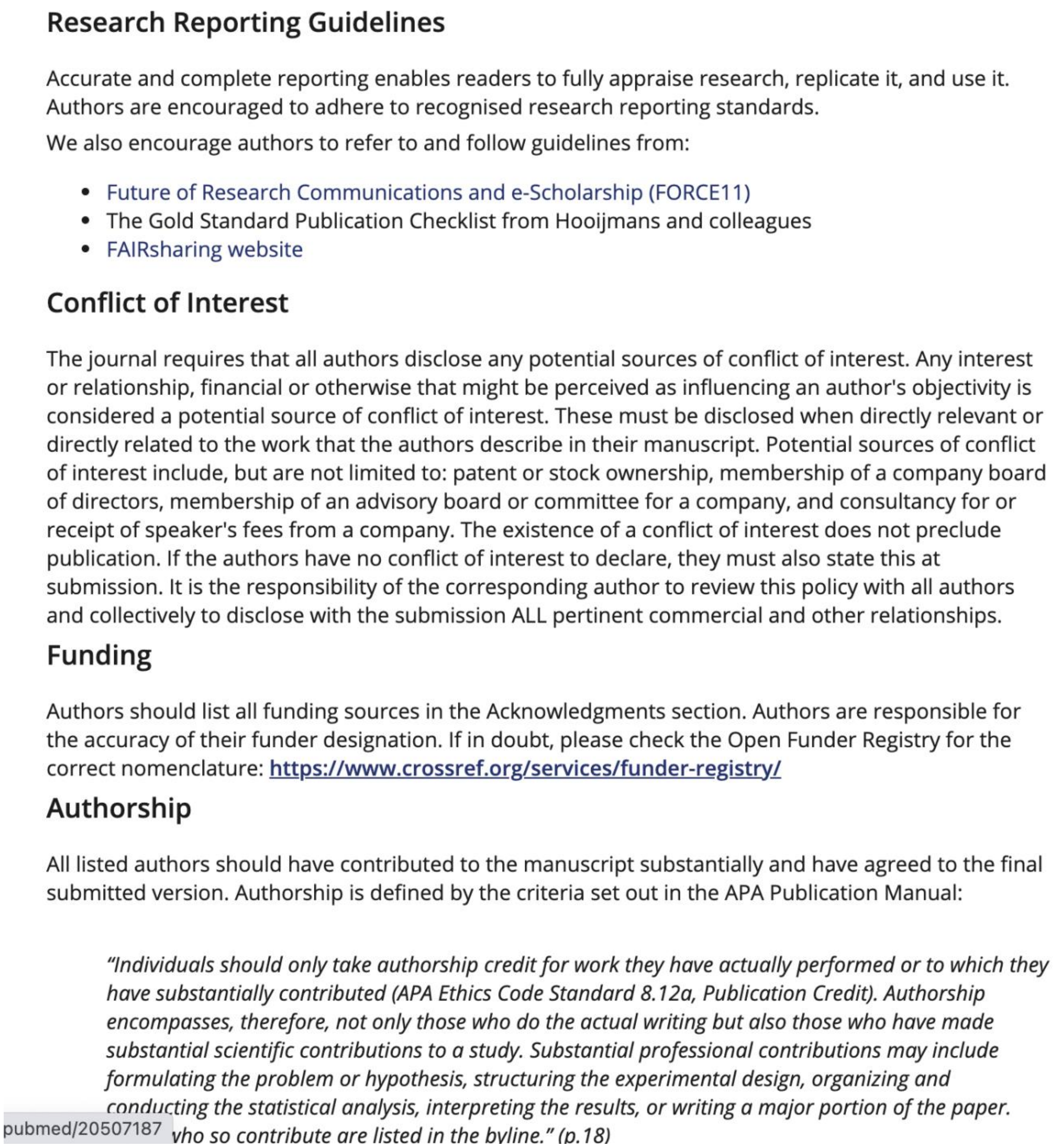
The journal requires that clinical trials are prospectively registered in a publicly accessible database and clinical trial registration numbers should be included in all papers that report their results. Authors are asked to include the name of the trial register and the clinical trial registration number at the end of the abstract. If the trial is not registered, or was registered retrospectively, the reasons for this should be explained.



Research Reporting Guidelines

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. Authors are encouraged to adhere to recognised research reporting standards.

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- Future of Research Communications and e-Scholarship (FORCE11)
- The Gold Standard Publication Checklist from Hooijmans and colleagues
- FAIRsharing website

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The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

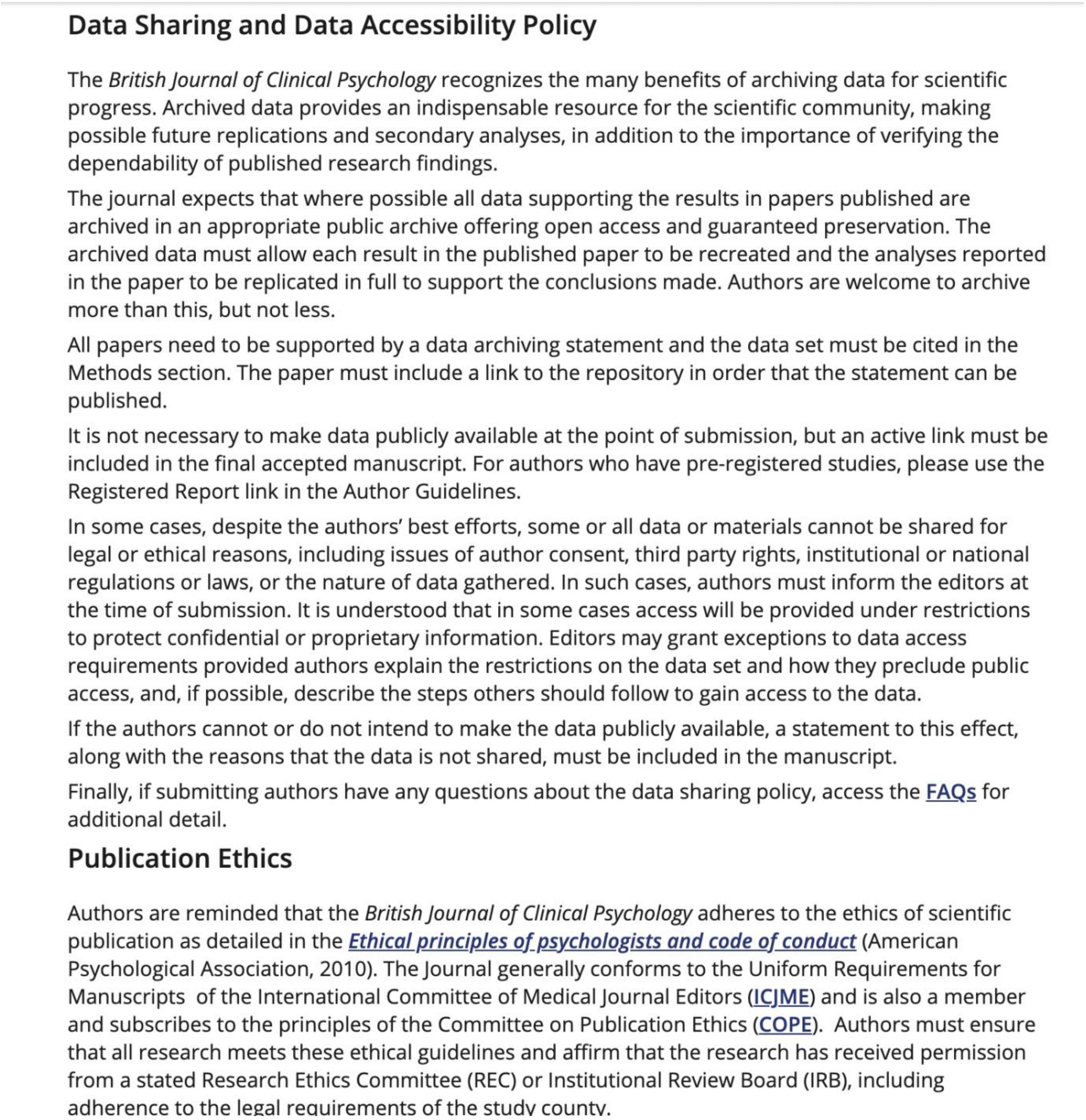
Funding

Authors should list all funding sources in the Acknowledgments section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature: **https://www.crossref.org/services/funder-registry/**

Authorship

All listed authors should have contributed to the manuscript substantially and have agreed to the final submitted version. Authorship is defined by the criteria set out in the APA Publication Manual:

> *"Individuals should only take authorship credit for work they have actually performed or to which they have substantially contributed (APA Ethics Code Standard 8.12a, Publication Credit). Authorship encompasses, therefore, not only those who do the actual writing but also those who have made substantial scientific contributions to a study. Substantial professional contributions may include formulating the problem or hypothesis, structuring the experimental design, organizing and conducting the statistical analysis, interpreting the results, or writing a major portion of the paper.*
> *vho so contribute are listed in the byline." (p.18)*



Data Sharing and Data Accessibility Policy

The *British Journal of Clinical Psychology* recognizes the many benefits of archiving data for scientific progress. Archived data provides an indispensable resource for the scientific community, making possible future replications and secondary analyses, in addition to the importance of verifying the dependability of published research findings.

The journal expects that where possible all data supporting the results in papers published are archived in an appropriate public archive offering open access and guaranteed preservation. The archived data must allow each result in the published paper to be recreated and the analyses reported in the paper to be replicated in full to support the conclusions made. Authors are welcome to archive more than this, but not less.

All papers need to be supported by a data archiving statement and the data set must be cited in the Methods section. The paper must include a link to the repository in order that the statement can be published.

It is not necessary to make data publicly available at the point of submission, but an active link must be included in the final accepted manuscript. For authors who have pre-registered studies, please use the Registered Report link in the Author Guidelines.

In some cases, despite the authors' best efforts, some or all data or materials cannot be shared for legal or ethical reasons, including issues of author consent, third party rights, institutional or national regulations or laws, or the nature of data gathered. In such cases, authors must inform the editors at the time of submission. It is understood that in some cases access will be provided under restrictions to protect confidential or proprietary information. Editors may grant exceptions to data access requirements provided authors explain the restrictions on the data set and how they preclude public access, and, if possible, describe the steps others should follow to gain access to the data.

If the authors cannot or do not intend to make the data publicly available, a statement to this effect, along with the reasons that the data is not shared, must be included in the manuscript.

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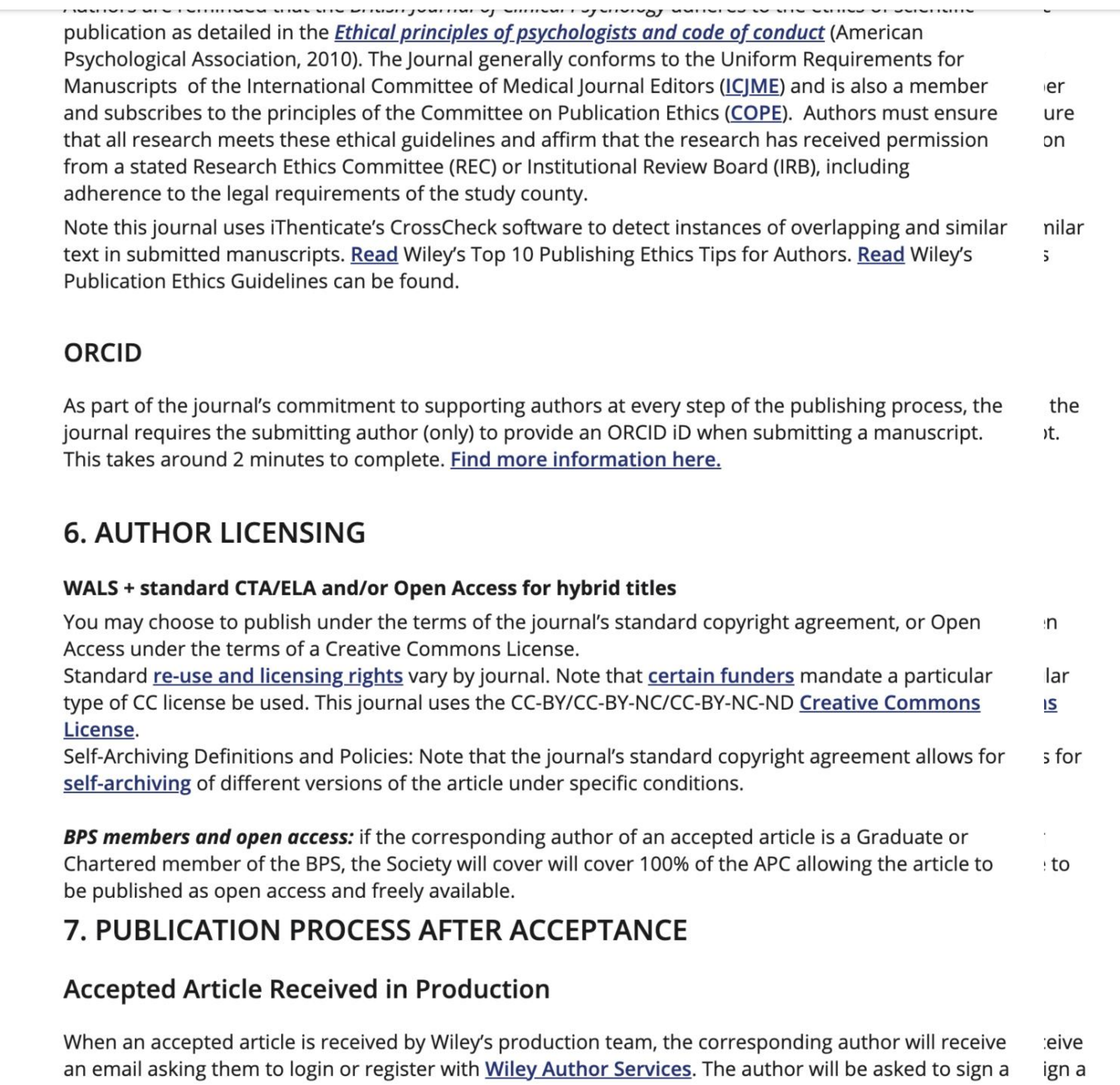

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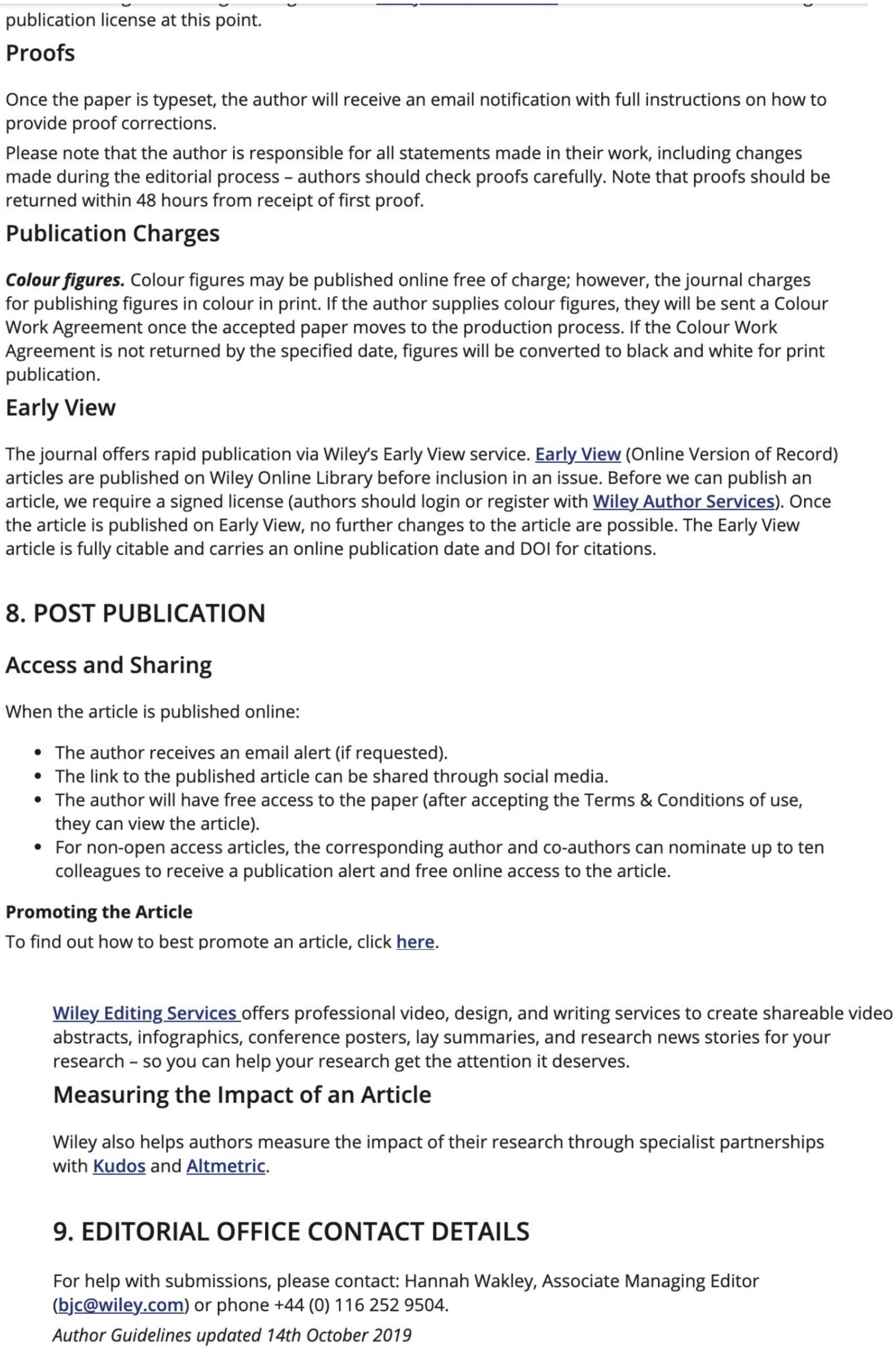

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- The author receives an email alert (if requested).
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- The author will have free access to the paper (after accepting the Terms & Conditions of use, they can view the article).
- For non-open access articles, the corresponding author and co-authors can nominate up to ten colleagues to receive a publication alert and free online access to the article.

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To find out how to best promote an article, click here.

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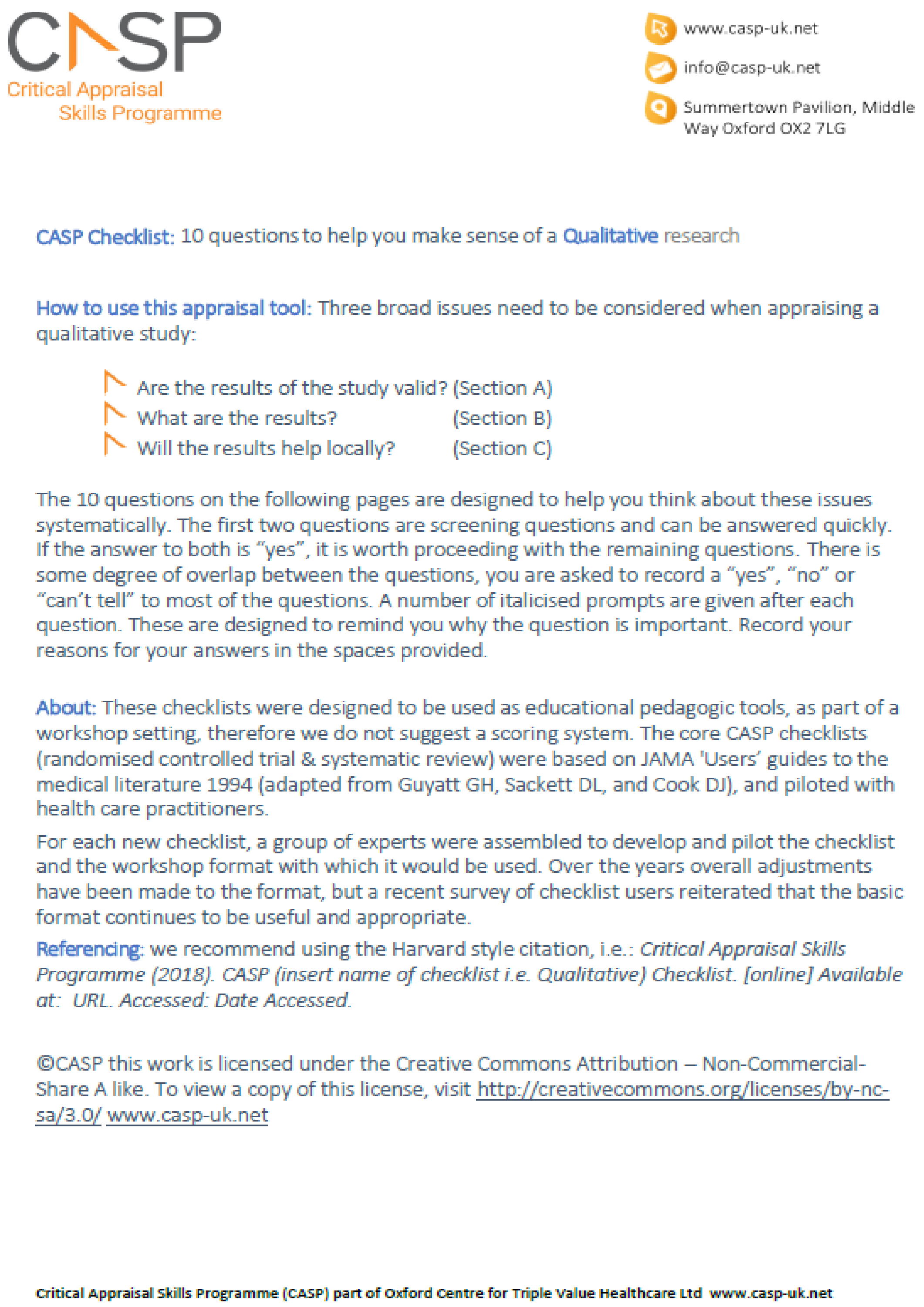
For help with submissions, please contact: Hannah Wakley, Associate Managing Editor (bjc@wiley.com) or phone +44 (0) 116 252 9504.

Author Guidelines updated 14th October 2019

Appendix 2. – Critical Appraisal Skills Programme, Qualitative Research Checklist.



CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

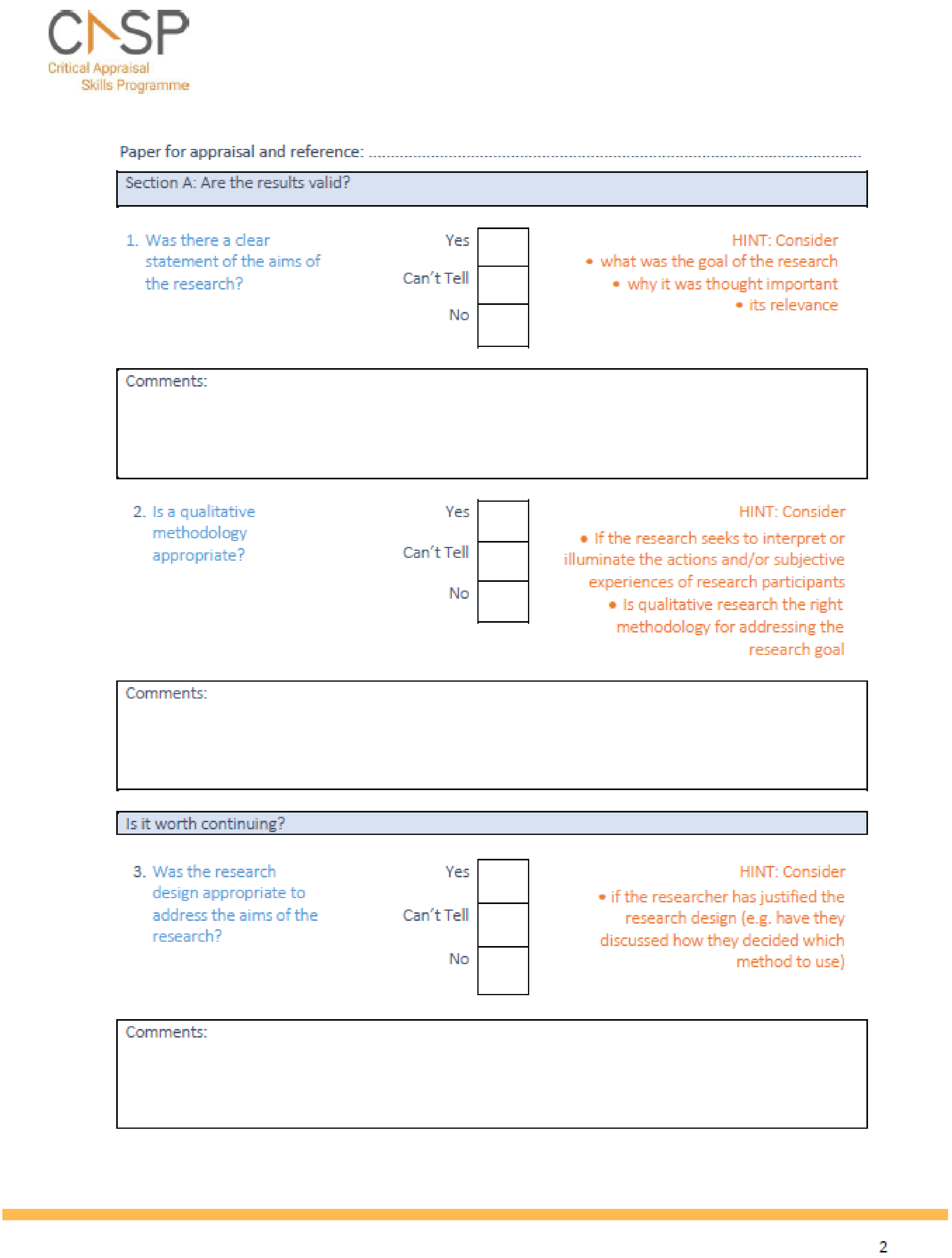
The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

Critical Appraisal Skills Programme (CASP) part of Oxford Centre for Triple Value Healthcare Ltd www.casp-uk.net



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Paper for appraisal and reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

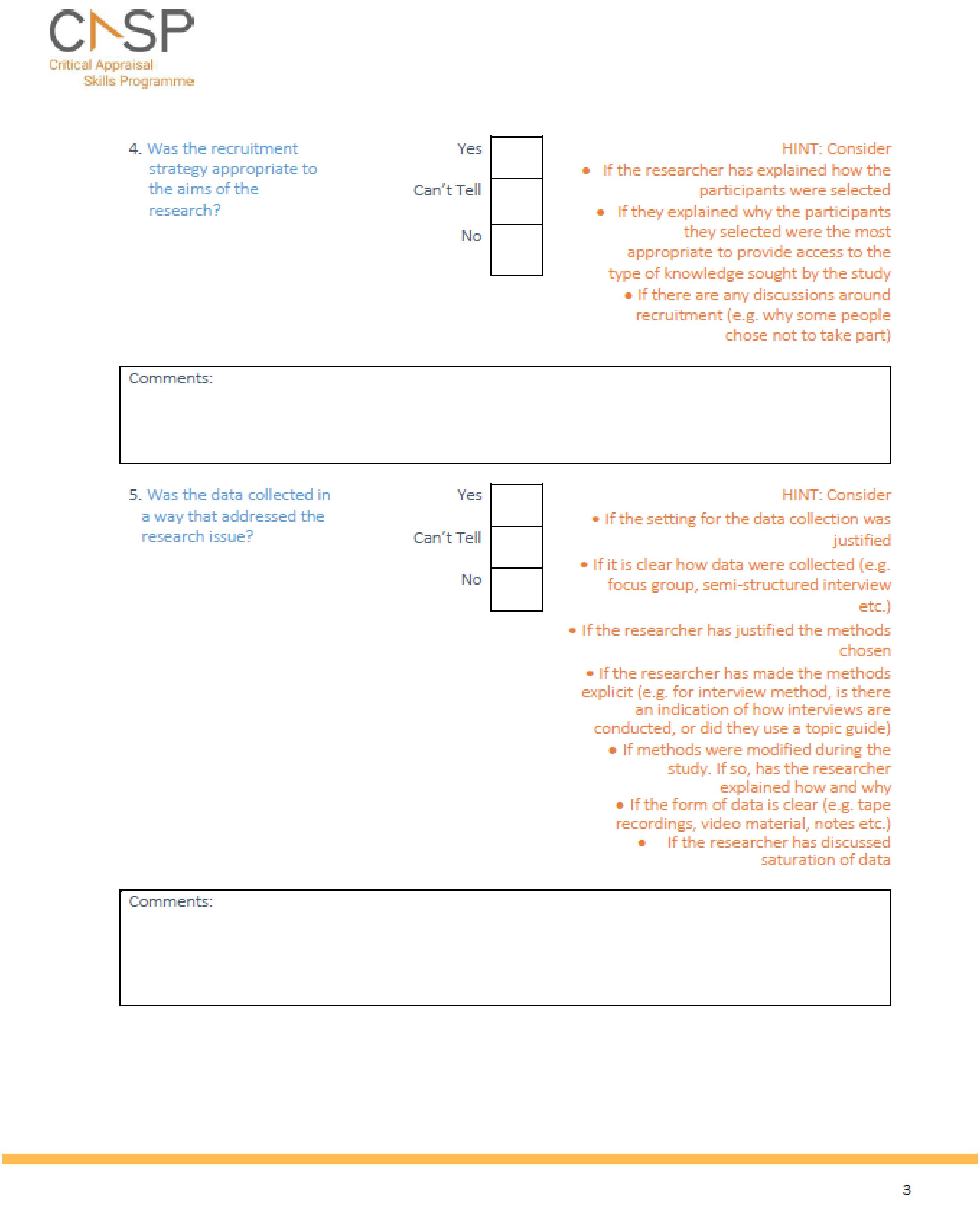
3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

2



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4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

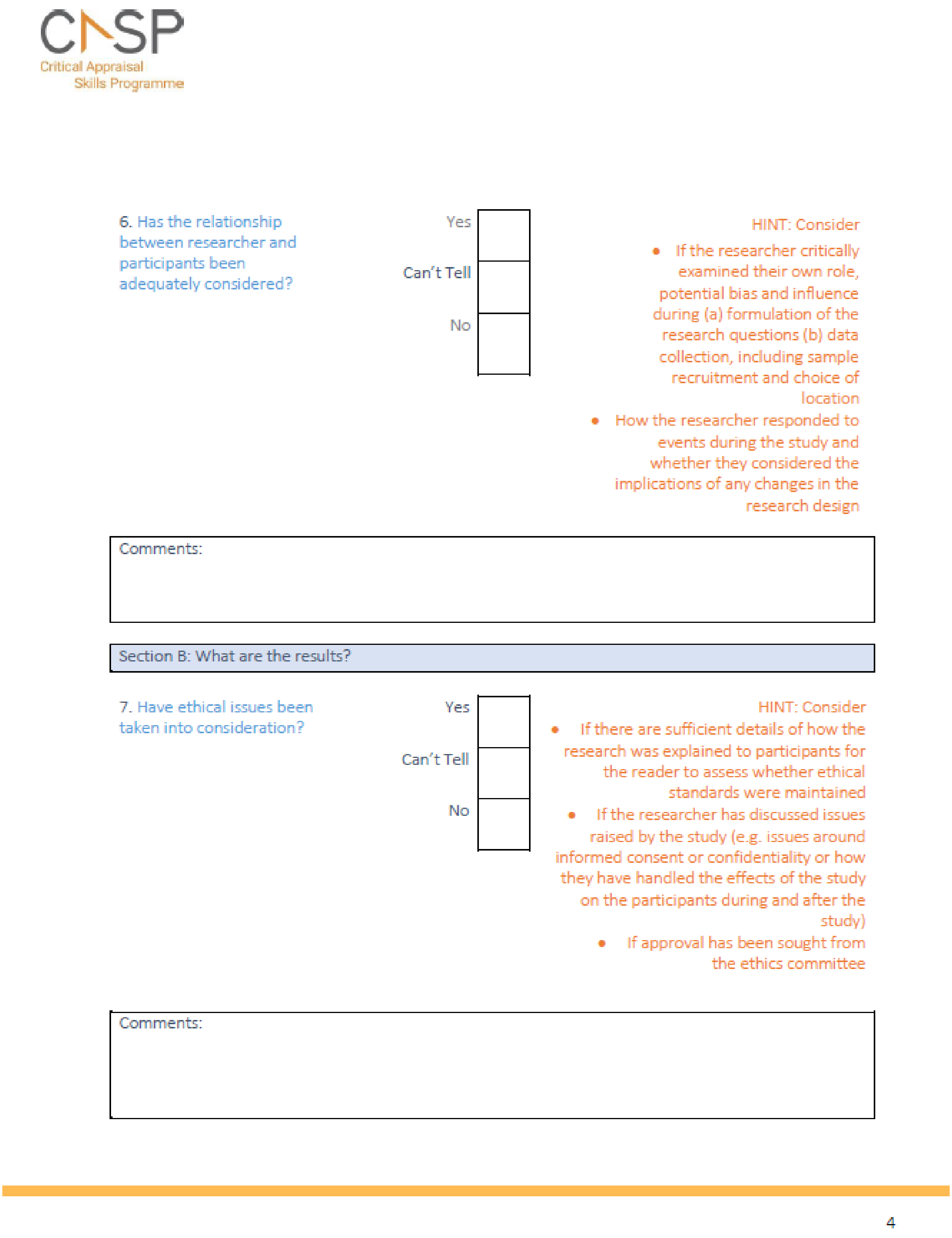
Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:



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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

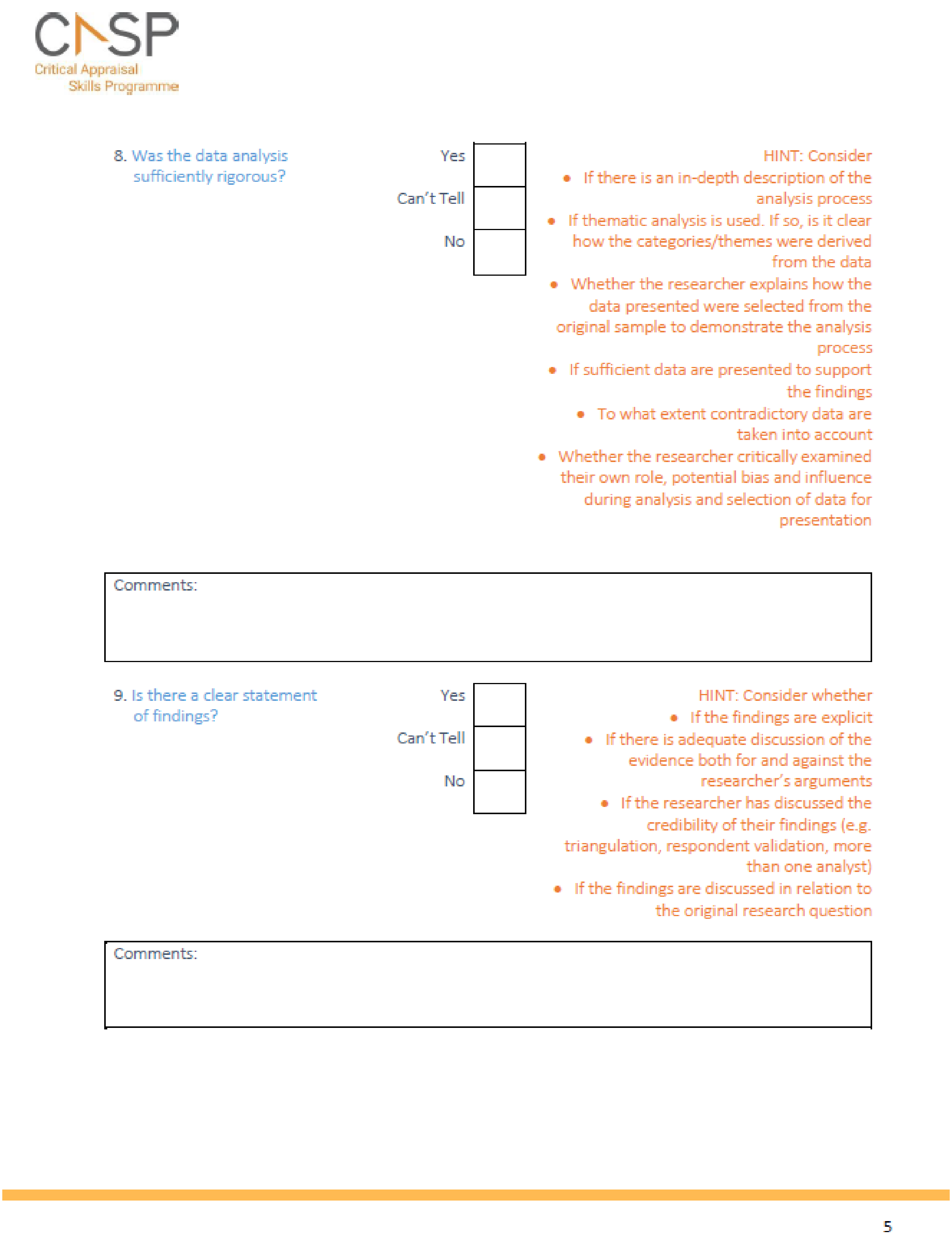
Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:



Critical Appraisal Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

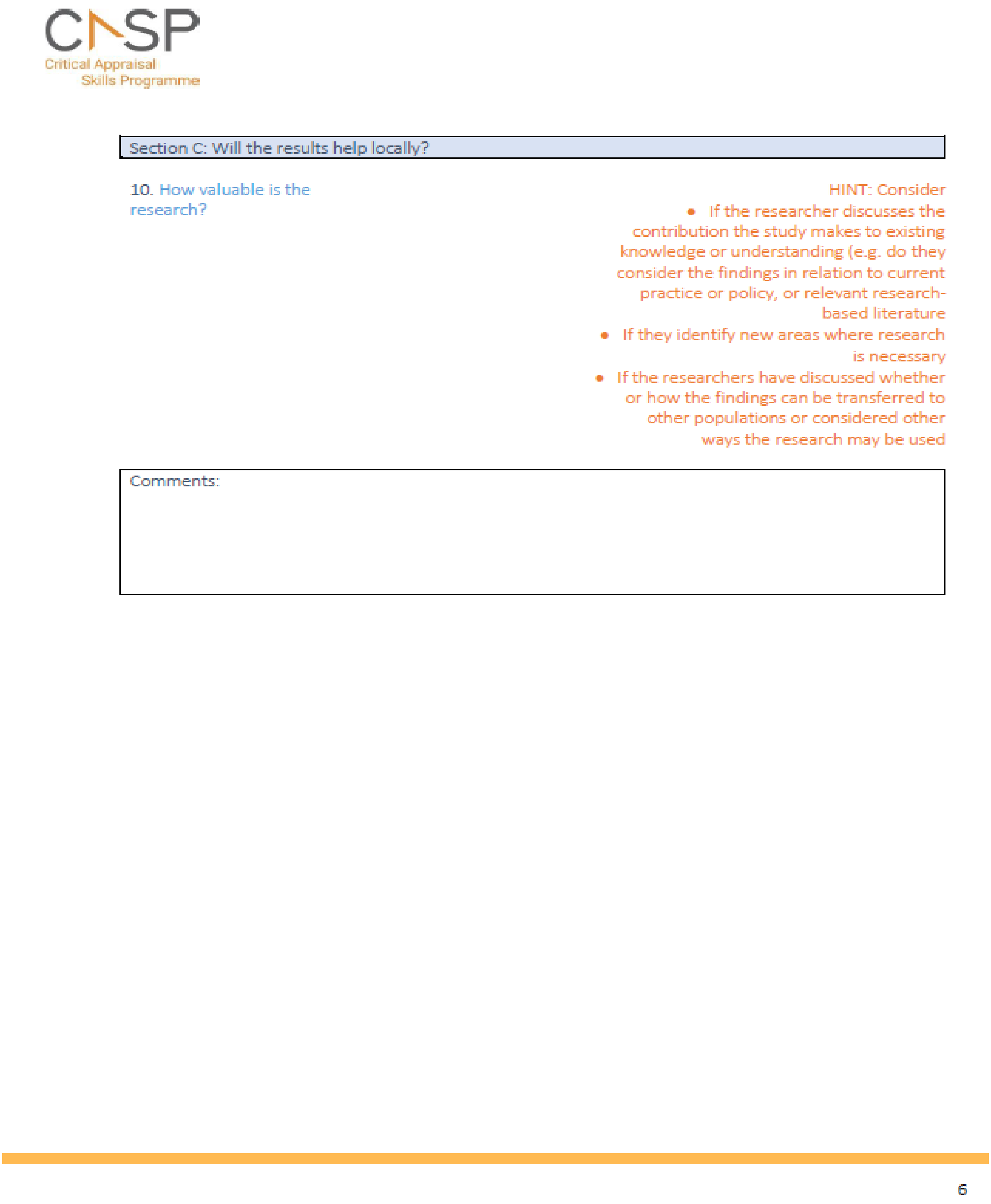
Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:



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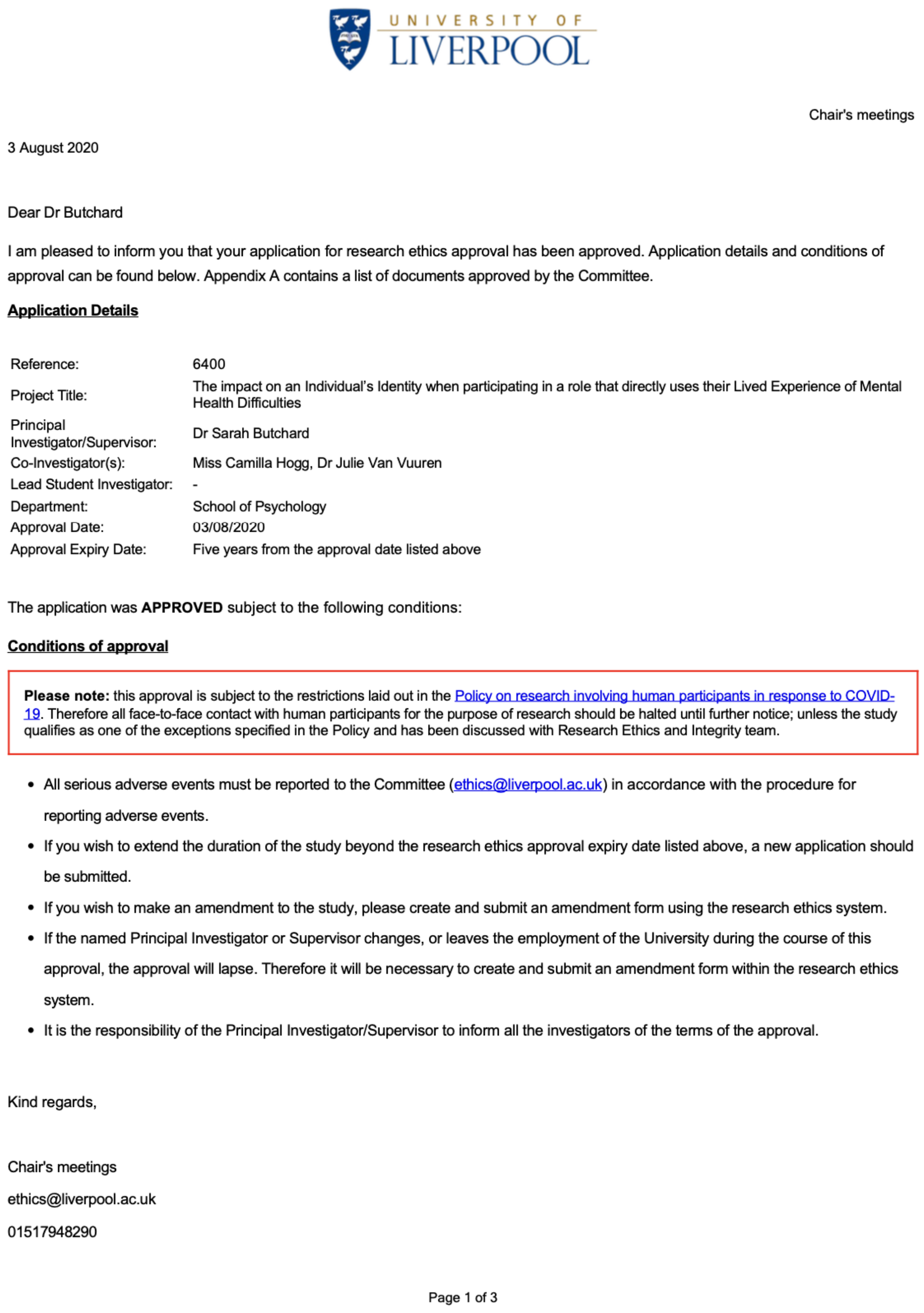
Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 3 – Ethical Approval from the University of Liverpool



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Chair's meetings

3 August 2020

Dear Dr Butchard

I am pleased to inform you that your application for research ethics approval has been approved. Application details and conditions of approval can be found below. Appendix A contains a list of documents approved by the Committee.

Application Details

Reference:	6400
Project Title:	The impact on an Individual's Identity when participating in a role that directly uses their Lived Experience of Mental Health Difficulties
Principal Investigator/Supervisor:	Dr Sarah Butchard
Co-Investigator(s):	Miss Camilla Hogg, Dr Julie Van Vuuren
Lead Student Investigator:	-
Department:	School of Psychology
Approval Date:	03/08/2020
Approval Expiry Date:	Five years from the approval date listed above

The application was **APPROVED** subject to the following conditions:

Conditions of approval

Please note: this approval is subject to the restrictions laid out in the Policy on research involving human participants in response to COVID-19. Therefore all face-to-face contact with human participants for the purpose of research should be halted until further notice; unless the study qualifies as one of the exceptions specified in the Policy and has been discussed with Research Ethics and Integrity team.

- All serious adverse events must be reported to the Committee (ethics@liverpool.ac.uk) in accordance with the procedure for reporting adverse events.
- If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.
- If you wish to make an amendment to the study, please create and submit an amendment form using the research ethics system.
- If the named Principal Investigator or Supervisor changes, or leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form within the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

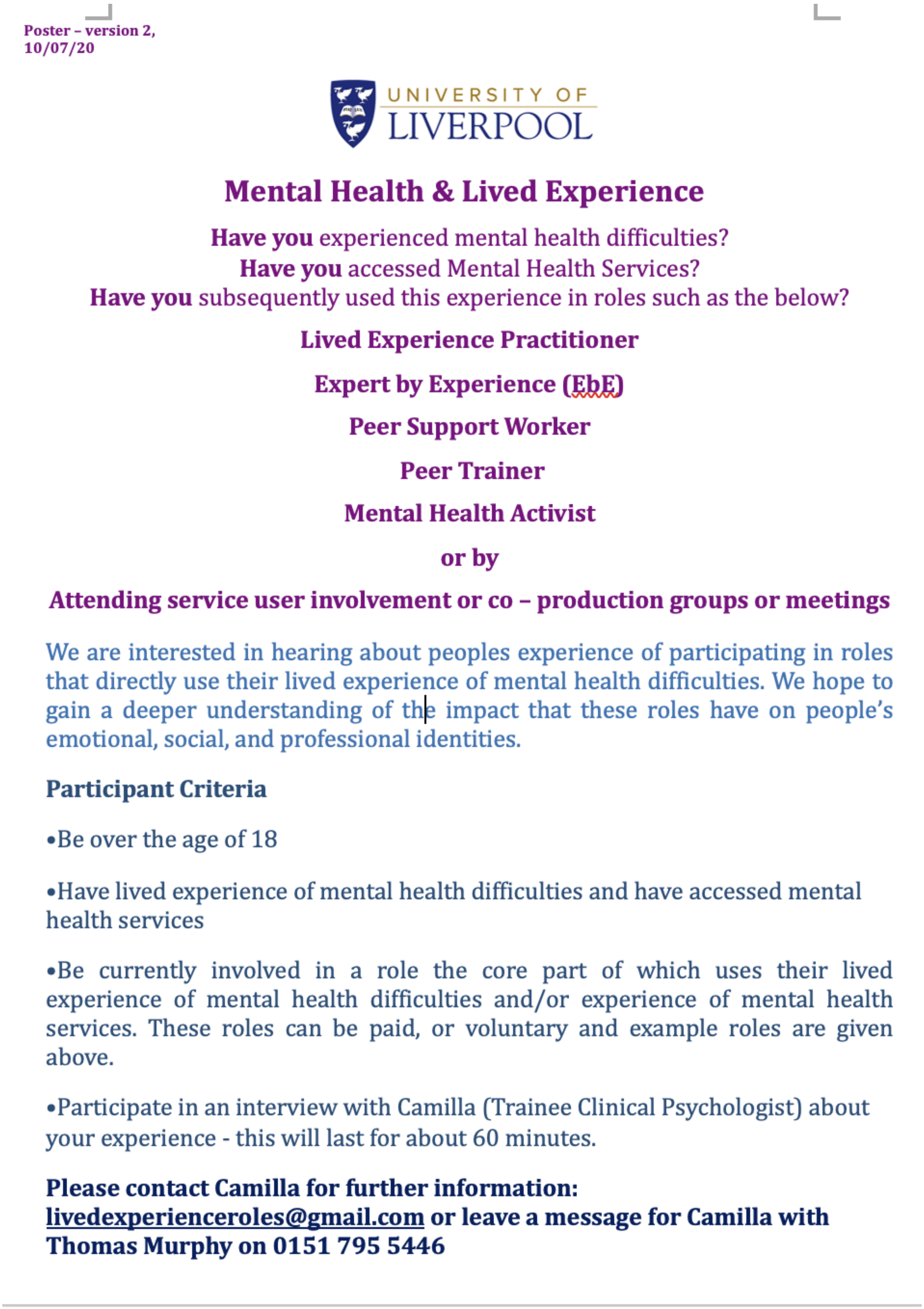
Chair's meetings

ethics@liverpool.ac.uk

01517948290

Page 1 of 3

Appendix 4 – The studies advertisement



**Poster – version 2,
10/07/20**

UNIVERSITY OF
LIVERPOOL

Mental Health & Lived Experience

Have you experienced mental health difficulties?
Have you accessed Mental Health Services?
Have you subsequently used this experience in roles such as the below?

Lived Experience Practitioner

Expert by Experience (EbE)

Peer Support Worker

Peer Trainer

Mental Health Activist

or by

Attending service user involvement or co – production groups or meetings

We are interested in hearing about peoples experience of participating in roles that directly use their lived experience of mental health difficulties. We hope to gain a deeper understanding of the impact that these roles have on people's emotional, social, and professional identities.

Participant Criteria

- Be over the age of 18
- Have lived experience of mental health difficulties and have accessed mental health services
- Be currently involved in a role the core part of which uses their lived experience of mental health difficulties and/or experience of mental health services. These roles can be paid, or voluntary and example roles are given above.
- Participate in an interview with Camilla (Trainee Clinical Psychologist) about your experience - this will last for about 60 minutes.

**Please contact Camilla for further information:
livedexperienceroles@gmail.com or leave a message for Camilla with Thomas Murphy on 0151 795 5446**

Appendix 5 - Participant Information Sheet

UNIVERSITY OF LIVERPOOL

The Emotional, Social and Professional impact on an Individual's Identity when participating in a role directly utilising their Lived Experience of Mental Health Difficulties

Version number 2:10/07/20

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives, and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

1. What is the purpose of the study?

There is an increasing emphasis in mental health services being placed on service user involvement, co-production, peer support and other roles that use an individual's lived experience of mental health problems which is combined with an active survivor movement. Research has tended to focus on the benefits to services and service users rather than what these roles are like for the individuals doing them. We therefore want to know more about what it is like to participate in these roles and understand the impact that this has had on your emotional, social, and professional identity.

2. Why have I been chosen to take part?

You are being invited to take part because you have identified that you have experience of participating in a role that directly utilises your own lived experience of 'mental health problems'.

3. Do I have to take part?

No. Participating in this research is voluntary and you are free to withdraw participation at any time prior to analysis starting, without explanation and without incurring any disadvantage.

4. What will happen if I take part?

If you agree to take part, a one-to-one interview will be arranged either online or in a location of your choice. Camilla Hogg, the researcher will ask you a number of questions about your participation in these roles. The interview will be audiotaped and anonymously recorded. We expect the interview to last around 60minutes.

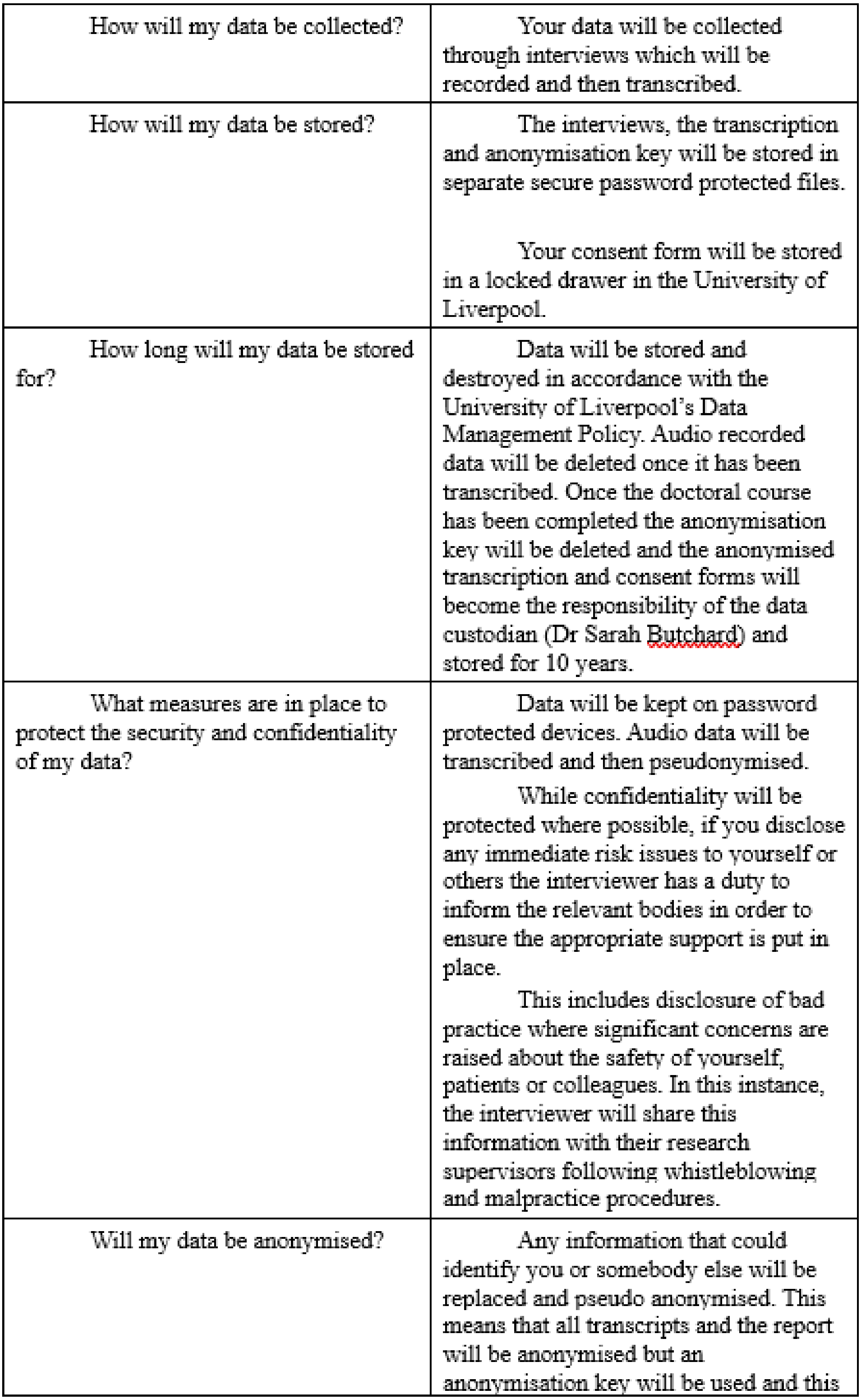
5. How will my data be used?

The interview will be transcribed, and the recording will then be deleted. Any potentially identifiable information will be removed from the transcripts and report for example, names and locations will be replaced with pseudonyms. An anonymization key which links your name to your transcript will be kept stored separately to the transcripts and report.

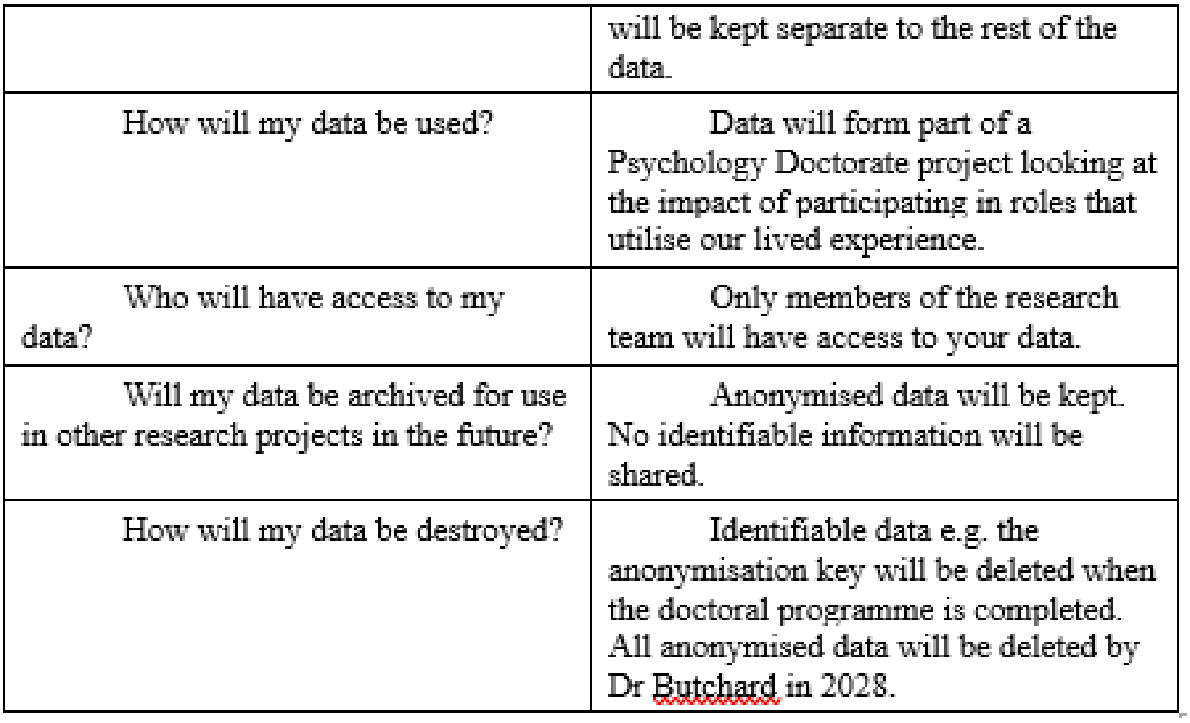
The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of ‘public task’, and in accordance with the University’s purpose of “advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University’s research. Dr Sarah Butchard acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent Dr Sarah Butchard, butchard@liverpool.ac.uk.

Further information on how your data will be used can be found in the table below.



How will my data be collected?	Your data will be collected through interviews which will be recorded and then transcribed.
How will my data be stored?	The interviews, the transcription and anonymisation key will be stored in separate secure password protected files. Your consent form will be stored in a locked drawer in the University of Liverpool.
How long will my data be stored for?	Data will be stored and destroyed in accordance with the University of Liverpool's Data Management Policy. Audio recorded data will be deleted once it has been transcribed. Once the doctoral course has been completed the anonymisation key will be deleted and the anonymised transcription and consent forms will become the responsibility of the data custodian (Dr Sarah Butchard) and stored for 10 years.
What measures are in place to protect the security and confidentiality of my data?	Data will be kept on password protected devices. Audio data will be transcribed and then pseudonymised. While confidentiality will be protected where possible, if you disclose any immediate risk issues to yourself or others the interviewer has a duty to inform the relevant bodies in order to ensure the appropriate support is put in place. This includes disclosure of bad practice where significant concerns are raised about the safety of yourself, patients or colleagues. In this instance, the interviewer will share this information with their research supervisors following whistleblowing and malpractice procedures.
Will my data be anonymised?	Any information that could identify you or somebody else will be replaced and pseudo anonymised. This means that all transcripts and the report will be anonymised but an anonymisation key will be used and this



	will be kept separate to the rest of the data.
How will my data be used?	Data will form part of a Psychology Doctorate project looking at the impact of participating in roles that utilise our lived experience.
Who will have access to my data?	Only members of the research team will have access to your data.
Will my data be archived for use in other research projects in the future?	Anonymised data will be kept. No identifiable information will be shared.
How will my data be destroyed?	Identifiable data e.g. the anonymisation key will be deleted when the doctoral programme is completed. All anonymised data will be deleted by Dr Butchard in 2028.

6. Expenses and / or payments

All participants will be offered a £15 voucher for taking part. If required participants will be able to claim reasonable local travel expenses.

7. Are there any risks in taking part?

Whilst we do not expect there to be any direct risks to taking part, we are aware that some participants may find talking about their experiences of participating in these roles distressing and/or upsetting. If this is the case the researcher will follow the distress protocol and pause the interview and be led by what you want to do going forward for example do you want to continue after a break or stop and withdraw. All participants will be given the option of speaking with the interviewer and will be provided with a list of places to get support.

8. Malpractice or whistleblowing

During the course of the interview should any participant reveal information that indicates that either the participant or another individual is at significant risk of significant harm then this would have to be taken forward. In this situation the researcher would discuss this with yourself and in turn with their supervisory team and would follow the distress protocol and appropriate guidance around safeguarding, malpractice and/or whistleblowing.

9. Are there any benefits in taking part?

We do not expect you to directly benefit from the research, but we hope the results of the research will benefit those participating in roles using their lived experience of mental health difficulties in the future.

10. What will happen to the results of the study?

Results will be written up for a Clinical Psychology doctoral thesis and may be shared with the wider research and lived experience community in presentations and publications. You will not be identifiable in any study results. If you would like to receive a copy of the results, please let Camilla Hogg know at the time of interview.

11. What will happen if I want to stop taking part?

You are free to withdraw at any time prior to the data being analysed this will take place approximately two weeks after your interview has been conducted. To withdraw please email Camilla.Hogg@liverpool.ac.uk or Dr Sarah Butchard on butchard@liverpool.ac.uk

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Sarah Butchard, butchard@liverpool.ac.uk, **0151 7945530/34** and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

12. Who can I contact if I have further questions?

Please contact Dr Sarah Butchard

Dr Sarah Butchard, Clinical Psychologist
School of Psychology, University of Liverpool
butchard@liverpool.ac.uk
0151 7945530/34

Appendix 6 – Pre-interview phone calls

Pre-Interview Proforma

Introduce self (name, I'm a second-year trainee psychologist at Liverpool University)

Do you have any questions?

Provide an overview of the study, outline process of participating including Grounded Theory methodology. Explain that more participants have come forward than we need so we cannot guarantee that we will be able to interview you. However, we will do an update to the study though details are currently unknown.

Ask if they have any questions and if they are happy to proceed.

If yes continue, if no thank them for their time.

Inclusion criteria:-

1- Are you over the age of 18?

2- Do you consider yourself to have or had mental health difficulties and/or have you accessed mental health services?

3- Do you participate in a role that uses your lived experience of mental health difficulties? *(give examples if needed).*

If they answer yes to these then ask are you willing to answer a few more questions that will be used to help with the theoretical sampling stage?

If yes continue, if no thank them for their time.

Screening questions

- Can you explain very briefly what the roles entail?
- What sectors do you work in e.g. NHS, VCSE, Charities?
- Are you paid for doing the roles e.g. salary, consulting rate, vouchers?
- How long have you been doing the roles for?

- How much time do you commit to the roles e.g. full time, part time, ad hoc?

- Where have you heard about the study from?

Ask if they have any questions? Outline the next steps (interviews will go through until March 2021) including the consent process and send through the consent form, for them to return if they agree to participate.

Appendix 7 – Consent form

Participant consent form

Version number – 2
Date: 10/07/2020
Research ethics approval number:
Title of the research project: The Emotional, Social and Professional impact on an Individual’s Identity when participating in a role directly utilising their Lived Experience of Mental Health Difficulties
Name of researcher: Camilla Hogg

Please initial box

1. I confirm that I have read and have understood the information sheet dated 11/05/2020 for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand and aware that taking part in the study involves taking part in an interview that will either be face to face (if COVID-19 restrictions allow or using a video conferencing system or over the telephone. The interview will be audio recorded and this will be typed up (either by the researcher or an approved University of Liverpool transcriber) and analysed. ☐

3. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐

4. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to data analysis starting. I understand that following this I will no longer be able to request access to or withdrawal of the information I provide. ☐

5. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is anonymised and once the researcher has completed the Doctorate in Clinical Psychology it will be held for ten years by the Principal Investigator – Dr Sarah Butchard. ☐

6. I understand that the audio recording will be deleted two weeks after transcription has taken place. The interview transcripts will be retained in the School of Psychology until the researcher has completed the clinical doctorate. ☐

7. I agree that my information can be quoted in research outputs such as posters, publications and oral presentations. ☐

8. The information you have submitted will be published as a report; please indicate whether you would like to receive a copy. ☐

9. I agree to take part in the above study. ☐

____________________________ ___________ ________________________

Participant name Date Signature

_____________________________ ___________

____

Name of person taking consent Date Signature

Principal Investigator	**Student Investigator**
Dr Sarah Butchard, Clinical Psychologist	Camilla Hogg, Trainee Clinical Psychologist
School of Psychology, University of Liverpool	School of Psychology, University of Liverpool
0151 7945530/34	0151 795 5446
butchard@liverpool.ac.uk	Camilla.Hogg@liverpool.ac.uk

Appendix 8 – Interview schedule

Three interview schedules were developed with additional questions being added after interview five and nine. These changes are highlighted below:-

Questions in black text asked to all participants.

Questions in red text asked from participant number five.

Questions in purple text asked from participant number nine.

Interview Schedule

Demographics

Gender
Age
Ethnicity

Background

1 I am interested in roles that directly use an individual's lived experience of mental health difficulties so I am wondering if you can you tell me about any roles like this that you have been involved in?

Prompts: –

- In these roles were you paid or unpaid? If paid were you paid as a volunteer/service user involvement rate/salaried/consultancy fees?
- Was this in the NHS/private sector/ Third sector/charitable sector/VCSE
- Can you tell me a bit about what the role entails?
- Did you have any relevant training or accreditation before starting the role?
- Did you get any training at the beginning or during the role to help you do it?

The past

2 Can you tell me about how you have found participating in these roles up till now?

Prompts: –

- How did you first hear about them?
- What made you interested in them/how did you get involved?
- How does this work make you feel?
- What have been the positives of these roles?
- What have been the challenges of these roles?
- Do you feel you have adequate support/supervision in doing these roles?
-

3 Have you felt valued in your roles?

Prompts

- Have you ever felt the way your role is organised, recognised and supported isn't as it should be?

  - *Have you got any ideas for any improvements that your role could put in place to help support you to do it?*
  - *Do you have access to support structures and employee wellbeing resources and perks? (e.g. occy health, NHS discount, staff counselling etc)*

4 Can you tell me about the negative experiences that you have had in the role?

The present

5 Has participating in these roles changed how you see yourself?

Prompts: -

- What impact have these roles had on you emotionally - what positive/negative impact has it had on you?
- Has it changed how you see yourself professionally?
- Has it had an impact upon you socially?
- Do you think it has had an impact upon your confidence?

6 Do you think participating in these roles has changed the way other people see you?

Prompts: -

- Did other people seeing you differently impact on the way you see yourself at all?"
- Has your view of the service user community changed since you have started doing these roles?
- Has the way you relate to the service user community changed since you started doing these roles?
- Has the way you relate registered professionals changed since you started doing these roles?

7 In what context do you tell or share your experiences (e.g. live events or 1:1 with service users or training or with clinical staff in MDT)

Promptst:-

- What is your motivation for sharing your experiences?
- What is the expectation from others for you to share your experiences?

The future

8 Where do you want to go with these roles in the future?

Prompt: -

- What would need to happen to facilitate this?
- What impact do you think this will have on yourself?
- Do you have other career plans?
- (If going to a new profession) Why don't you want to stay in this field going forward?

Coronavirus

9 Do you feel that the current situation with COVID-19 has impacted on anything that we have spoken about today?

Vouchers and debrief.

Appendix 9 – Debrief Form

Participant Debrief Form

Title of project:
The Emotional, Social and Professional impact on an Individual's Identity when participating in a role directly utilising their Lived Experience of Mental Health Difficulties

Thank you for taking part
Thank you for participating in this research study. This forms part of my Doctoral thesis. I am interested in the experiences of individuals who participate in roles that use their lived experience of mental health difficulties. I am hoping to find out more about how these roles impact on an people's emotional social and professional identity.
I am recruiting 10-15 individuals who participate in these roles be it paid or voluntarily, for the NHS, a charity or as part of the mental health survivor movement.
As these roles are becoming more popular it feels important to consider what impact these roles have on the individuals doing them. Most of the current research focuses on the benefit of these roles to either the services involved or the service users accessing them.

1. **Signposting**

Whilst there are no explicit benefits of taking part in this research project it is my hope that this research will provide meaningful information about the impact of doing these roles that can in turn be fed back to the services that offer these opportunities.
However, it is possible that talking about your experiences may have caused you some distress and I have attached a sheet with numbers on it should you wish to contact someone.

2. **What happens next?**

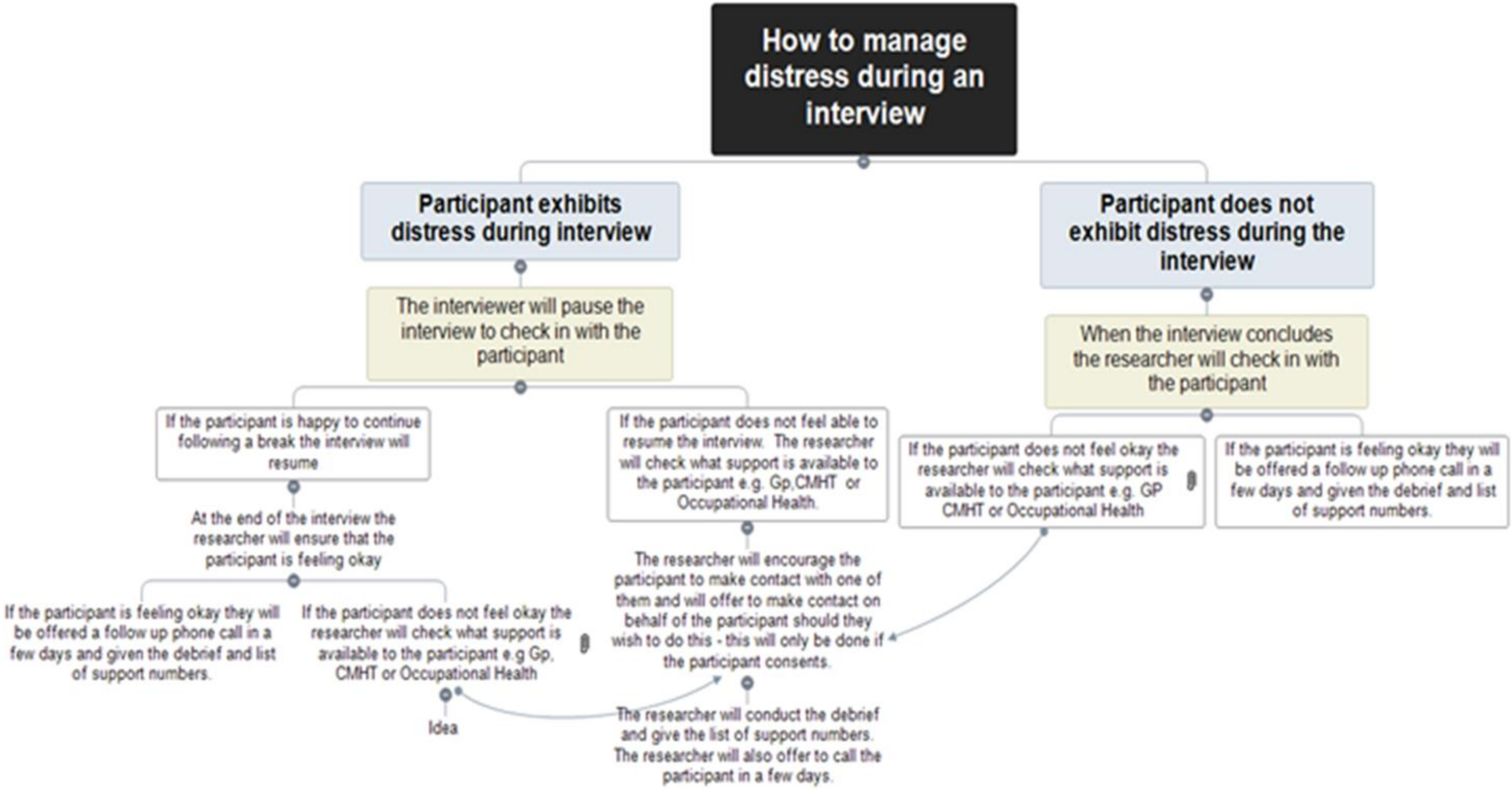
Your interview has been recorded via IPad and will now be stored securely and password protected, ready for transcription. I will transcribe your interview ready for analysis. Your audio recording will be used only for analysis and will be destroyed once transcribed. All information will be stored securely. Transcribed interviews will be anonymised and any personally identifiable information will be redacted.
You have a right to withdraw from the study in the next two weeks and you do not need to give any reason to do this. This deadline is due to the analysis of the study, at this point it will not be possible to remove your data from the project. If you decide before to withdraw from the study, any data that has been collected will be deleted. You can withdraw by contacting Camilla at Camilla.hogg@liverpool.ac.uk
Alternatively, you can contact the primary supervisor of this study Dr Sarah Butchard (Butchard@liverpool.ac.uk)

Where to access support

These are some areas where you may be able to access support should you feel upset after the interview:-
Your **GP or mental health care team** if you have one e.g. CMHT
The Samaritans can be contacted on - **116 123** with more information found on there website - https://www.samaritans.org/
If you work in a large organisation or for the NHS you can self-refer to **Occupational Health or access staff support.**

If you have a supportive **Supervisor** you may wish to get in touch with them.
Rethink have an advice line for those who may wish to get support for issues around employment (0300 5000 927) and have produced a list of support lines - https://www.rethink.org/aboutus/what-we-do/advice-and-information-service/get-help-now/
ACAS – can provide advice on workplace disputes - 0300 123 1100 with more information found on there website - https://www.acas.org.uk/
Citizens Advice - provides advice on a range of topics including work. There website provides more information - https://www.citizensadvice.org.uk/

Appendix 10 – distress protocol



How to manage distress during an interview

Participant exhibits distress during interview

The interviewer will pause the interview to check in with the participant

If the participant is happy to continue following a break the interview will resume

At the end of the interview the researcher will ensure that the participant is feeling okay

If the participant is feeling okay they will be offered a follow up phone call in a few days and given the debrief and list of support numbers.

If the participant does not feel okay the researcher will check what support is available to the participant e.g Gp, CMHT or Occupational Health

If the participant does not feel able to resume the interview. The researcher will check what support is available to the participant e.g. Gp,CMHT or Occupational Health.

The researcher will encourage the participant to make contact with one of them and will offer to make contact on behalf of the participant should they wish to do this - this will only be done if the participant consents.

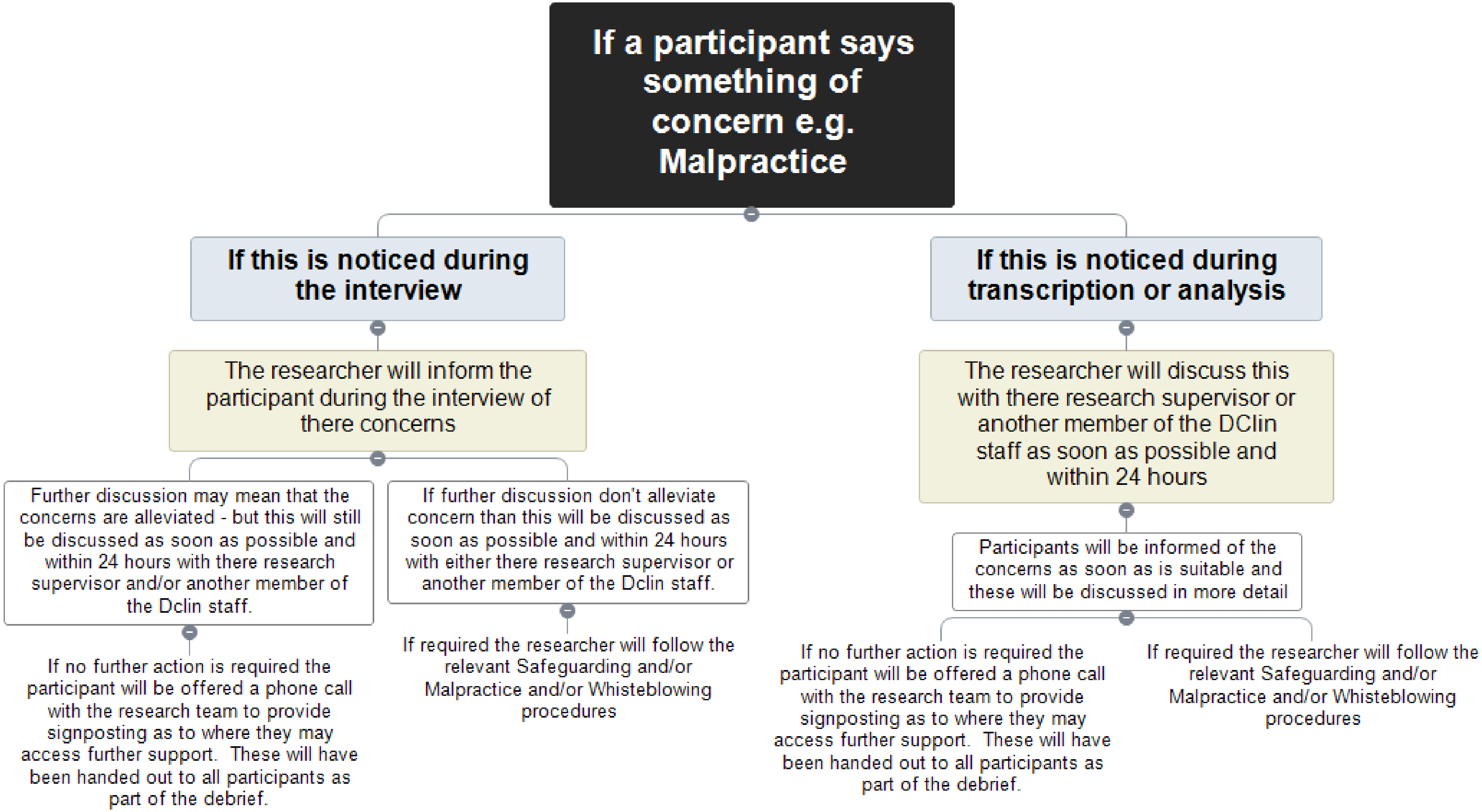
The researcher will conduct the debrief and give the list of support numbers. The researcher will also offer to call the participant in a few days.

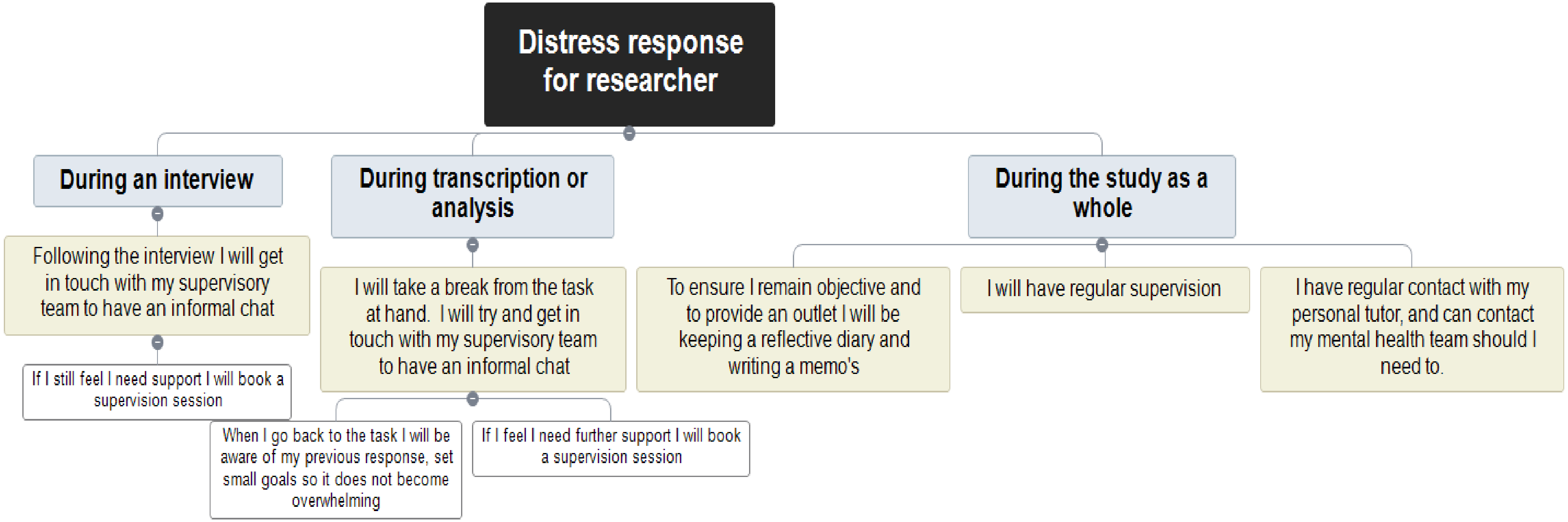
Participant does not exhibit distress during the interview

When the interview concludes the researcher will check in with the participant

If the participant does not feel okay the researcher will check what support is available to the participant e.g. GP CMHT or Occupational Health

If the participant is feeling okay they will be offered a follow up phone call in a few days and given the debrief and list of support numbers.


If a participant says something of concern e.g. Malpractice
If this is noticed during the interview
The researcher will inform the participant during the interview of there concerns
Further discussion may mean that the concerns are alleviated - but this will still be discussed as soon as possible and within 24 hours with there research supervisor and/or another member of the Dclin staff.
If no further action is required the participant will be offered a phone call with the research team to provide signposting as to where they may access further support. These will have been handed out to all participants as part of the debrief.
If further discussion don't alleviate concern than this will be discussed as soon as possible and within 24 hours with either there research supervisor or another member of the Dclin staff.
If required the researcher will follow the relevant Safeguarding and/or Malpractice and/or Whisteblowing procedures
If this is noticed during transcription or analysis
The researcher will discuss this with there research supervisor or another member of the DClin staff as soon as possible and within 24 hours
Participants will be informed of the concerns as soon as is suitable and these will be discussed in more detail
If no further action is required the participant will be offered a phone call with the research team to provide signposting as to where they may access further support. These will have been handed out to all participants as part of the debrief.
If required the researcher will follow the relevant Safeguarding and/or Malpractice and/or Whisteblowing procedures



Distress response for researcher

During an interview

Following the interview I will get in touch with my supervisory team to have an informal chat

If I still feel I need support I will book a supervision session

During transcription or analysis

I will take a break from the task at hand. I will try and get in touch with my supervisory team to have an informal chat

When I go back to the task I will be aware of my previous response, set small goals so it does not become overwhelming

If I feel I need further support I will book a supervision session

During the study as a whole

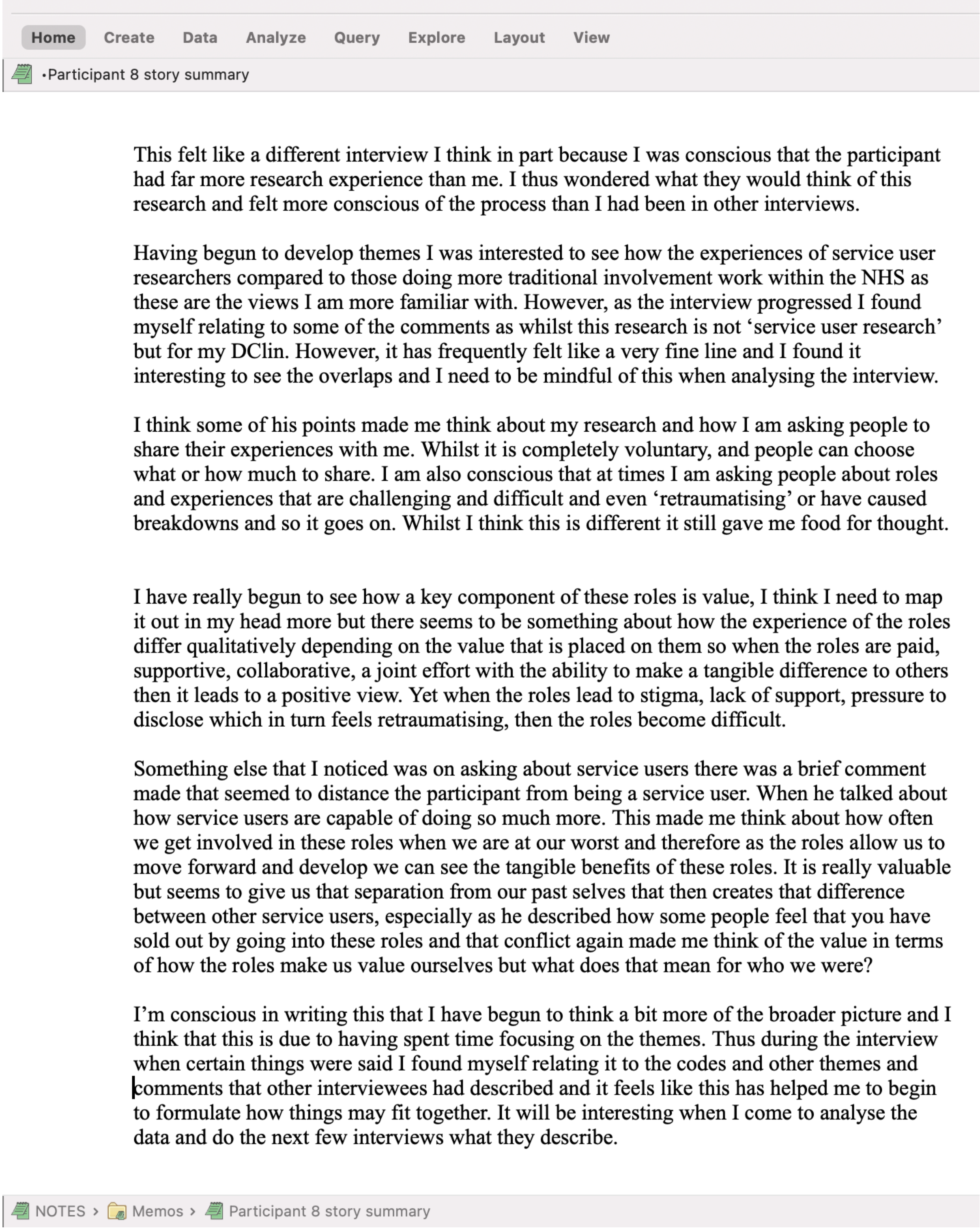
To ensure I remain objective and to provide an outlet I will be keeping a reflective diary and writing a memo's

I will have regular supervision

I have regular contact with my personal tutor, and can contact my mental health team should I need to.

Appendix 11 – Sample Story Summary

Participant 8 story summary



This felt like a different interview I think in part because I was conscious that the participant had far more research experience than me. I thus wondered what they would think of this research and felt more conscious of the process than I had been in other interviews.

Having begun to develop themes I was interested to see how the experiences of service user researchers compared to those doing more traditional involvement work within the NHS as these are the views I am more familiar with. However, as the interview progressed I found myself relating to some of the comments as whilst this research is not ‘service user research’ but for my DClin. However, it has frequently felt like a very fine line and I found it interesting to see the overlaps and I need to be mindful of this when analysing the interview.

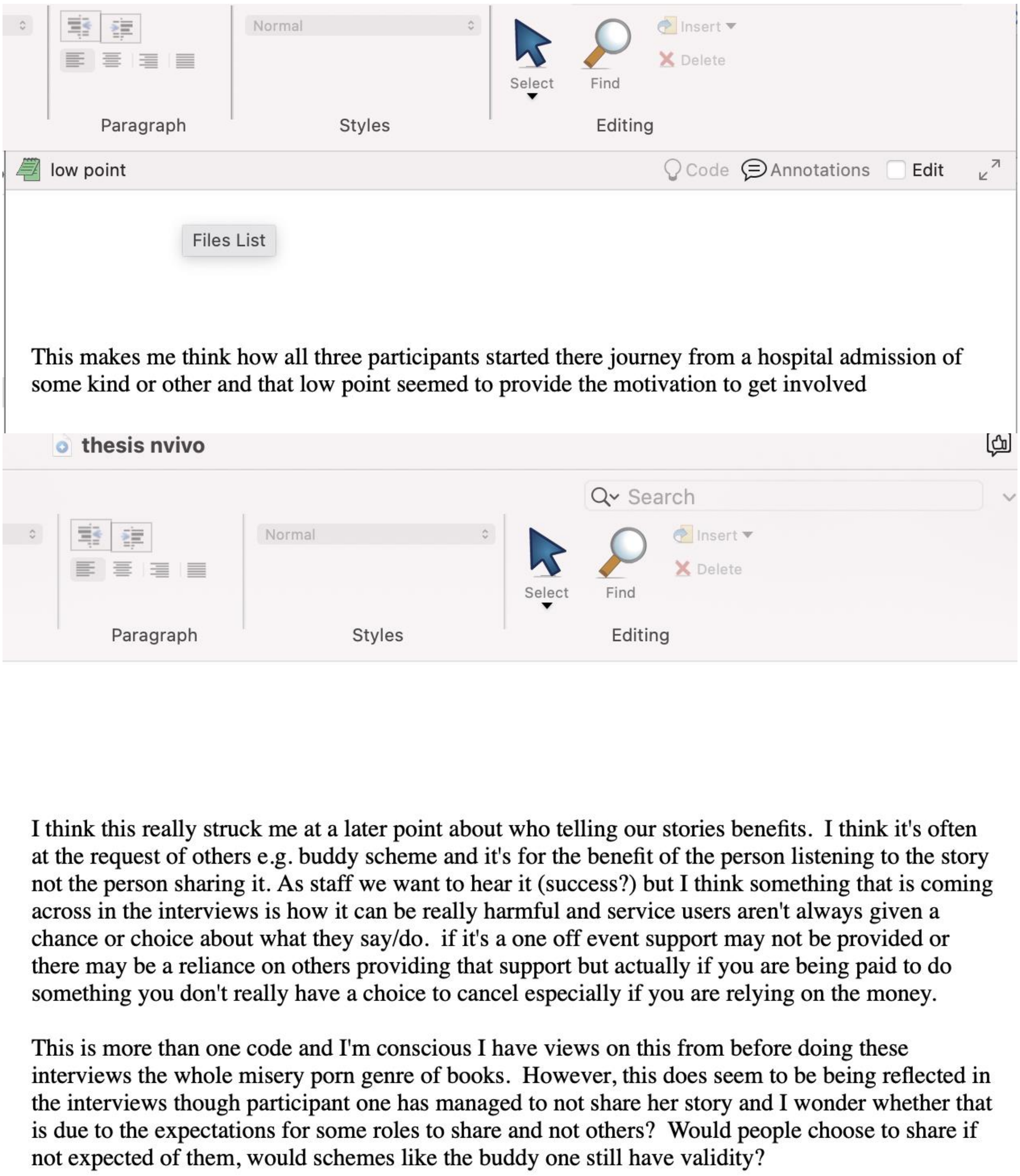
I think some of his points made me think about my research and how I am asking people to share their experiences with me. Whilst it is completely voluntary, and people can choose what or how much to share. I am also conscious that at times I am asking people about roles and experiences that are challenging and difficult and even ‘retraumatising’ or have caused breakdowns and so it goes on. Whilst I think this is different it still gave me food for thought.

I have really begun to see how a key component of these roles is value, I think I need to map it out in my head more but there seems to be something about how the experience of the roles differ qualitatively depending on the value that is placed on them so when the roles are paid, supportive, collaborative, a joint effort with the ability to make a tangible difference to others then it leads to a positive view. Yet when the roles lead to stigma, lack of support, pressure to disclose which in turn feels retraumatising, then the roles become difficult.

Something else that I noticed was on asking about service users there was a brief comment made that seemed to distance the participant from being a service user. When he talked about how service users are capable of doing so much more. This made me think about how often we get involved in these roles when we are at our worst and therefore as the roles allow us to move forward and develop we can see the tangible benefits of these roles. It is really valuable but seems to give us that separation from our past selves that then creates that difference between other service users, especially as he described how some people feel that you have sold out by going into these roles and that conflict again made me think of the value in terms of how the roles make us value ourselves but what does that mean for who we were?

I’m conscious in writing this that I have begun to think a bit more of the broader picture and I think that this is due to having spent time focusing on the themes. Thus during the interview when certain things were said I found myself relating it to the codes and other themes and comments that other interviewees had described and it feels like this has helped me to begin to formulate how things may fit together. It will be interesting when I come to analyse the data and do the next few interviews what they describe.

Appendix 12 – Sample Memos

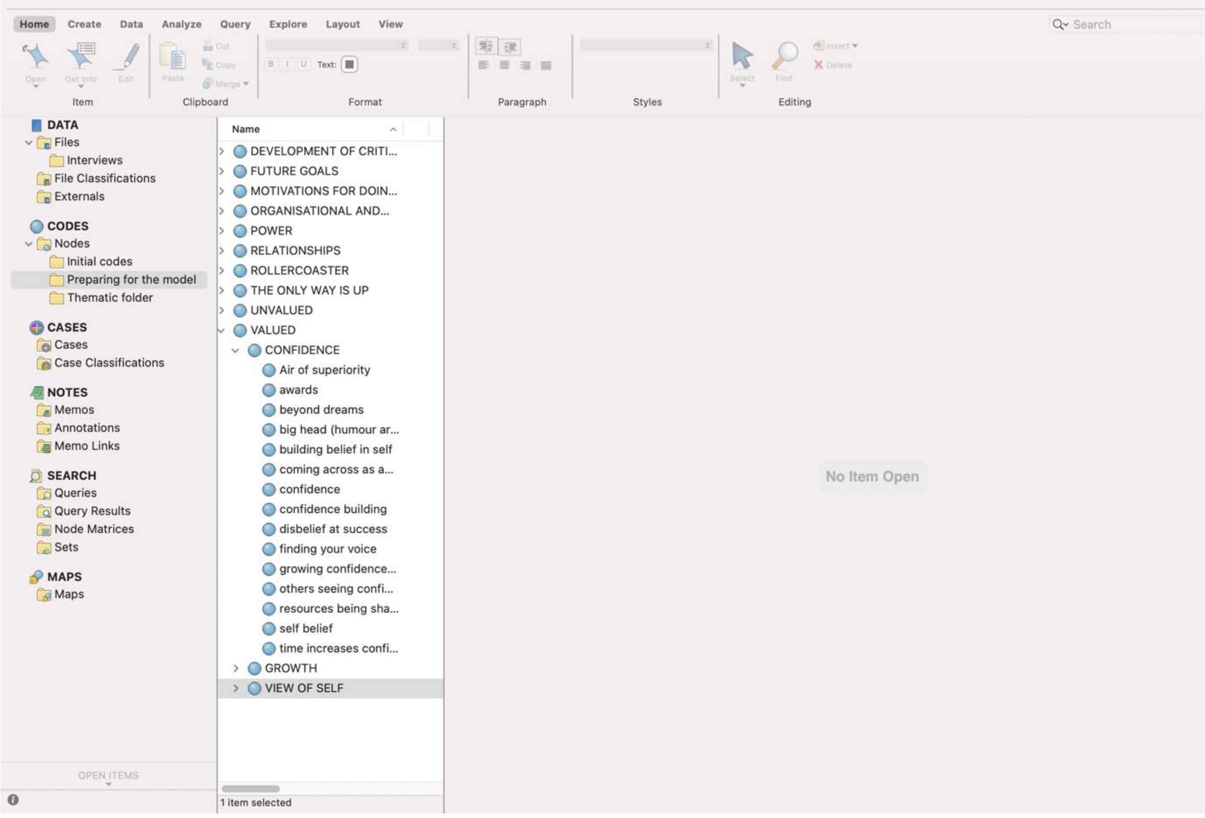


This makes me think how all three participants started there journey from a hospital admission of some kind or other and that low point seemed to provide the motivation to get involved

I think this really struck me at a later point about who telling our stories benefits. I think it's often at the request of others e.g. buddy scheme and it's for the benefit of the person listening to the story not the person sharing it. As staff we want to hear it (success?) but I think something that is coming across in the interviews is how it can be really harmful and service users aren't always given a chance or choice about what they say/do. if it's a one off event support may not be provided or there may be a reliance on others providing that support but actually if you are being paid to do something you don't really have a choice to cancel especially if you are relying on the money.

This is more than one code and I'm conscious I have views on this from before doing these interviews the whole misery porn genre of books. However, this does seem to be being reflected in the interviews though participant one has managed to not share her story and I wonder whether that is due to the expectations for some roles to share and not others? Would people choose to share if not expected of them, would schemes like the buddy one still have validity?

Appendix 13 – Example of NVIVO coding



- DEVELOPMENT OF CRITI...
- FUTURE GOALS
- MOTIVATIONS FOR DOIN...
- ORGANISATIONAL AND...
- POWER
- RELATIONSHIPS
- ROLLERCOASTER
- THE ONLY WAY IS UP
- UNVALUED
- VALUED
  - CONFIDENCE
    - Air of superiority
    - awards
    - beyond dreams
    - big head (humour ar...
    - building belief in self
    - coming across as a...
    - confidence
    - confidence building
    - disbelief at success
    - finding your voice
    - growing confidence...
    - others seeing confi...
    - resources being sha...
    - self belief
    - time increases confi...
  - GROWTH
  - VIEW OF SELF

Appendix 14 - Draft Model shown to Participant 11