"Being a nurse is like being an actress": Examining the experiences of nurses working in palliative care a systematic review and qualitative study in the acute care setting.

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Contents

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Introductory Chapter: 1348

Chapter 1 (including quotes): 8276

Chapter 2 (including quotes): 7940

Appendices: 7010

Total: 24,574

Introductory Chapter

Thesis Overview

With an ever-increasing elderly population, and improved medical care that can prolong life for patients with chronic incurable life-limiting diseases. There has been an increasing demand for palliative care services [1]. Furthermore, high mortality rates resulting from COVID-19 has meant an even greater need for palliative care provision, in turn causing a strain on existing services and palliative healthcare professionals. Hence, this thesis aims to better understand the experiences of providing end-of-life care by qualified nurses, working within palliative care settings to better support staff delivering end-of-life care.

A definition provided by The World Health Organisation (WHO) [2] stated that palliative care is:

> *"An approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with a life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual…".*

Whilst comprehensive for patients and their families, the current definition neglects to mention the staff, and their role within palliative care. This is at odds with later guidance from the WHO [3], which outlines the importance of having: *"a range of services delivered by a range of professionals that all have equally important roles to play…*" The WHO Assembly [4] however, outlined an expectation for staff training for those who provide support for patients. It would be concluded that research is required to see what training, and support staff need, alongside the effects of caring on staff.

During the last 30 years, there have been significant advances in palliative care. Many countries have developed education programs and specialist services, thus palliative care ideas have started to infiltrate national health policies [5]. Palliative care has developed to inform care in hospices, acute care settings, community teams and at home. However, over the last decade, the WHO has highlighted inadequate access to palliative care. On average it has been estimated that 40 million people need palliative care, with 78% living in low- and middle-income countries. Several barriers are highlighted, including that *"national health systems often do not include palliative care at all"* [3]. To address this unmet need, the WHO suggested the integration of palliative care services into their financing and structures across all levels. More recently, to address the challenge in the acute care setting, academic palliative care units (APCU) have begun to develop.

APCUs are based within acute hospital settings, providing access to specialist palliative care for patients and their families whose care would benefit from specialist input from clinicians focused on palliative care delivery. The purpose of the unit is to alleviate symptoms and enable discharge to other services (including home, care home, and hospice) within the community or to support someone's death in hospital. Academic palliative care units provide a dual function of enabling access to high quality care of an acute unit, but also supporting research studies to address and improve the evidence base. Hence a core function of an ACPU is to drive a research agenda and enable patients (and their families) the opportunity to participate in research studies in a supported environment, and for the APCU team to contribute to the development of the evidence base. As a relatively new clinical service within the acute setting, palliative care units provide a unique opportunity for research to examine this development within clinical practice.

The NICE Guidance on improving palliative care for adults with cancer in 2004, [6] outlined key skills and roles primarily for specialist nurses. However, within this document guidance is provided on the expectation that all nurses should be able to provide "day-to-day" support (p101) for patients and their families, though appropriate assessment of needs, information giving, and social and psychological support, but this requires an active programme of education to address these issues. For example, there is a suggestion as to the levels of psychological support that should be available to patients corresponding to the health care professional's training, and within this we can see that nurses should be able to recognise psychological needs and respond with appropriate information giving, compassionate communication and psychological support.

More recently, Health Education England has provided a document regarding palliative care competencies for different grades of nursing staff [7]. Reviewing this documentation provides an overview of the skills and roles of nursing working in an academic palliative care unit, such as skills around communication, assessment and care planning, symptom management, advanced care planning, key values, knowledge, leadership, collaborative practice, improving quality and developing yourself and others [7]. Please see appendix A for further information.

Aims

Overall, there is a lack of understanding around the impact of delivering end-of-life care on qualified nurses. Previous literature has yet to conduct a synthesis focusing on the current evidence base of qualified nurses' lived experience of providing end-of-life care, highlighting a lack of direction for future research. Further to this, little is known about academic palliative care units, indicating an avenue for further exploration. Hence, this study was developed to explore the lived experience of qualified nurses providing end-of-life care within this particular setting alongside a systematic review of the existing literature across settings.

COVID-19

Data collection for the empirical paper was carried out during the COVID-19 pandemic, providing further challenges to palliative care services due to the high mortality rate and the public health measures employed to control the spread of the virus. There is growing research looking at the impact of the pandemic upon palliative care staff [8, 9] providing evidence that healthcare workers have struggled psychologically with the high volume of critically ill patients. Research has shown that nurses experience the highest level of occupational stress compared to other groups, when reviewing similar outbreaks [10, 11]. A mixed-method systematic review covering published research between January 2020 - April 2020 suggested that healthcare workers were experiencing anxiety, insomnia and depression as a consequence to the COVID-19 outbreak. According to the same review, further evidence suggested that COVID-19 could be an independent risk factor that affects healthcare workers [12]. The current literature would propose that the impact of COVID-19 will increase occupational stress, and, in turn, psychological distress in healthcare staff, particularly nurses.

Given the current climate of COVID-19, little is known about the impact this has on staff working within palliative care. The context of COVID-19 provides a unique opportunity to explore this impact, together with the other gaps highlighted to expand the evidence base.

The projected benefit of this research is to help understand nurses' lived experience alongside the additional impact of COVID-19. This thesis will add to the ever-growing body of literature in palliative care and new literature reviewing the effects of COVID-19. It may help us think about the long-term psychological impact for staff and how we can best support them.

Chapters Overview

The systematic review makes up the first chapter of this thesis. The review will explore the existing qualitative research on the experience of qualified nurses working across a range of palliative care settings. Findings offer insight into how complex and diverse their experiences are, and how providing specific forms of support may enable nurses to better do their job and maintain their psychological wellbeing. This review will be submitted to the ‘Journal of Palliative Medicine’ (Appendix B).

The second chapter is an empirical, Interpretative Phenomenological Analysis (IPA) study. To the authors knowledge there has been no previous research exploring the lived experience of qualified nurses working in an Academic Palliative Care Unit in an acute setting. As such, this study aimed to provide a detailed understanding of the lived experience of qualified nurses working within such a setting. The research hoped to develop a deeper insight into nurses' lived experience, highlighting important areas for future research. This study will be submitted to the journal of ‘BMC Palliative Care’ (Appendix C).

The research will be disseminated in both virtual and face-to-face conferences, alongside being submitted for publication in the above journals. The word limit for each chapter may exceed the selected journal word limit to allow for the level of detail required for this thesis.

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Chapter 1: Qualified Nurses Experience of Working in Palliative Care; A Systematic Review

Abstract

Background – An increasingly ageing population and advances in life-sustaining medical care is likely to result in higher demand for palliative care provision. In turn, increased clinical complexity, combined with patient numbers, is likely to impact the workforce providing care.

Objective - This systematic review explored qualitative research on qualified nurses experience of working in palliative care across palliative care settings.

Methods – 5 electronic databases and Google Scholar were searched in April 2020. Databases searched for peer-reviewed, qualitative, English language studies exploring qualified nurses' experiences of working in palliative care. Selected studies were appraised using ENTREQ and CASP. Data was then analysed using thematic synthesis. PRISMA guidelines were used to report the review.

Results – 12 studies were included in the final review, with six analytical themes developed: 1) Palliative Care Standards, 2) The Role of a Nurse – A Split Role, 3) Weighing up the Pros and Cons, 4) 'The Pain of Saying Farewell', 5) Nurses - the Pillars of Support, 6) Organisational Issues.

Conclusions – Working in palliative care is complex and diverse, requiring clear governance and organised support. Whilst mutual support between staff members attends to some psychological needs, nurses may benefit from structured/ reflective groups, enabling mental health to be put on the agenda. Furthermore, targeted education and training are required to give staff skills in managing both their patients, and the nurses own high levels of distress and psychological wellbeing.

Originality/Value

To the authors knowledge this is the first systematic review to synthesise qualitative literature on qualified nurse’s experience of working within palliative care, and across palliative care settings. Findings offer insight into our understanding of the lived experiences of qualified nurses working in multiple palliative care settings, from which current practice can be reviewed. Equally, this review points to gaps in the evidence base that can be addressed, which may lead to improvements in practice to support nurses.

Introduction

Palliative care delivery centres on the individual patient’s needs and the needs of the patient’s family. Palliative care is most frequently offered by non-specialist palliative care staff as part of normal practice. For example, district nurses supporting patients through an individual’s care plan for their long-term health condition. However, specialist palliative care services comprising dedicated palliative care professionals and clinicians differ in that care is delivered by multidisciplinary teams, addressing complex patient (and family) needs in various settings such as hospitals, hospices, and the community [1,2].

Research evidence clearly shows that individuals who are approaching the end of their life benefit from support from palliative care services [3,4]. Internationally, the WHO (2020) has found that if mortality rates increase as currently predicted, more people will need palliative care across the developed world, and large gaps in service provision within the developing world [4]. The data projections mean that a concurrent increase in palliative care delivery will be required due to the additional demand on healthcare services. Internationally, as the demographic picture is changing, healthcare systems must adapt in order to prepare for the increase in the number of patients with palliative care needs and deaths from chronic illnesses [5].

Working in palliative care presents both clinical and personal challenges, requiring professionals to make complex ethical and clinical decisions, alongside supporting patients, families, and staff. Additional stressors for staff may arise from the increasing demand for palliative care provision, more complex health conditions (co-morbidities), differing disease profiles and limited time with patients and their families. The effects of these additional stressors may vary but cause adverse outcomes e.g., stress and burnout. The risk of burnout and psychological morbidity is high, due to palliative care being identified as a stressful profession [6].

The World Health Organisation [7] identifies that work-related stress is a significant public health concern and research is needed to examine its impact. The prevalence of work-related stress, depression and anxiety in 2015-2016 accounted for 37% of work-related health issues [7]. Factors causing workplace stress to have been consistent over time and include things such as the organisational and workplace change and a lack of support from managers [8]. Furthermore, workplace stressors are prevalent across many countries and care settings, [9] with nurses reporting similar issues in their workplaces regardless of how their healthcare system is organised [10].

The WHO has noted a growing concern about the disproportionate prevalence of stress in the healthcare workforce. The WHO highlighted that, nurses had a higher prevalence of stress when compared to skilled merchants [8]. Excessive and prolonged stress can lead to burnout. Burnout has been defined as a prolonged response to chronic emotional and interpersonal stressors defined by three dimensions; exhaustion, cynicism, and professional inefficacy [11]. Burnout is seen as a reliable job stress syndrome, meaning the individual's distress is related to their work. It is seen to impair the individual's personal, professional, and social functioning [11] due to a decline in their quality of work and psychological health, which is costly for the organisation, the people supporting that individual, and the individual themselves. Interventions can work at both the organisation level and the individual level to help alleviate burnout. Burnout has a solid research basis and has generated significant social focus which makes it a valuable area when looking at staff health and wellbeing [11].

Considering Maslach's theory of burnout and the gaps within the healthcare workforce and the struggle to meet the healthcare system's demands, staff may be at greater risk of burnout [12]. For example, it is predicted that there will be a global shortage of nurses within the next 10–20 years [13]. Within the UK National Health Service, the numbers of vacancies have doubled in the past three years, alongside a decrease in the number of people entering nurse training when compared to those leaving [14]. Therefore, it is imperative to ensure measures are taken to understand and ameliorate the stresses nurses may face to protect against stress-induced ill-health and absences. Given the stresses nurses face research has shown that there are a wide range of motivations for remaining in nursing e.g., self-validation, a desire to help and a sense of achievement, all of which constitute someone's professional identity [15]. If nurses are not able to nurture these motivational factors it could prevent nurses from remaining in the profession.

Staff that are over-stretched and over-worked are more prone to error, and the quality of care experienced by patients is negatively affected [16, 17]. Johnson [18] looked at healthcare professionals' ability to cope and noted that their ability to cope is compromised when the distress associated with the perceived failure undermines their resilience. This can lead to negative outcomes such as shame and depression, increasing their susceptibility to further distress. Within generic nursing many recognise the inherent stressors, some claim that palliative care in more stressful due to working with terminally ill patients, their families and dealing with frequent losses [19-22].

Understanding existing knowledge of nurses' palliative care experiences may be supported by systematically conducting a synthesis of the existing qualitative evidence. While quantitative findings are of importance, a qualitative synthesis can offer a rich, in-depth understanding of practice experiences and thus contribute to continuing professional development (CPD), governance, policy, and clinical practice.

Aims

This review aims to systematically identify, appraise, analyse, and synthesise research exploring qualified nurses' experience of working in palliative care. The review addresses the research question, "What are qualified nurses' experiences of working in adult palliative care?"

Methods

Protocol and registration

The review protocol was pre-registered with the PROSPERO database for systematic reviews (167527). The review is reported according to the PRISMA guidelines [23] and the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) guidelines [24].

Search Strategy

Systematic literature searches were carried out in April 2020 and were updated in January 2021. To ensure any eligible recent articles were identified, an additional Google Scholar searched was conducted. Specialist library services at the University of Liverpool assisted with searching the following databases: PsychINFO, MEDLine, PubMED, CINAHL and Scopus.

The following search terms were applied to each database: ("Palliative care" OR "palliat*" OR "End-of-Life Care" OR "Hospice Care" OR "Support* care" OR "Advanced

Disease”) AND ("lived experience" OR understand* OR perspective* OR view*) AND (“Hospital” OR “Academic Medical Centre” OR “Inpatient” OR “Hospice” OR "Primary Care" OR "Secondary Care" OR "Tertiary Care" OR "Acute" OR "Community") AND ("health care professional*" OR "nurse*" OR "general practitioner*" OR "Healthcare worker*"). Date limits applied from 2010- 2021. See appendix D for an example search strategy.

The PROSPERO databases and Cochrane Library were searched to identify existing or anticipated relevant reviews. To allow for citation chaining, experts in the field were contacted, this allowed for eligible publications to be sent both forwards and backwards. Finally, to organise and store article Endnote software was used, which also supported with the screening and removal of duplicates.

Eligibility Criteria

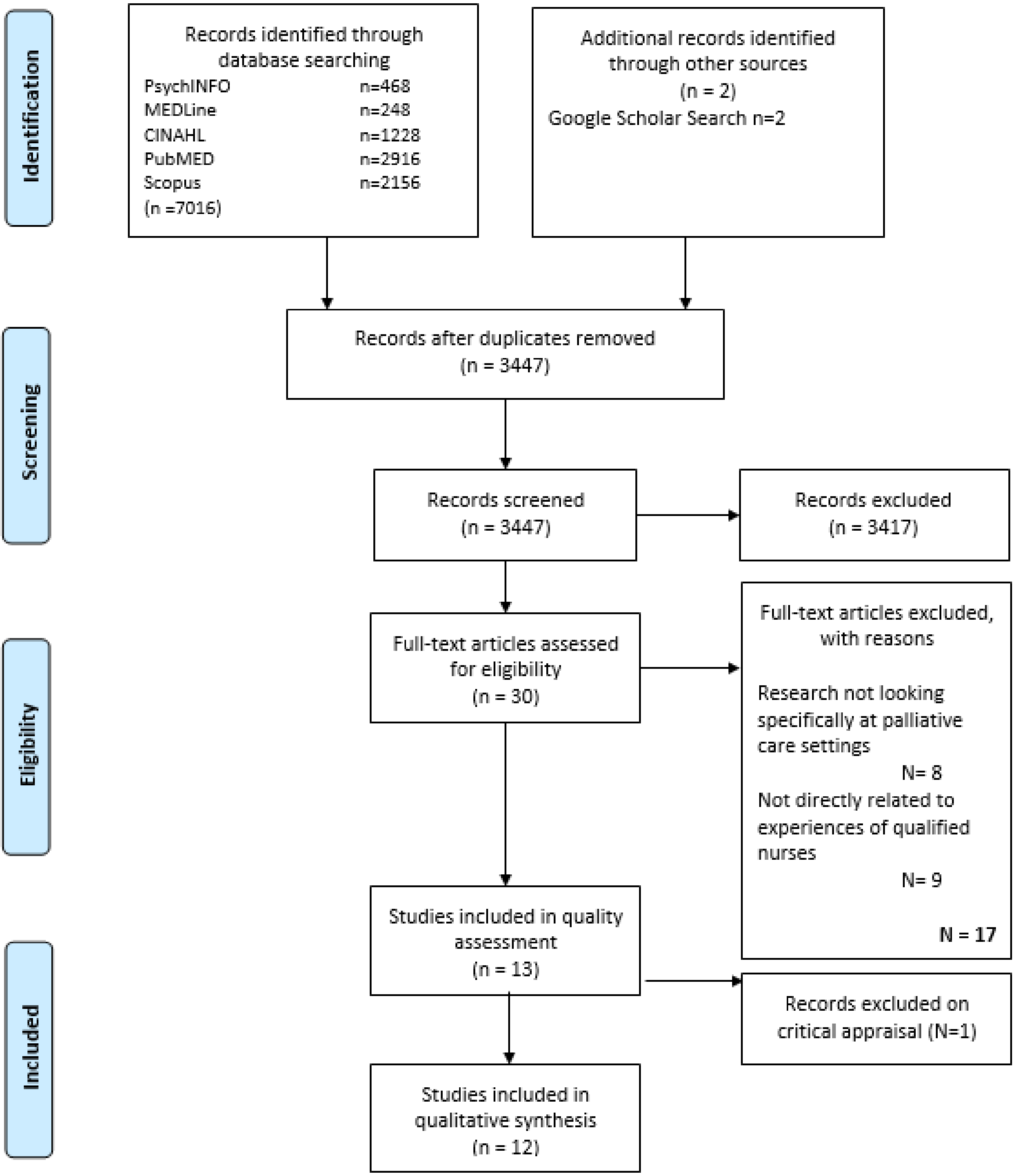
The inclusion and exclusion criteria were developed in relation to the Research Question “What are qualified nurses’ experiences of working in adult palliative care?” which was developed using PICo; population, phenomena of interest and context [25]. The following inclusion criteria were applied: (a) research published in peer-reviewed journals; (b) research published from 2010; (c) English language papers and (d) qualitative methods of data collection and analysis (e) studies on qualified nurses working with people experiencing a terminal illness within any palliative care setting. For inclusive and pragmatic reasons, Palliative Care settings were defined as an environment where there is a higher-than-expected death rate.

Articles were excluded that were; (a) quantitative research only; (b) mixed-method studies with limited qualitative data; (c) studies which investigate experiences/knowledge of other healthcare professionals or client group other than qualified nurses; (d) studies that do not include staff working within a palliative care setting with patients experiencing a terminal illness (e) any studies written in another language other than English and (f) non-peer-reviewed journal articles.

Study Selection

The initial search yielded 7016 articles (PsychINFO 468; CINAHL 1228; MEDLINE 248; PubMED 2916; Scopus 2156). A second search using google scholar highlighted two additional papers for review, giving 7018 articles. Following the removal of duplicates, 3447 remained. Two researchers (AB; SM) independently and sequentially screened titles, abstracts, and full papers (n=30) against exclusion and inclusion criteria. Both researchers discussed any disagreements and sought the opinion of the wider team where necessary. Thirteen papers were included for review and were quality assessed using the Critical Appraisal Skills Programme [26], and one paper was removed, leaving 12 final papers to be included in this review (See figure 1).

Figure 1. Flow diagram showing identification of papers [Adapted from: Moher et al, (2009).]



Quality assessment

To appraise the study quality, The Critical Appraisal Skills Programme [26] tool was used (see appendix E). The protocol comprising of 10 questions captures the main principles of research: relevance, rigour, and credibility [27]. Each paper was reviewed, and each criterion within the tool was graded as follows: item not met, partially met/unsure or fully met, which then corresponded to a points system (not met = 1, unsure = 1, fully met = 2) [28]. This gave each paper a score out of a possible 20 (Table 1). Although no formal quality scoring system is provided with the tool, this review applied the following scoring system to support critical reflection. All papers were reviewed using the tool to evaluate their quality, examining the strengths and limitations of each paper's new insight.

Overall, one paper [29] was excluded from the review based on scoring significantly lower on the quality assessment tool compared to the other papers. The paper failed to have a clear statement of aims for the study, failed to provide enough detail around methodology for this to be assessed to be appropriate. They also failed to provide enough detail regarding the research design in order to assess if this met the aims for the study. Finally, there was a lack of information regarding the way in participants were recruited for the study and no discussion of future research avenues to explore or how the study contributes to the current evidence base. The paper lacked sufficient information to score a number of the criterion reducing this paper's quality compared to the other papers reviewed, providing evidence for removing the paper so as not to affect the quality of the review. Table 1 indicates the scores given to each study, and further exploration of quality is included within the discussion section.

Table 1: Quality appraisal-based on the CASP tool for qualitative research.

Authors	*Aims*	*Methodology*	*Design*	*Recruitment*	*Data Collection*	*Researcher Bias*	*Ethical Issues*	*Data Analysis*	*Findings*	*Valuable*	*Score /20*
Cagle et al., (2017)	Yes	Yes	Can't tell	Can't tell	Can't tell	No	Yes	Yes	Yes	Yes	15
Devik, Enmarker & Hellzen, (2019)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	19
LaToya & Harris, (2013)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	19
Johansson & Lindahl, (2011)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	19
Karlsson, Kasen & Warna-Furu, (2017)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	19
Oliveira et al., (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	20
Parola et al., (2018)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	19
Penz & Duggleby, (2011)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	19
White & Meeker, (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	18

	Question	**Type**	**Inclusion**	**Quality**	**Combination**	**Overall results**	**Population**	**Outcome consideration**	**Harms & Costs**	**Valuable**	**Score /20**
Rabbetts, Harrington & Breaden, (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	19
Zheng, Lee & Bloomer, (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	19
Zheng, Lee & Bloomer, (2017)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	19

Data Extraction and Synthesis

Joanna Briggs Institute Qualitative Data Extraction Tool [30] (Table 2) was used to extract descriptive data for the analysis, ensuring consistency among reviewers and researchers. Thomas and Harden [31] regard thematic synthesis as a method of conducting *"systematic reviews that address questions about people's perspectives and experiences"* (pg. 46), and this technique was used to synthesise the review findings.

Thematic synthesis is about developing descriptive and analytic themes that 'go beyond' the original findings. It takes on board methods from meta-ethnography and grounded theory to generate new constructs. Data was extracted for the analysis within the sections labelled as 'results' and 'findings' including both author interpretations alongside primary data. There are three stages within the synthesis. The first being line-by-line coding in order to capture the *"meaning and content of each sentence"* [31] (pg. 49). Secondly, similarities and differences between codes were then reviewed allowing for the researchers to identify descriptive themes across and within each study. In order to develop analytical themes, the descriptive themes were grouped and discussed with the wider team. The first author completed all stages, supported mainly by the primary supervisor and then wider team.

Table 2: Data Extraction for included studies

Authors/ Year	Method	Phenomena	Setting	Geography	Participant Characteristics	Sampling Method	Analysis	Master Themes & Conclusions
Cagle et al., (2017)	Qualitative open-ended survey data	Nursing home staff experience caring for dying patients	Nursing Home	Indiana, America	N=707; Female = 93%, White = 78%, Black = 14.6%, Hispanic = 2.6%	Not reported	Thematic Content Analysis	1. Going the extra mile 2. Feeling helpless 3. Painful emotions 4. Family discord Findings showed there is a richness and complexity to providing EOL care in nursing homes.
Devik, Enmarker & Hellzen, (2019)	Secondary Qualitative Analysis	Nurses' experiences of compassion when caring for palliative patients in home nursing care.	Community nursing teams	Norway	N=10; Women=6, Men=4, Aged 29-63. Diversity not reported.	Not reported	Hermeneutic Circling	1. Valuing caring interactions as positive, negative or neutral 2. Perceiving the patient's plea 3. Interpreting Findings 4. Reasoning about accountability and action Nurses experience both the presence and absence of compassion when caring for palliative patients in their homes.
LaToya & Harris, (2013)	Qualitative focus group interviews	Nurses coping processes and availability and adequacy of workplace coping resources	5 Community Hospice Settings	South Carolina, America	N=19; Mid-aged white women= 84.2%, 1 male took part	Convenience Sampling	Content Analysis	1. Social Support 2. Humour 3. Prayer/Meditation 4. Organisational resources Vary in their coping strategies when dealing with workplace stress.
Johansson & Lindahl, (2011)	Qualitative interviews	Meanings of generalist registered nurses' experiences of caring for	2 different hospitals	Sweden	N=8; diversity not reported	Not reported	Phenomenological hermeneutical approach	1. Being grateful to be able to share in the end of another's life 2. Being touched by physical and existential meaning 3. To give and receive energy

		palliative care patients in general wards						4. Being open in relation to patients and colleagues 5. Being in embodied knowledge 6. Time that does not exist Need for various forms of support for the nurses to meet their need for new and updated knowledge and support in existential matters.
Karlsson, Kasen & Warna-Furu, (2017)	Qualitative focus group interviews	Nurses' existential questions around caring for dying patients	Hospice, community and palliative care unit	Sweden	N=14; diversity not reported	Purposive Sampling	Thematic Analysis	1. Physical emotions that foster recognising and taking responsibility 2. Spatial emotions that fostered perceived and witnessing 3. Temporal emotions that fostered insight and understanding 4. Existential Level Nurses can experience growth both professionally and as human beings when caring for patients at the EOL.
Oliveira et al., (2017)	Qualitative interviews	Experience of nurses providing EOL care on an acute medical unit	Hospital	Ontario, Canada	N= 10; Males:3, Females:7	Purposive Sampling	Thematic Analysis	1. Caring in complexity 2. Caught in a tangled web 3. Bearing witness to suffering 4. Weaving a way to get there: Struggling through the process 5. Creating comfort for the patient 6. Working through the dying process with the family 7. Finding a way through the web Nurses experience was that of battling a tangled web

Parola et al., (2018)	Qualitative Interviews	Lived experience of nurses caring in a palliative care unit	Palliative Care Unit	Portugal	N=9; Female= 6: Male=3	Purposive Sampling	Giorgi	1. Experience centred on the relationship with the other 2. Experience centred on the relationship with one's self 3. Exhausting experience 4. Rewarding experience 5. The team as a pillar of experience Nurses are living an experience that focuses on the relationship with the other.
Penz & Duggleby, (2011)	Qualitative open ended telephone interviews	Explore the hope experience of registered nurses who provide palliative care in community settings	Community	Canada	N=14;	Not reported	Constructivist Grounded Theory	1. Social context of hope 2. Defining hope 3. Keeping hope 4. Harmonising hope Hope is very important and helps to preserve and sustain them when face with work life challenges.
White & Meeker, (2019)	Qualitative Systematic Review	Explore experiences of nurses providing home based palliative care for patients who live in country settings	Community	Australia	12 studies included	Literature review	Descriptive thematic analysis	1. The nature of nursing in country communities 2. Emotional Responses Literature is sparse reporting on the lived experience of nurses providing palliative care in country areas for patients wanting to die at home.
Rabbetts, Harrington & Breaden, (2018)	Qualitative Semi-structure interviews	Examine the views of acute care nurses caring for	Inpatient units	America	N=26, 1 male; 25 female; aged between 23-	Network sampling	Inductive Content Analysis	1. Sources of distress 2. Moral distress 3. Managing analgesia 4. Care/Cure dichotomy

		patients during transition to comfort care. Describe the personal impact on nurses and strategies for self-support and development of competence			54. Most employed for less than 9 years. 85% white.			5. Sources of Support 6. Nursing Fulfilment Providing EOL care continues to be ethically challenging and emotionally demanding. Preparation for the role and retention of professionals is dependent upon leadership and staffing.
Zheng, Lee & Bloomer, (2016)	Qualitative & Mixed methods Systematic Review	Summarise new graduate nurses experience with patient's death by examining the findings of existing literature	Palliative care, medical wards, acute hospital, intensive care unit.	Variety	12 studies included	Meta synthesis	Meta-aggregation	1. Emotional experiences 2. Facilitating a good death 3. Support for family members 4. Inadequacy 5. Personal and professional growth 6. Coping strategies New graduate nurses experienced a variety of feelings when faced with patient death. The nurses benefitted from this challenging encounter though they lacked coping strategies.
Zheng, Lee & Bloomer, (2017)	Qualitative Systematic Review	To review literature on nurses coping strategies with patient death.	Medical units, ICU, Palliative care, Critical Care, Hospice.	Australia, Canada, New Zealand, Taiwan, Hong Kong and South Africa	16 studies included	Meta synthesis	Meta-aggregation	1. Setting boundaries 2. Reflection 3. Showing emotion 4. Spiritual practices 5. Education 6. Debriefing This systematic review synthesised the findings about what resources nurses use when coping with patient death. Nurses

								need more support resources, which better assist them in coping with patient death.

Results

Evaluation of quality

Applied CASP scores in the selected papers ranged from 15-20/20 (see Table 1). Clear aims were specified across all articles and were assessed appropriately for the qualitative methodology used. Findings were thought to be presented clearly and deemed to be valuable research.

There was a lack of consideration for potential research biases within each paper for example, the relationship between research and participants, was the most common methodological limitation [32-38]. Furthermore, the process and subsequent findings may have been subject to researcher bias. Reflective accounts for the current synthesis can be found in shortened reflective journal (see appendix F). Moreover, although all papers reported ethical committee approval, five papers did not expand further on how they maintained ethical standards [32,34, 37-39]. For instance, there was a lack of discussion around managing informed consent and confidentiality. Furthermore, the analytical applicability of the findings may have been impacted due to the variation of sample sizes. For instance, Cagle's [32] study of 707 participants is likely to be more applicable than Johansson & Lindahl's [35] study, which included eight participants. Subsequently, this must be considered when interpreting the findings as the impact of these articles may vary.

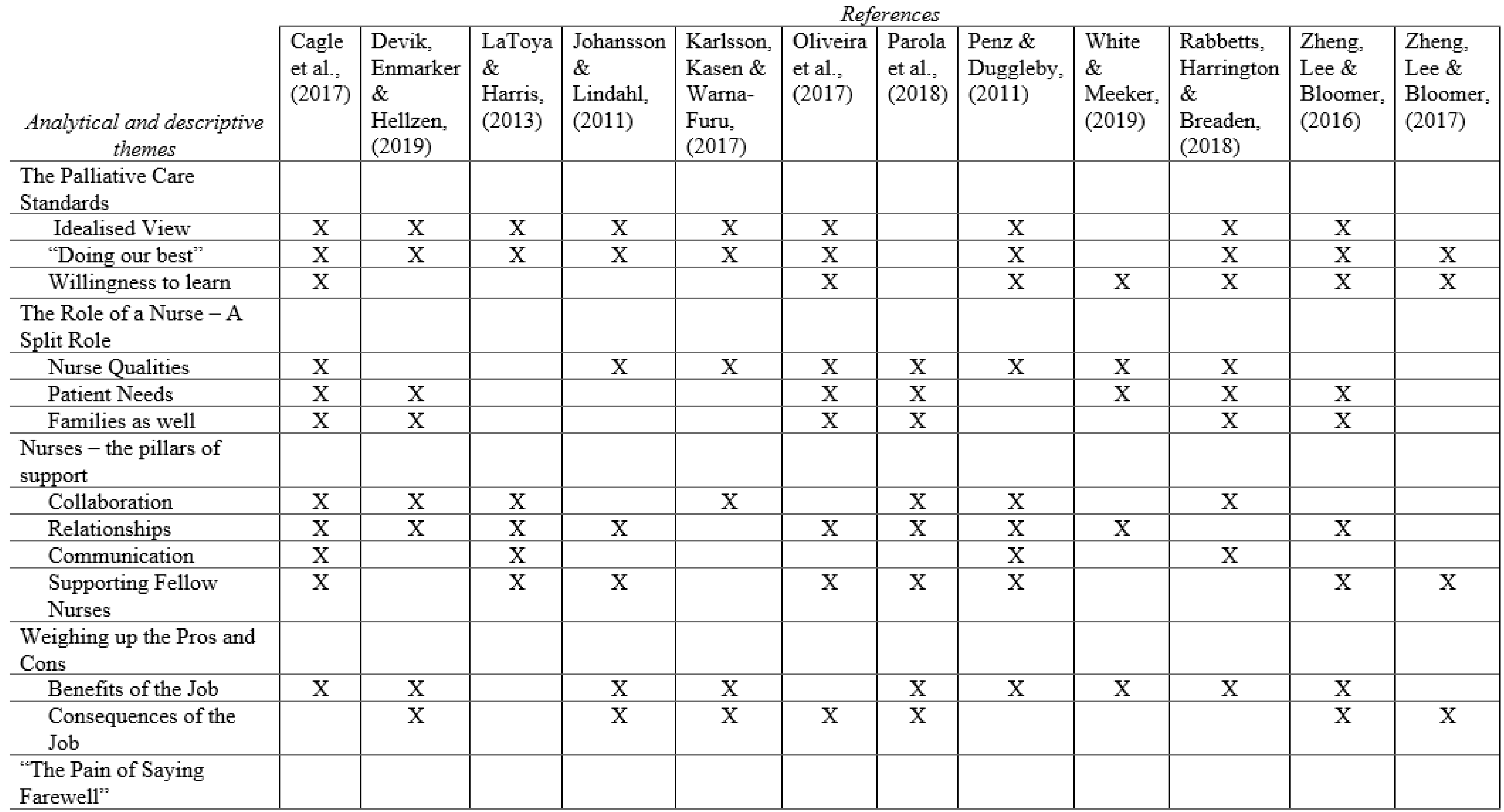
CASP results are inevitably influenced by journal criteria as some journals allow for greater word counts. For instance, the highest scoring paper [33] was published in a journal with a 6000-word limit compared to the lowest scoring paper [32] published with only 3500-word limit. A cautious stance must be taken when considering the scores. It should also be noted that the CASP quality appraisal tool does not include appraisal of the theoretical aspects of the papers included in this review.

Authors reviewed each paper in terms of its theory and concepts and noted that across all papers there was limited information provided around the theory and concepts utilised within each study. There was also a lack of information provided around the author’s epistemological stance. This needs to be taken into consideration when reviewing the results of this systematic review.

Thematic Synthesis

Six themes and 17 sub-themes regarding participants’ experience of working in palliative care were identified (See Table 3). For direct quotes that respond to the relevant master theme and sub themes, please see appendix G. This table provides direct quotes alongside the paper reference.

Table 3: Distribution of Analytical and Descriptive Themes



	References											
Analytical and descriptive themes	Cagle et al., (2017)	Devik, Enmarker & Hellzen, (2019)	LaToya & Harris, (2013)	Johansson & Lindahl, (2011)	Karlsson, Kasen & Warna-Furu, (2017)	Oliveira et al., (2017)	Parola et al., (2018)	Penz & Duggleby, (2011)	White & Meeker, (2019)	Rabbetts, Harrington & Breaden, (2018)	Zheng, Lee & Bloomer, (2016)	Zheng, Lee & Bloomer, (2017)
The Palliative Care Standards												
Idealised View	X	X	X	X	X	X		X		X	X	
"Doing our best"	X	X	X	X	X	X		X		X	X	X
Willingness to learn	X					X		X	X	X	X	X
The Role of a Nurse – A Split Role												
Nurse Qualities	X			X	X	X	X	X	X	X		
Patient Needs	X	X				X	X		X	X	X	
Families as well	X	X				X	X			X	X	
Nurses – the pillars of support												
Collaboration	X	X	X		X		X	X		X		
Relationships	X	X	X	X		X	X	X	X		X	
Communication	X		X					X		X		
Supporting Fellow Nurses	X		X	X		X	X	X			X	X
Weighing up the Pros and Cons												
Benefits of the Job	X	X		X	X		X	X	X	X	X	
Consequences of the Job		X		X	X	X	X				X	X
"The Pain of Saying Farewell"												

Inner Dialogue/ Conflict			X		X	X	X			X	X	X
Emotional Coping	X	X	X	X	X	X	X	X		X	X	X
Physical Coping		X	X	X		X				X	X	X
Organisational Issues												
Navigating the System	X	X	X	X	X	X		X	X			
What Governance?	X	X	X	X		X		X	X	X	X	X

Analytic Theme 1: Palliative Care Standards

The 'Palliative Care Standards' analytic theme reflects participants' views around the standards of care expected of nurses. The analysis showed that palliative care requires high standards of care delivery. Nurses are left feeling honoured to work within palliative care, as they witness the care they provide to patients. Alongside this, they have high standards to meet, meaning that nurses feel the need to constantly improve and learn new things, to continue to meet the self-imposed standards expected of them.

Idealised View

Participants reported an idealised view of palliative care, meaning that they felt palliative care was seen to provide care that other services strive for. Staff felt that they were privileged to do their job:

"It is an honour to be the person taking care of a dying resident." [32]

Staff felt that they were seen to be delivering high-quality patient care due to the nature of where they worked. Nurses are seen to *'go the extra mile*' for their patients. *'Going the extra mile'* suggests going above and beyond with the care they provide, not only meeting their patients' needs but exceeding them.

"Doing our best"

Participants highlighted the willingness to do their best at their job by trying to give patients want they want, staying strong by holding their own emotions and trying to juggle all the competing demands placed upon them.

"… I truly knew we did everything in our power to make the resident's final moments as comfortable as possible." [32]

Nurses referenced the idea that patients deserve the best end to their lives; however, there was an appreciation of how difficult it is to *"do our best"* when every patient's needs are different. Due to the complex and differing needs of patients, nurses settle with doing their best as there is a feeling that they *'cannot do it all',* meaning sometimes they feel this is not enough.

Willingness to learn

There is an understanding that nurses working in palliative care need to keep on top of their personal and professional development. Nurses reported a willingness to learn and develop new skills, complementing the varied nature of their work.

"I really learnt a lot through that patient experience…" [40]

Equally, being a nurse in palliative care was not thought to be something learnt solely within the classroom. It requires *'on the ground'* experiences, meaning nurses learn most through their lived experience. Finally, nurses referenced a willingness to learn new things, allowing them to become a more experienced nurse, helping them to manage their work better than when first qualified.

Theme 2: The Role of a Nurse – A Split Role

The "***Role of a Nurse – A Split Role"*** theme referred to the different aspects of a nurse's role when working in palliative care. Participants referred to their role as being complex and diverse, speaking about various qualities needed in order to be able to meet all the demands and needs that are placed upon them. Nurses discussed the needs of patients and the needs of families, and how this requires different qualities and skills that other specialities may not require.

Nurse Qualities

Participants spoke about different qualities that make up a *'typical'* nurse that could work in palliative care. The idea that nurses need to step into different roles and respond to patients' needs was central in this.

> *"It is really a matter of, yes… I always say that being a nurse is a little bit like being an actress. I think, sort of, that you can almost get caught up… yes you take on another role in some ways…"* [35]

Equally, nurses need to be able to sit and witness patients' vulnerability and take pride in being able to be there for others rather than always actively doing something to help. Participants reflected on how this is often different to other specialities, as it requires nurses to promote a different approach to what they would instinctively do. Finally, participants brought up the ability to be open-minded, taking an empathic stance to advocate for the patient when others might not be able to. For example, understanding and honouring a patient's wishes to die at home, when others may argue their needs may be better met in the hospital.

Patients' Needs

Nurses described how the patient's needs must come first; keeping the patients comfortable being a priority and treating each patient individually, providing personalised care tailored to their wishes:

> *"…each patient is unique, so the nurses described how they provided personalised and singular care tailored to the preferences, wishes and needs of each patient."* [37]

On the other hand, nurses reflected on how difficult it is to get the balance right as often some patients may present more clinical demands for staff than others. For example, some patients may struggle more with pain and require more medication and attention, which can cause nurses to be pulled away from others. However, participants were able to reflect on how they know the patients the best, as they have the most bedside contact, so are the best person to answer to the patient's needs

Families As well

Given that patient's needs are paramount, participants also reflected on their role in incorporating care for their families. Participants noted how the family needs support just as much as the patient and how often they need nurses to attend to their expectations. Families can often have very different hopes for the patient compared to staff, and staff have to develop a common collaborative goal, while helping families to have realistic expectations.

> *"Families will have their own goals and expectations. Physicians will have their own goals and expectations. And nurses are kind of suck in the middle."* [40]

Nurses also often have to balance conflicts between family members, which diverts attention from the patient.

> *"The patient was taking her last breaths and the family was fighting in the patient's room over her belongings."* [32]

Theme 3: Weighing up the Pros and Cons

The third analytical theme, 'Weighing up the Pros and Cons', focuses on the benefits and consequences of working as a nurse in palliative care. Participants repeatedly reflected on how they balance between the pros and cons of the job they do. When reflecting on their experience, nurses often spoke about the problematic consequence of their job, which would then be balanced with a benefit (and vice versa) as their way of potentially justifying why they do the job they do.

Benefits of the Job

Nurses reported numerous benefits of working in palliative care, the main benefit being job satisfaction alongside the intrinsic rewards of caring for someone at their most vulnerable.

> *"It was a positive experience to offer comfort and education to the family when they had fears… It is comfort to me as well as the patient and family to provide end of life care."* [32]

Participants often referred to patients having a *'good death'*, meaning that they were pain-free, and their needs had been met, and how in doing this, nurses felt rewarded. Experiences such as this allowed nurses to develop new perspectives permitting them to be better persons.

Consequences of the Job

Participants discussed the problematic aspects of their role and the consequences they faced in caring for someone who is dying. Nurses highlighted the ethical dilemmas staff have to face, such as patients asking for euthanasia, requiring staff to manage expectations of both patients and their families.

> *"Feeling like 'my hands are tied' during times when there are families in conflict over treatment…"* [32]

Another consequence discussed was the idea that patients/ families could often be dissatisfied with their care, causing them to feel disappointed and doubt their professional abilities.

> *"No matter how hard I tried, it was never enough for him. I felt annoyed and helpless because I always fell short."* [33]

They spoke about how they feel helpless if they cannot get patients' pain under control, which can lead to stress and negative views of themselves.

Theme 4: 'The Pain of Saying Farewell'

The fourth analytical theme, *'The Pain of Saying Farewell'*, reflected the personal challenges and pain of delivering palliative care to dying patients, and was the summative outcome of the three subthemes. Nurses reflected on how difficult and emotionally exhausting it can be to experience repeated losses and how nurses have to develop their ways of coping, with when continuing to work in palliative care. Participants were able to reflect on how each nurse will have their own ways of coping. The inner dialogue that nurses experience is tailored to them and will be different from the inner dialogue of their colleagues.

Inner Dialogue/ Conflict

Participants described an inner dialogue that they have with themselves (like a conversation) reflecting on the existential and spiritual aspects of experiencing dying. Within this dialogue, nurses turn inwards, reflecting on their work and their mortality,

> *"I think that everyone who works with this reflects on their own death or that something could happen."* [36]

evaluating and often re-evaluating the day's events and frequently continuing this dialogue at home and in their own time.

> *"[the nurse] can see that she has extreme pain, and [the nurse] really tries, but she does not want to take pain relievers… then goes home with a lump in her stomach that 'Why didn't I do more?' or 'What more could I have done?"* [36]

Nurses reported that this inner dialogue could feel like conflict between their personal and professional selves, allowing emotion to linger after a patient passes and causing emotional and physical exhaustion.

Emotional Coping

In response to, and as an outcome of the inner dialogue, participants reported on the emotional coping strategies they engaged in. The nurses referred to blocking out their emotions and switching off their feelings to focus on work.

> *"…. Stop pull yourself together and then go into the room very quietly. That's part of your nursing being able to switch…"* [40]

Participants reflected on how they focus on positive aspects of negative situations, to help them cope with the distress that comes with the job. Finally, nurses spoke of using humour to cope with challenging situations, such as sharing jokes, often referring to this as *'dark humour'*: finding humour in things that others may not find humorous.

> *"It's interesting how dark we get, the more tired and fried we are."* [41]

Physical Coping

Alongside emotional ways of coping, participants also discussed physical ways of coping, including physically avoiding emotional situations.

> *"…and sometimes, you deliberately avoid getting involved because there is not enough time to deal with any struggles."* [33]

Nurses referred to different hobbies they engaged in outside of work that helped them manage difficult emotions, such as physical exercise. Engaging in physical coping strategies allows nurses to distract themselves from their thoughts and improve their mood by releasing endorphins [37]. These strategies helped nurses detach and do their job without letting emotions surface and get in the way.

Theme 5: Nurses – the pillars of support

The fifth analytical theme, 'Nurses – the pillars of support', explores how nurses support patients, families, and their fellow nurses. Participants talked about how they want the best for their patients, and they support the families, trying to meet their expectations, but they also reflected on how they support each other to do the job. The pillar of support refers to this idea that nurses are the pillar that keeps everyone supported, and without this pillar, palliative care would not be the same.

Collaboration

The need for a shared responsibility to work together as a team, when working in palliative care, is central to this subtheme.

> *"Your chaplain and your social worker are always there, and you can go, and you know gain some support."* [41]

Participants identified that in palliative care, nurses need to work collaboratively with patients and families to respect their wishes and provide the best care. Participants referred to palliative care as being a *'team effort',* the idea that everyone needs to work together to provide the best care, not just the staff. Even so, nurses discussed how leaders within palliative care need to be effective, to prompt collaboration across disciplines and with patients and their families.

Relationships

Participants reported the need for meaningful relationships and having a deep connection with the patients and their families as part of the care process.

> *"The hardest part of taking care of a dying resident is the heartache that follows. We grow attached to people, and sometimes it can cause grief."* [32]

Close connections provide a shared understanding and allow families and patients to trust and feel supported by staff. Nurses reflected on how palliative care is centred around relationships with all the individuals involved in patients’ care: this process can be enlightening when done correctly and effective in improving quality of life and quality of care.

Communication

A recurring subtheme centred on communication, via the need to respect other views and have a clear and open dialogue with patients and their families to provide the best care. Having early conversations about end-of-life care helps build trust and support and allows staff to assess and manage identified needs accurately. Communication was also crucial in organising and coordinating services to help with patient care plans.

Supporting Fellow Nurses

Participants reported that supporting fellow nurses was critical, in order to be able to do their job and have support within the team when other nurses may be struggling.

> *“There are always situations that raise doubts in me… I turn to the team… we need to speak to each other.”* [37]

The idea here is that they support each other, often across professions, but nurses always look after their own.

Theme 6: Organisational Issues

The final analytical theme is ‘Organisational issues’, the difficulties nurses have in navigating the various healthcare systems, and the lack of governance. Nurses reported that working within the healthcare system can be frustrating when systems are not set up to effectively support patients. Participants reflected on how the system may not support staff to do their job, and often this can be a constant battle nurses face.

Navigating the system

The healthcare systems made nurses feel that the nursing profession is isolated and not always included in core decisions regarding care compared to other professionals.

"Fighting a lot of prejudices… fighting to be part of a team…" [40]

There was an element of frustration with service provision and how services are set up, which does not always support patients or staff. Nurses described that the system often does not appreciate the work they do, which can cause frustration in staff and the separation of disciplines. Environmental factors within the setting nurses worked in were a recurring source of stress and distress, with nurses resigned to working within existing systems due to the emotional effort and exhaustion of trying to change it.

What Governance?

Finally, participants discussed the lack of organisational support that is there for them emotionally and physically. Lack of guidance, resources, and space to reflect were central. Participants often highlighted the need for more support and how they feel better able to do their job when feeling supported. The lack of support received caused more pressure on staff and left staff trying to seek support elsewhere, often through colleagues who may need support themselves. Nurses reported how they would like support through debriefs and reflective spaces; however, when this was facilitated, nurses were often unable to attend due to the amount of bedside contact they are required to do.

Discussion

The synthesised review has highlighted that working within palliative care is complex and engenders a high level of emotional stress that nurses engage in multiple ways to mitigate negative effects. Importantly, data suggests a lack of governance and support for nurses when managing emotional distress and the psychological impact of death. From the themes developed, evidence indicates that environmental factors have a significant impact on nurses' psychological wellbeing. As a result, further research needs to individualise psychological support for nurses based on their work environment.

Strengths and Limitations of Study

Twelve studies were considered eligible to be included within this review. Conclusions drawn from the review must be considered in relation to the context and readers must remain tentative to further hypothesis for investigation. Additionally, the studies were all based in western countries meaning the findings may not reflect other countries or cultures. The majority of papers were based in hospice and community clinical settings; therefore, findings do not factor in all the different ways of delivering palliative care. Equally, the nature of the studies included within this review where qualitative, and therefore there are challenges with making generalisations of the findings. Qualitative research does not seek to make generalisable findings; however, the majority of papers had homogeneous samples allowing for an in-depth exploration of the group. Moreover, when limiting the inclusion criteria to only peer reviewed literature, insights from grey literature may have been missed.

Despite the limitations outlined above, this is the first systematic review to synthesise existing qualitative evidence regarding the experience of qualified nurses working across palliative care settings and provides a foundation for further critical examination of the evidence around environmental factors that impact a nurse's ability to care for dying patients.

The review elucidates the main benefits and challenges of working within palliative care and points to the internal and externally identified standards that staff are required to meet in the face of organisational issues. A robust and transparent methodology [25] and processes were employed including 2 independent reviews to quality assess and screen all articles. The review was reported following the PRISMA and ENTREQ guidelines [21]. The quality of the included studies was a key strength within this synthesis, with the majority of studies considered to be high quality, therefore this increases the rigour of this systematic review findings.

Strengths and Limitations in Comparison to Existing Literature

When examining the qualitative literature, we begin to understand more about the experiences of qualified nurses. The current synthesis acknowledged the idea of complexity within the caring role, as discussed below.

Findings showed that the identity that comes with professionals working in palliative care is complex due to the number of roles nurses undertake, when caring for patients and their families. This finding relates to what is known about developing a professional identity and why nurses remain motivated [15]. Research has shown a wide range of motivations for remaining in nursing, such as the sense of self validation, desire to help and sense of achievement, all of which constitute to someone's professional identity [15]. Without the nurturing of these motivational factors, it begs questions as to whether nurses would remain in nursing. Parsons systematic review looked at why experienced nurses remain in the profession and found that a positive professional identity allowed them to remain motivated and encouraged later retirement [42]. This supports the findings of the current review, suggesting that the pros of working within palliative care out way the cons, allowing nurses to remain motivated constituting to their professional identity.

For the novice nurse, professional acculturation is complex, taking a number of years to navigate [43]. The accumulative effects of skill acquisition and socialisation has been showed to positively influence caring relationships with patients and colleagues. Hence, newly qualified nurses working in palliative care may need additional support from fellow colleagues to help them navigate this complex area and feel settled in their job. Ten Hoave et al., [44] looked at the experience of newly qualified nurses taking their first qualified job. Findings revealed that developing a sense of professional identity is established through colleagues and senior management teams. In essence, this means that the environment nurses work within has a significant impact on psychological wellbeing and retention, providing evidence for further research looking into different palliative care settings. The evidence relates to the current review findings as nurses felt they had multiple roles, and often had to provide support for each other. However, there is a lack of structure and support for nurses trying to reach professional acculturation, leaving this down to fellow nurses to support.

Malloy [45] conducted a qualitative study looking at how 60 nurses found meaning in their challenging work across five countries. Findings were that the relationships among nurses, community, workplace, their patients, and families were central to facilitate meaning in their work. The relationships were categorised as caring and compassionate and strengthened their commitment to the nursing profession over time, creating a sense of personal identity. Such findings relate to this synthesis, as nurses developed an idealised view of palliative care, developing a personal identity around the ethos of palliative care. Nurses are then encouraged to perform at their best, while being open to developing new and existing skills.

A central tenant in the data was the identification of the rewarding yet challenging aspects of the job. The data identifies that, nurses who work in palliative care, enjoy managing the challenges that come with their role and found the nature of their work rewarding. The findings encapsulate the negative and positive impacts of the workplace on nurses' experience, including issues around organisational changes and workforce culture.

Research has taken an interest in exploring the impact of poor work environments on nurses. Research looking at hospital nurses have has identified found various work stressors, such as workload, working shifts, patient acuity, ethical conflict, and violence [46-49]. An established predictor of low job satisfactions, high turnover and poor health has been showed to be workplace stress [50,51]. Overall, if work stress predicts poor health and job satisfaction, it can be assumed that it will negatively impact the nurse's experience working in palliative care. It may also explain why nurses may consider leaving the speciality. In this review, nurses did reflect on the work stress they experience and the lack of support; however, nurses did not describe wanting to leave the profession.

Lack of clarity of the job role and organisational structure/ support presented a constant challenge across the data reviewed. Nurses described their role being a split role, they not only have patients to look after, but they have the family dynamics to manage alongside paperwork and admin, which may result in workplace stress. The consequences of excessive and prolonged stress can lead to distress, such as burnout. As previously stated, the WHO has highlighted the higher rates of stress in nurses than other skilled workers [9], providing evidence that psychological support may be needed when working in healthcare settings. Given the current changes to healthcare systems and a depleting/ struggling workforce in some countries, staff may be at greater risk of burnout [12]. It has been predicted that there will be a global shortage of nurses within the next 10-20 years [52], and it is imperative to ensure measures are taken to understand and ameliorate the stresses nurses may face to protect against stress-induced ill-health and absences.

When staff are stressed, overstretched and over-worked, this negatively affects the quality of care experienced by patients and make staff more prone to error [17]. As referenced previously a professional's ability to cope is questioned when it undermines staff resilience [18]. Palliative care has been reported to be more stressful due to numerous factors, one being the frequent losses experienced, [19-22] alongside the inherent stressors in generic nursing. This review highlighted some of the different strategies that staff utilise in response to workplace stress (emotional and physical coping); however, each nurse develops these strategies due to the lack of support within their work environment.

When reviewing Maslach's theory of burnout it would suggest that burnout professional inefficacy was reported to be a key dimension of her model, nurses within this review reported experiencing professional efficacy through developing a positive professional identities and acculturation. As nurses develop a professional efficacy this may aid as a protective factor against burnout. Nurses also discussed different strategies that they utilise as a way of preventing exhaustion another key dimension of Maslach's theory [11]. The strategies prevent stress from being prolonged enabling staff to continue to work within the profession and reduce the risk of burnout. Further research is now needed to explore what environmental factors may impact on the psychological wellbeing of staff.

Despite limitations, the current synthesis offers a new insight into how participants appear to experience their role as nurses in palliative care. Reviewing workplace stress and psychological wellbeing is high on the national agenda [8]. Overall, the detailed account from nursing staff in the present synthesis suggests that working in palliative care is a complex experience with effects on the individual, structural and organisational level that requires a detailed examination to unpick and ensure that nurses are provided with the environments that promote personal and professional development, enabling them to provide the level of care they aspire to.

Clinical Implications

The findings from this review suggest that working as a qualified nurse within palliative care is multifaceted. Clinical implications for this synthesis have been reviewed per the analytical theme.

Theme 1: Palliative Care Standards

Both personal and professional learning is essential, especially when linked to lived experience. Providing nurses with opportunities to engage in learning to develop and enhance experience may help staff feel better equipped to undertake their role. A study by Dinas [53] developed an end-of-life nursing training program, for nurses working within critical care. This was developed due to the lack of education around various aspects of palliative care, such as pain/ symptom management and communication strategies. It was concluded that the training program enabled staff to feel better equipped when working with palliative care patients within critical care.

It is also essential to consider what the payoff is when nurses go the *'extra mile'*, which seems to be a self-imposed standard associated with the nature of palliative care nursing and is viewed as a positive factor. Little is known about the toll this takes and how this will be accounted for. For example, it may be unlikely that staff will stop *'going the extra mile'* given how reinforcing this is. Helping staff learn about balance and managing how far they will go with their care is important, preventing negative consequences such as burnout and compassion fatigue. Overall, staff need help to cope with the idea that they are *'good enough'*, a principle originally based on Winnicott's concept of the *'good enough mother'* who describes attending to a child's needs in a way that does not require perfection. This concept has more recently been applied to the care provided by healthcare professionals such as therapists and neonatal nurses and suggests that caregiving in these contexts should provide a reasonable level of acceptability rather than perfection. However, this notion maybe particularly challenging for palliative care nurses '*given the high standards of care they set for themselves and the importance of this narrative to their professional identities'* [54]. Nurses reported that they are *'doing their best'*; however, the thought of not being able to operate according to this standard feels unimaginable to them. Nurses within this review reported always having to do their best; however, nurses need may need to acknowledge that they may not be able to do their best. In doing this it helps to redefine this narrative, taking the pressure off nurses and allowing them to develop effective coping strategies to manage its impact.

Theme 2: The Role of a Nurse – A Split Role

The current synthesis showed that nurses expect to take on different roles as part of their job, alongside witnessing vulnerability and an expectation to care for families. Thought is needed to be given to the level of training nurses receive to carry out these additional roles. Training packages need to encompass the additional unspoken responsibilities that nurses carry out, alongside their typical day to day tasks. The Nursing Midwifery Council states that nurses within the 21st century need to be: *"emotionally intelligent and resilient individuals who can manage their health and wellbeing and know when to access support"* [55]. In the standards framework for nursing and midwifery education, there is no reference to areas of the curriculum that provides training around helping nurses to manage their emotional health and wellbeing, or specialist training for end-of-life care [55]. When reviewing the standards of proficiency for registered nurses, there is no reference to professional development post qualification or how nurses can continue to learn and improve as qualified practitioners [56]. Overall, this supports the current synthesis, highlighting that, nurses do feel overwhelmed by the additional responsibilities and feel they have no formal training in managing their own and others' psychological distress.

Theme 3: Weighing up the Pros and Cons

Findings from the current synthesis showed the importance of multidisciplinary team training, as often nurses feel they are the only professionals to take on sole responsibility for patients and their families. Multidisciplinary team working is essential when working across and between professionals. Collaboration is imperative when trying to manage the dilemmas inherent in balancing the needs of both the patient and their families. Again, training packages incorporating effective multidisciplinary teamwork would help staff feel equipped to manage these complex and challenging situations. Atwal et als study reviewed nurses' perceptions of multidisciplinary teamwork and found three barriers: differing levels of skill acquisition, differing perceptions of teamwork and dominance of the medical power. Findings suggest that education establishments need to ensure that the acquisition of team-playing skills is an integral part of professional development [57].

Theme 4: 'The Pain of Saying Farewell'

The experiences of the palliative care nurse tend to lead to reflection, re-evaluation, and detachment. Hence, there may be justification for the availability and increase in regular, consistent and safe reflective spaces. Before facilitating this, training about 'what is reflection' and exploration of coping methods may be a starting point. Parrish and Crookes have provided a wide range of research looking at reflective practice within nursing. They suggest that nurses who can effectively reflect are equipped to provide a *"holistic approach to patient care and are more inclined to monitor and enhance their professional competence"* [58]. Research provides evidence that reflection training would better support staff to provide safer care to patients. A qualitative study by Perez et al., reviewed everyday stressors, coping strategies and training needs among palliative care clinicians. Findings showed that the three areas of stressors were: systematic challenges to managing demanding emotional caseloads, patient factors and personal challenges [59]. This suggested that training to look at stress reduction and strategies that clinicians can utilise during work could be valuable. Implementing training which also focuses on developing ways of coping could be an effective way to support staff and increase staff sustainability.

This review suggests that professionals feel they need further support due to the *'pain of saying farewell'*, indicating that increased exposure to the psychological distress of others may impact nurses' psychological wellbeing. Providing a space for nurses to reflect on their experiences may help staff feel supported to discuss any struggles or concerns. Schwartz rounds have provided staff with a space to meet regularly to explore both psychological and physical factors affecting their work [60]. A national evaluation of Schwartz rounds showed that staff found them to positively influence their work while helping them gain insight into their colleagues' experiences [61]. Through this, staff teams develop an open culture that allows conversations around mental health to be fundamental and acceptable.

Theme 5: Nurses – the pillars of support

The concept of collaboration as being essential to both team members and patients may indicate a need for the team-building process. Team building processes may help staff improve communication and work closer together, alongside training regarding effective communication.

Theme 6: Organisational Issues

The review has highlighted the importance of the environment in facilitating staff wellbeing and psychological flexibility. A review of the literature of staff wellbeing during COVID-19, appeared to provide evidence that many environmental factors impacted the anxiety and stress levels of staff working in hospital settings. The findings indicated that changes to the hospital environment during this time were a significant theme throughout the transcripts, impacting staff psychological wellbeing [62]. The environment is essential when developing palliative care services, helping to facilitate positive wellbeing in staff.

Future research

Several areas warrant further investigation to understand nurses' lived experience better. Although this review focused on the experience of nurses across clinical settings, it is likely specific clinical settings will further shape experience. As such, studies focusing on particular palliative care settings that are under-researched, such as palliative care units within the acute care setting, could add additional information to the pre-existing literature. It is important to explore each setting individually so that strategies to help manage difficulties staff face are tailored to the individual's environment. Such research could offer valuable insights and a more holistic understanding of the experience of working in palliative care as a qualified nurse, and what strategies could be implemented to help improve staff wellbeing.

Summary and Conclusions

This review of the evidence throws new light on the complexities of working in palliative care as a qualified nurse and documents the high levels of emotional distress within this role. Nurses do not feel that they have the appropriate support or governance to manage the challenges and complexity of the job and the environment they work in.

After reviewing 12 research papers describing qualified nurse’s experience of working in palliative care settings, six analytical themes were identified, synthesised through the notion of complexity across three key areas: identity, rewarding yet challenging and lack of clarity. Overall, although working as a qualified nurse is positive, staff can also feel a lack of support and come up against organisational challenges, which can often negate the benefits of the job. Findings suggest a need for a detailed understanding of palliative care qualified nurses' lived experience within specific palliative care settings. It will help better understand what strategies and support are needed to allow staff to maintain psychological flexibility, when working in an emotionally demanding environment.

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Chapter 2: Finding Meaning in End-of-Life Care. An Interpretative Phenomenological Analysis Study of Acute Palliative Care Nurses.

Abstract

Background: Palliative care nurses care and support people, and their families, with life-limiting illness. Patients may be admitted to the acute care setting due to in having complex and distressing symptoms, causing significant suffering. Witnessing this distress can impact on the nurse's emotional well-being, with existing literature highlighting the significant number of professionals working in palliative care suffering from burnout, trauma, and compassion fatigue. Few studies have attempted to understand qualified nurses lived experience of providing end-of-life care when working in an acute Academic Palliative Care Unit.

Methods: This study explores qualified nurses experience of providing end-of-life care from a phenomenological and existential perspective. Eight nurses were interviewed from one acute palliative care unit and analysed using Interpretative Phenomenological Analysis (IPA).

Results: Three themes describing the lived experience of nurses providing end-of-life care were developed: 1) The Pressure to Provide 'Perfect Care', 2) 'Get on with it' in Silence, 3) 'Bargaining' with the system. The findings are grounded in psychological theory and discussed in relation to existing research.

Conclusion: The study data highlights the lack of control as a key factor in psychological processes involved in participants' experiences of providing end-of-life care in an acute setting.

Introduction

The Nursing Midwifery Council (NMC) states that 21st century nurses need to be *"emotionally intelligent and resilient individuals who are able to manage their own personal health and wellbeing and know when to access support"* [1]. However, in the standards framework for nursing and midwifery education there is no reference to areas of the curriculum that provides training to help nurses to manage their emotional health and wellbeing [1]. This is despite the World Health Organisation (WHO) highlighting that, nurses have a higher rate of stress when compared to other skilled workers [2].

It has been predicted that there will be a global shortage of nurses within the next 10-20 years [3]. Given the current changes to healthcare systems, and in some countries a depleting/ struggling workforce, nursing staff may be at a greater risk of burnout [4-6], compassion fatigue [7] and vicarious trauma [8]. Crucially, patients' experience of care quality is affected when staff are stressed, [9] and when staff are overstretched and overworked, they are more prone to error. Johnson and colleagues report that when a healthcare professional's ability to cope is compromised, the resultant distress undermines their resilience and promotes a perceived sense of failure [10]. Overall, this produces negative outcomes e.g., shame, depression, and anxiety, enhancing the likelihood for further distress. While many recognise the stressors that are inherent in generic nursing, Grafton and other colleagues claim that palliative care is especially stressful due to managing frequent losses, working with complex families, and varying disease profiles [11-14].

Over the last decade researchers such as Rushton, Kavallieratos, and Back, have been interested in understanding the experience of palliative care clinicians [15-17]. Studies, such as Kamal's National Survey of burnout within palliative care clinicians, suggested that 50% experience distress due to the adversity of working in their field [5]. Recent research, including Vachon's qualitative examination of how nurses handle death proximity, looked at the misalliance between the professional environment and the workers values [15, 18, 19]. Mismatches are often detected in palliative care when there are inadequate resources and demanding workloads, all of which can hinder the quality-of-care professionals strive to provide. Clinicians often find excessive workloads exhausting, causing a conflict with their values and goals [17]. Various work stresses such as *"workload, ethical conflict, working shifts, patient acuity and violence"* [20-24] have been outlined as key stresses within the existing literature.

An established predictor of, poor health, low job satisfaction and high turnover, is workplace stress [25,26]. Overall, if work stress predicts poor health and job satisfaction, it can be expected that it will have a negative impact on nurses' experience working in palliative care and may also explain why nurses may consider leaving the specialty. Research has found that palliative care nurses are at greater risk of work stress due to their role involving frequent losses and the exposure to grieving families [27]. Little is known about whether their degree of stress is greater than that of other disciplines.

Furthermore, the standards of proficiency for registered nurses make no reference to professional development post qualification, or description as to ways in which nurses can continue to learn and improve as qualified practitioners [28]. With no reference to areas of the curriculum [1] about providing training around end-of-life care, exploration is needed to understand how nurses can develop specific palliative care skills and manage their own psychological wellbeing in the absence of any formal training.

Factors that influence an individual career choice to become a nurse is the desire to help others and a way of contributing to society [29-31]. Nursing gives nurses a sense of achievement and self-validation which build up a professional identity and motivates them to continue to work in nursing [32]. Parson et al's., systematic review examined why experienced nurses remain in the profession and found that positive professional identity allowed them to remain motivated and encouraged later retirement [33]. Malloy's [34] study looked at how nurses find meaning in their work, highlighting that the power of relationships and how these relationships strengthened their commitment to their profession, creating a sense of personal identity. In essence, the psychological well-being and retention of nurses may be significantly impacted by the extent to which their working environment facilitates the ability to operate in a caring role and maintain identity and relationships.

Thus, research examining specific palliative care environments may help to better understand the role this plays in mitigating workplace stress and longevity within the profession.

Aims and Objectives

The main objective of the current study was to explore the lived experience of nurses providing end-of-life care for dying patients on an academic palliative care unit within an acute care setting. The aims were to explore qualified nurses' experiences of the impact of providing end-of-life care on their physical and psychological wellbeing; the ways in which nurses cope with the emotional aspects of their role and the environmental impact of working within an acute care setting.

Theoretical and Methodological Approaches

The study was conducted using an existential, hermeneutic, and phenomenological approach, encapsulated within a constructivist-interpretative framework [35]. This paradigm claims that the co-creation between research and participant holds the meaning of an individual's experience [35]. In keeping with this paradigm, the study focused on the lived experiences of participant's while using the researchers' subjectivities to help better comprehend the experience of providing care for dying patients for palliative care nurses. When using this paradigm, the researcher is required to be authentic and transparent about assumptions and theories when taking an active role in interpreting and exploring participants experiences [36-37].

The researchers used both theoretical and experiential sources of knowledge. The wider supervisory team had a wealth of knowledge through professional clinical and academic experience which were used to help aid reflexivity through peer-discussions and research journal keeping of the Lead Researcher (AB). Doing this ensured that this contextual and experiential understanding enhanced rather than limited the study [35-37].

The study's methodological and theoretical stance was anchored in Interpretative Phenomenological Analysis (IPA) [38-41]. IPA is defined as *"a flexible and versatile approach to exploring, describing, interpreting, and situating the participants sense-making of their experiences"* [39] of which the main aim is to describe and explore in detail a participant's personal lived experience

[40], taking a phenomenological perspective. IPA, unlike traditional phenomenology rejects the idea that all judgement can be reduced which is helpful as the nature of the study is one that will have a personal connection to us all [38, 39]. IPA identifies more closely with the hermeneutic approach allowing for the researcher's interpretation to play an active role within the analysis which is something that other methods such as thematic analysis and ground theory are unable to offer [36, 43]. Within this context meaning is seen to be fluid and is open continuously for interpretation, new insight, revision and reinterpretation [38]. As a Trainee Clinical Psychologist, this allows me as the researcher to bring my wider clinical and theoretical knowledge into the analysis of the data and generate analysis and interpretation underpinned by a clinical psychology perspective. However, given this idea it can make the analysis process time consuming and somewhat complex to navigate as it may be open to the researcher interpretation.

"Double hermeneutics" is often referred to within IPA as the researcher making sense of the participants sense-making [41]. This encourages the researcher to take a more active role during the interpretation, as a way of unravelling the meaning of a participant's experience. When unravelling the meaning it also allows the researcher to explore how participants make sense of their experience [39, 40]. The study paid close attention to how participants exposed their experience when caring for dying patients for ethical, reflexive, and relational reasons Tracy's [37] key markers were used throughout the research process to allow for quality in qualitative research (please see in appendix H).

IPA specifies having a guided by a theoretical framework and research questions focused on personal experience and meaning making in a particular context and the use of a small purposive sample alongside the use of interviews to collect first person accounts of personal experience [44]. This approach is more appropriate for this study in comparison to thematic analysis as IPA incorporates an idiographic approach (focus on unique details of each participant) and thematic orientation which focuses on the identification of themes across participants. This is different from themes developed in thematic analysis where themes are developed across participants and focuses on staying close to the participants overt meanings.

Method

Participants

All qualified nurses working within an acute academic palliative care unit in the North West of England were invited to take part via internal advertisement. Detailed information sheets were provided via email to each qualified nurse interested in taking part (N=10). The following inclusion criteria were required for study selection: registered nurse, > 21 years of age and had worked on the acute palliative care unit continuously for > 6 months (allowing them to have a good understanding of the ward environment). Exclusion criteria included any other healthcare professional, < 21 years of age and had worked on the acute palliative care unit for < 6 months continuously. Tindall and colleagues [45] have suggested that in IPA research "there is no right answer to the question of sample size" and that between four and 10 participants are advised for professional doctorates. The research recruited eight registered nurses that worked on the acute palliative care unit with one nurse not wanting to take part and one not meeting the criteria for the study. Table 2 provides the sociodemographic characteristics of the sample.

Table 2. Sociodemographic Characteristics.

		Mean (SD)	**Range**
Age		35.25 (9.01)	24-49
Gender (Number of Participants)			
Woman	N=8		
Men	N=0		
Work status			
Part time	N=1		
Full time	N=7		

Ethical Approval/ Considerations

This study protocol received approval from the Doctorate of Clinical Psychology Research Review Committee. Following this university ethical approval was granted from the University of Liverpool and Health Research Authority (HRA). Approval was then sought through the Integrated Research Application System (IRAS). The protocol was subsequently approved at the Single Point of Access to Research and Knowledge (SPARK) research team at recruiting hospital. Once approval was granted recruited commenced.

Procedure and Setting

A written participant information sheet was provided electronically to all participants, providing them with information about the studies purpose, ability to withdraw at any time and the voluntary nature of their participation. Confidentiality was assured to all participants, and they were informed that the analysis would be completed with the intention of holding the integrity of the participants. Informed consent was obtained for each participant before the interview.

Detailed semi-structured interviews (n=8) were completed by main researcher, with supervision provided by the wider team. Each interview ranged from 40 minutes to 60 minutes (Mean = 52.25). The NHS Trust and Palliative Care Ward Manager approved for each participant to be interviewed, in a confidential private space of their choosing at their workplace either during or after their shifts. The interview schedule was co-developed by the research team and validated by a specialist palliative care community nurse who could provide an expert by experience perspective. Participants were invited to share, during the interview, their experiences of providing care for dying patients as a qualified nurse. Prompts were used to deepen the exploration. Finally, participants were invited to share their experience of the interview upon conclusion, enriching our understanding of the participants experience and ensuring relational and situational ethics [36]. All interviews were audio recorded and fully transcribed and discussed between interviewer (trainee clinical psychologist) and the supervisory team.

Governance

As the study addressed sensitive issues, signpost information was provided to different services that participants could access if they needed support (see appendix I). Due to the nature of the interview, a distress protocol was developed to provide guidance should any participants become distressed during the interview (see appendix J). In addition, contact details were provided for the research team should any concerns with the study, or procedure, be raised. The research team also met regularly for supervision to ensure that the interviewer had space to reflect and discuss any difficulties.

Data Analysis

The analysis started by gaining insight into the data through immersion in the data by reading and re-reading the transcriptions and writing down any initial notes (descriptive, linguistic, or conceptual). Each transcript was examined individually identifying initial notes for each, reported in the right-hand margin. The researcher then noted any emergent themes that came out of each participant transcript in the left-hand margin. The researcher then manually organized these emergent themes to group them into clusters for each participant transcript (see appendix K). Finally, once clusters had been developed for each participant, overarching themes were developed by manually grouping across participants clusters (see appendix L). Finally, this resulted in three different superordinate themes with multiple sub themes that described the significant dimensions of the experience for providing care for dying patients (see appendix M). Supportive descriptions of each three themes were then created alongside specifying specific participant narratives and quotes. Each transcript was reviewed to make sure they encapsulated all three themes and fundamental parts of the participants experiences and that each experience was embodied.

Results

The analysis outlined three master themes that carried the meaning of providing care for dying patients for qualified nurse; 1) The Pressure to provide ‘Perfect Care’, 2) ‘Get on with it’ in Silence, 3) ‘Bargaining’ with the System. The three themes will be presented and illustrated through participant’s quotes helping to support and clarify the meaning of their experiences.

Master Theme	Subthemes
(1) The Pressure to provide ‘Perfect Care’	• The Importance of the Context of Care • Palliative Care Standards: Putting the Best Foot Forward
(2) ‘Get on with it’ in Silence	• Connection the Only Form of Support • Silencing of Nursing • Emotion is a Sign of Weakness
(3) Bargaining’ with the system	• Burden of Being a Nurse • Pressure of Being the Professional

The Pressure to provide ‘Perfect Care’

When trying to provide end-of-life care participants shared experiences in which they felt a lack of control over various external influences. A lack of control manifested itself in many different ways such as the lack of control over the standard of care they provided and the context in which care was delivered.

Palliative care was referred to by participants as *‘the perfect care’* the idea that patients received the *‘best’*. In turn, due to the high standard set by the acute palliative care unit, this had an influence on the quality-of-care nurses delivered to their patients. Participants reported that they made sure to put their *‘best foot forward’* when providing care to patients, allowing them to feel a sense of *‘achievement*’ and *‘pride’*. One nurse stated the following:

“I feel like its God its very like high standard, I know I’m saying that, but I feel it is compared to other places I have worked…” (Pt1)

Nurses saw working in an acute palliative care unit as being a *'privilege'* due to the high standards of care however, this then had an influence on staff expectations of themselves. Alongside the standards set by working in an acute palliative care unit there were also unspoken standards of what qualities a qualified nurse should possess. Participants talked about how palliative care *'was not for everyone'* you are either *'built'* for palliative care or you are not. Nurses needed to have *'shared values'*, *'be brave'*, a desire to help others and putting others before yourself. This left a felt sense that personal characteristics were an uncontrollable influential factor as to whether nurses worked in palliative care.

"…yes, it's just you either are or you're not there's no in-between, you can't blag this you can't blag it." (Pt7)

Another external influence for nursing within an acute palliative care unit was the misconceptions that other professionals and patients had of palliative care. Participants reported receiving comments that palliative care is *'boring'* and that other professionals stated *'why would someone want to work there'* due to the association with death, all of which insinuate that palliative care is a negative place to work. Palliative care was referred to as being a *'sad & miserable'* place to work again indicating that only negative feelings are associated with palliative care. Misconceptions of palliative care cannot be controlled by nurses, but there was a felt sense of wanting to challenge the misconceptions through providing the best care, allowing people external to palliative care to see the positive aspects of providing end-of-life care.

"But, yes, I think it was just an opportunity to be part of something new… a palliative care ward specifically, it was the first of its kind and I thought it would be a really good way to get into revolutionising palliative care and trying to change people's perceptions by providing good care." (Pt5)

The clinical environment was identified as another uncontrollable influence for nurses working within an acute palliative care unit, particularly during the COVID-19 pandemic. Participants referred to how the COVID-19 pandemic had a significant impact on the way care was delivered and in turn the psychological well-being of staff. COVID-19 prevented families from seeing patients face-to-face, reduced levels of staff due to sickness and social distancing between staff and patients. These factors impacted on staff's ability to do their job as they felt that they were unable to fulfil patients' wishes. The environmental changes caused additional stressors preventing them from utilising previous ways of coping, such as peer support causing more psychological distress. One participant states the following:

"…its totally out of our comfort zone erm because we have families in all the time, some families are staying 24/7. Erm… but obviously now they can't because with the COVID and that and sometimes they're only allowed in the last hours of life and its only one person. So sometimes because like a mum dying with 3 or 4 daughters who do you choose, that's where it's been difficult. So, we found it hard with patients when it first all started." (Pt6)

"So, it was really weird to us because we're so used to loads of people being round, so yes that was difficult because I suppose we were with the majority of patients that came and died quite quickly. So, then it was like quite sad because you were just thinking it could have been one of your family it was just awful…" (Pt1)

The quotes suggest that having key facilities such as a family room and an environment which is an open access ward, allowed for better patient care and allows staff to be able to perform better. However, participants were aware that the environmental factors were not something they were able to control:

"I think if they're on a normal ward and they're palliative sometimes it's quite hard to have that initial conversation with families. Whereas if you say there is a palliative care unit, they kind of get that seed planted because people are so scared of the word." (Pt4)

"…it's not the best you know it's very much… next but in an environment like this you've no choice like well someone might have just taken their last breath in the next room you might have someone with a new diagnosis, and you might have someone in the room after who potentially could

die today. Like there's that much going on and you can't… you can't be sitting in the staff room crying." (Pt8)

The quotes suggest that qualified nurses working in palliative care feel they have a lack of control over their environment; however, the environment had a significant impact on their experience of delivering end-of-life care. Overall, there is a clear idea that there are various external influences that can impact upon a nurse's experience of providing end-of-life care. Participants are able to reflect on how palliative care standards impact on how they view their work and the level at which they expect themselves to perform alongside challenging the misconceptions of their work. Finally, the standards must endure and transcend the challenges of the environment and have little impact on how nurse perform their role. These challenges were most apparent when in a pandemic, staff struggled to meet the unspoken standards as the social and physical environments changed and had a significant impact on the nurses' experience providing end-of-life care.

'Get on with it' in Silence

Participants referenced different experiences where they felt that they were alone when dealing with the psychological consequences of providing end-of-life care. There was felt sense that nurses were not able to talk about their own psychological well-being as patients' needs were seen to be a priority. It was seen to be *'unprofessional'* to be upset and that nurses have to *'be strong'*. Participants felt unable to express their emotions and described '*not being allowed'* to express their feelings:

"It's not even a case of getting on with it, it's like I say we still get upset we can still feel for people, but do you know what, it's not happening to me so I can feel, and I can take the experience from it and I can be genuinely upset by something. But at that time, I need to just keep my head and do the best for them, I can handle my own feelings later, I can handle my own responses to it later on. Right now, this is what's needed, and I think to a certain extent you have to go onto autopilot because we've had some really sad cases on this ward really sad cases and if you sat and thought about it too much you wouldn't be able to provide what they need… you just wouldn't." (Pt7)

"…because I think it's for me personally it's actually for the patient it's for their families to show the emotion not me." (Pt2)

"…yes, you just have to try and put on a face, be your professional self like normal, treat it like normal." (Pt1)

Nurses reported experiencing an emotional impact when providing end-of-life care however, they have to be in control over their emotions so as not to show them to patients, families, and other staff. When discussing the different avenues of support nurses reported that their only external form of support was fellow nursing colleagues, again giving a felt sense of suffering alone and being silent to others outside of nursing.

"I think we had about 4 deaths in the shift and they were just one after the other and my colleague were both on long days, so it was only us dealing with the impact of those deaths." (Pt5)

One participant described the connection with fellow nurses and how all nurses cope differently, but come together to support one another:

"We bounce of each other we're not scared to cry in front of each other, some of us are more criers than others. Some of us, some of us are softer than others, some of us can suck it up. But I think every single member of this team that I work with at some point I have seen upset because we are human. We support each other a hell of a lot a hell of a lot it its we've never worked together until we came here but the way that they selected us has been amazing. Because we've all brought different things and we've all bounced of each other and it's a cracking little team…" (Pt7)

Participants reported that they felt there was no physical space offered to them to express their emotion in a safe, contained way. With the limited physical space, nurses felt unable to speak about their difficulties, silenced by the environment in which they work, resulting in nurses feeling they had to seek support in secret:

"If they're being truly honest about how it affects them and we've had loads of conversations, you'll just know by looking at your colleague ahh she's or he they're struggling there and then we'll

go inside the cupboard or the meds room and the tears will flow and then we're trying to pull ourselves back together and put our professional face back on and then walk out and then you go to give someone pain relief…" (Pt5)

While having to seek support in secret from other professionals, patients and families, nurses reflected on how this developed a culture of emotion being a sign of weakness and a sign that nurses were unable to do their job. Alongside not being allowed to express emotion there was a culture of professional separation – an 'us and them'. Nurses felt different to other professionals in how they are treated and what was expected.

"Higher up above her there's people who they will never take the side of the nurse... oh, it's frustrating, it's frustrating when you've been like you've had someone screaming in your face, and they tell you they're just upset because they're not aggressive." (Pt8).

With this culture of being strong, nurses adopted a *'get on with it'* approach as a way of coping with the lack of support and emotional aspects of providing end-of-life care. Participants often referred to getting on with it many times during the interviews:

"you wouldn't be normal if you didn't have your blow out days and you need a blow-out day some days especially when it been one after the other after the other after the other and you've been short staffed and all the politics going on and all that. So, you just get on with it well I just get on with it." (Pt6).

When discussing other coping strategies aside from getting on with it, participants often struggled to articulate their different ways of coping. This may reflect the fact that nurses feel silenced and often do not get opportunities to talk about their own well-being and ways of coping. Participants did talk about trying to see 'positives' in negative situations and how this helps them to seek comfort. Another common way was through the use of humour:

"People tell inappropriate jokes and like nobody else would get it but it's just it's what like we get it and it's what you kind of need." (Pt2).

Using humour was an acceptable way of communicating any difficulties; however, it also masked the suffering that nurses were experiencing. The humour was described to be *'dark'* as a way of highlighting the lengths nurses have to go to in order to try and find a positive in a negative situation. Participants spoke about how they utilise other strategies at home such as exercise and alcohol, as a way to manage difficult emotions they were left feeling.

"*…so, I go to the gym a lot and I come before work and I feel like that clears my head and you know I go to CrossFit every morning at 6 am and I'm here… nightshifts I'll do it after my nightshift I'll go at half 9 and I just feel like it's just a place where nobody knows that I'm a I'm nurse nobody knows what day I've been through…" (Pt4)*

Researchers had a felt sense that the nurses needed to please people and that often the nurses felt powerless when compared to other healthcare professionals. It was perceived that, other professionals *'pass the buck'* to nurses who have to pick up the pieces. Overall, this reflects the idea that participants felt unable to speak up about their own psychological well-being and therefore adopted strategies to mask their suffering so to not come across weak to others however, in turn causing nurses to fall silent.

'Bargaining' with the System

The medical model of care recognised that the human body is complex and advocated for the treatment of symptoms through the use of medication intervention and procedures. Participants referred to the power the medical model has when making decisions about patient care and the added complexities it causes when working in this way.

"…it's just about symptom control really. I think they mainly focus on here erm is more symptom control" (Pt5)

One participant talked about an experience of wanting to help a patient but being unable to meet the patient's wishes due to the limitations of the medical model:

"…it's just really not nice when you've got someone begging you to take the pain away and to put them asleep and they don't care what you give them… just put me to sleep I just don't want to

know what's going on. To have someone ask you that and sometimes relatives they ask you about euthanasia, can you? Relatives have screamed at me and said you wouldn't leave a dog like this and its true you wouldn't but there is nothing you can say because it is it is true, but we have to follow our code of conduct and the policies and we can't do that." (Pt2)

Working within the medical model often requires nurses to manage the different complexities that come with their role such as *'bargaining with families'* and *'putting yourself in the patient's shoes'* finding this emotionally and physically exhausting. In addition, being a nurse on an acute palliative care unit provides an added layer of responsibility that can have an impact on their psychological well-being. For example, one participant highlighted how as well as patients, family care is central to ensuring well-being:

"…we build relations with not only the patient but their family as well and I suppose we're their like support network then if you know I suppose when people are deteriorating and things, we've got to be there to not only answer questions, but I suppose just be there for them and erm yes and like it is really difficult as well sometimes obviously it's not the, what's the word, not the happiest of places to work." (Pt1)

Managing the additional responsibilities and the ethical dilemmas of working within a medical model, nurses reported experiencing times where they were often battling between the personal and professional sides of themselves. Participants referred to having this professional and personal inner conflict causing dissonance between the two parts of themselves. However, by resolving such dissonance it can promote positive reflections on themselves and their lives.

"…you get the relatives they're like can't you give them something can't you just put them to sleep and it's so like difficult. Because as like a human being that is what you want to do, you don't want to watch someone suffer but as a professional and you know your code of conduct is that you have to do, follow the policy and you have to do it you know this way that's quite that's like yes a difficult bad day I would say." (Pt2)

"…it is very humbling, and you never know what's around the corner for you, you listen to people's stories and you listen to people's lives and you think you just haven't got a clue so just be grateful for what you've got and just keep yourself grounded." (Pt7)

When working within this model nurses feel the need to improve care and progress by learning new things and being open to learning from others. There was a need to continuously improve and be better so to be able to keep up with the medical model they work within. Participants reflected on how working in palliative care requires continuous improvement and that you cannot learn about the job alone by sitting in a classroom.

"…you learn more when you come into this colour, they can train me how to give injections and they can train me the right and wrongs they can't… they can't give you the experience that just comes over time and especially with the experience on this ward it's completely different." (Pt7)

Participants felt that there was a lack of training and education provided in palliative care, and across the wider profession, causing a lack of understanding leading to misconceptions of what palliative care actually entails:

"I just don't think there's enough training and I find the younger ones coming in now will ask more questions and they'll be like what would you give for this or they kind of listen to what a nurse has to say. Whereas you find that the ones who've been there a bit longer they try to be a bit more palliative care training they'll just be like no, I'll not prescribe yet or whereas the younger ones are more mouldable so that's why you need to get in from the get-go and train people." (Pt8)

Overall, there was a sense that the medical model had control of the professionals that worked within it. The model had power over the way in which nurses were able to deliver care and imposed extra responsibilities on nurses.

Discussion

This study explored the lived experience of qualified nurses providing end-of-life care within an acute palliative care unit. The eight interviews undertaken yielded three main themes which were:

1) ‘The Pressure to Provide ‘Perfect Care’, 2) ‘Get on with it’ in Silence and 3) “Bargaining” with the System. Findings highlighted the importance of the working environment on nurses’ lived experience of providing end-of-life care. Environmental factors can be viewed as external factors such as COVID-19, alongside the culture and social norms adapted within the setting.

Participants offered their emotive accounts of working within acute palliative care unit providing end-of-life care for dying patients. Nurses expressed a lack of control when working on this unit which was a common thread across all three main themes within the analysis. The term control is defined as *“the power to make decisions about how a country, an area, an organisation etc. is run”* [46]. In this study, a lack of control is a cross cutting theme that underpinned the experience of participants working on the unit. When looking at the theme of ‘The Pressure to Provide ‘Perfect Care’, participants had various external influence’s that affected their experience of providing end-of-life care. There was a high standard set on the unit about how palliative care should be delivered. Nurses expressed a lack of control over these standards, feeling that they had to perform to meet the high expectations. Outside of the unit other clinical areas had misconceptions of what palliative care is and nurses felt that they had to address these alongside doing their job role.

Research by Rotter [47] looked at internal and external locus of control. External locus of control is the idea that everything is down to the environment or fate not through one’s own doing. When reviewing the analysis, nurses working on this unit may have developed an external locus of control, due to their perceived limited control over their environment. The external locus of control may then impact on their lived experience of providing end-of-life care as nurses may not feel a sense of personal reward.

‘Get on with it’ in Silence was a master theme found within the analysis, suggesting that participants working on the unit do not feel heard by other professionals and senior managers and are unable to acknowledge their own feelings, due to the fact that the ‘patients are more important’. On the unit it was clear that the culture was ‘emotions are a sign of weakness’ which resulted in nurses resulting either not expressing their emotions or doing this in secret. When expression was done in secret, it was usually done in physical hidden spaces on the unit, such as the medicine cupboard. This had an impact on the interviews conducted, as nurses struggled to talk about their ways of coping and emotional responses, and often needed prompting. A psychodynamic perspective [48] would suggest that participants utilise denial as a defence mechanism and way of distancing themselves from the difficult unconscious emotions that they experience. Through the development of this coping strategy, nurses feel able to continue to work within this environment and manage their own emotions.

Despite the silencing and lack of control participants felt, nurses did feel able to provide a high standard of patient care and continued to work within palliative care, expressing positive feelings towards their chosen speciality. Nurses were able to reflect on aspects of their role that they felt were out of their control and causing a level of uncertainty and discuss how they often try to find positives within difficult situations. The Social Exchange Theory by Homan in 1958 [49] proposes that social behaviour is the result of an exchange process in order to maximise benefits and minimise costs. Research by Schaufeli [50] argues that professionals seek rewards in return for their efforts. The Social Exchange Theory would suggest that when staff are faced with difficult situations, they will look for positive reinforcement for their efforts within that particular situation. Participants continued to work within palliative care as they receive positive reinforcement for their efforts allowing them to maximise the benefits while minimising the costs to themselves. On the other hand, this balance may not always be possible for staff and this may cause a lack of fulfilment in staff efforts. For example, participants discussed the current COVID-19 pandemic and how staff felt unable to get their usual rewards from their clinical work, causing a lack of balance between giving and taking. Bunnk and Schaufeli [51] argue that reciprocity plays a central role in human life for establishing relationships and general health and wellbeing. Overall, this may explain why staff felt a lack of control when working within an acute palliative care unit during COVID-19 and that this had a significant impact on their psychological wellbeing, increasing their susceptibility to stress.

Alongside this the theme ‘get on with it’ in silence felt closely linked to the Social Learning Theory [52] as through the fear of being judged nurses felt that they were unable to express their emotions. Social learning theory [52] suggests that social behaviour is learnt by observing and imitating the behaviour of others. Nurses may not feel able to express their emotions based on the culture of the setting they are in and from what they have learnt from other nurses and co-workers about what is acceptable. The culture within this setting argues that emotions are seen to be a sign of weakness and therefore nurses see a direct link between showing emotions and being perceived as weak to other colleague/ peers. In turn nurses feel that in doing this they may be alienated from their co-workers and perhaps fear being mistreated by others if they were to reveal such feelings, which may compound their distress. In doing this, nurses may feel that this protects them from the shame and stigma of society associated with emotional expression and so maintains their social acceptability. However, this may be indicative of how certain societies conceptualises distress and mental health as a weakness. Emotional strength in this setting is judged as being preferable, as it may allow nurses a certain amount of control and allows nurses something to focus on in the face of not being able to influence systems/triggers. Although these mechanisms are ultimately unhealthy for our mental health these can be reinforcing / rewarding as in the short term it protects us from their negative emotional impact.

Overall, the findings of this study have provided insight into the pressures that staff experience when working in an academic palliative care unit. Nurses try to overcome the lack of control they experience by trying to exert control over what they can, which is their role and responsibilities. Due to the extra pressure and stress this caused, alongside the culture on the unit of emotion being a sign of weakness, nurses felt unable to express their emotion through the fear of rejection from others and through the fear of being viewed as weak. This provided insight into the social norms and culture within this setting and the limited power nurses felt they had to challenge the status quo.

Strengths and Limitations

This study gave voice to the qualified nurses working within an academic palliative care unit within an acute setting, their accounts were listened to and their personal meaning-making captured.

To the researcher’s knowledge there is currently no published literature in the field of palliative care exploring solely qualified nurses working within an academic palliative care unit within an acute care setting and this study will add depth and value to the current evidence base. The expert knowledge and experience of the researchers aided in-depth IPA, allowing the contextual and experiential understanding to be enhance; research has shown that this aids analysis instead of hindering [36-37]. Another strength of this study is the number of participants recruited for the study. Out of ten registered nurses, nine were eligible to take part in the study and with a sample size of eight this allowed for the analysis to get a detailed and rich understanding.

The main aim of qualitative research is not to see generalizable findings; therefore, this could be considered a limitation of the current study. With the sample being homogeneous it enabled the interviews to provide rich and detailed exploration of such an under-researched group. It allowed for the identification of commonalities and possible differences among the participants. To allow for preconception to be set aside, the research kept a reflective log throughout the process. The reflective log ensured that the interpretations had foundations within the participants' quotations. All three themes captured each of the eight participant's experiences.

The nurses appeared very tolerant of the context in which they worked, and they were empathic, non-blaming and understanding. The idea of *'social desirability'* in the qualified nurses' responses was considered, and the interview did not feel that nurses modified their experience or sense making to appear more desirable.

The recruitment process invited qualified nurses to take part and consent, which may encourage a particular type of individual, who may be more willing to express their story and take part in research. As eight out of a possible nine qualified nurses were recruited, that the sample was representative and posed no recruitment bias. Even so, since recruitment only took place at one palliative care unit this could be seen to impact on how specific the results may be to the unit they were recruited from. However, palliative care units are limited in numbers within the United Kingdom and therefore recruitment across multiple sites was not feasible.

Clinical Implications

Common themes across participant accounts were a lack of support and palliative care training. Furthermore, nurses felt unacknowledged and dismissed, resulting in a reduced sense of control and power, compared to other professionals.

Support and Initiatives

Nurses felt that their emotional wellbeing was rarely acknowledged and that there was a taboo around talking about mental health when working in a health setting. The introduction of initiatives relating to the psychological impact of their role may not only explicitly acknowledge the demanding aspects of the work but may also challenge the implicit but dominant culture of their 'getting on with it in silence'. Developing avenues for staff support would normalize and enable access when needed.

Nurses acknowledged their *'get on with it'* attitude and their need to be able to cope and be strong. Baring this in mind, nurses may need to be offered support routinely to give more opportunity for nurses to accept and access this. Support needs to be tailored to their level of experience and other additional training that they may have previously undertaken so to enhance their understanding.

Support could be offered through regular weekly reflective practice sessions to give space to allow staff to acknowledge the difficult emotions that they experience at work. Research has suggested that reflective practice is regarded as an essential characteristic for professional competence [53]. Further evidence indicates that the use of reflective practice with palliative care nurses increases their critical thinking, listening and observation skills [54].

Other ways of providing support for nurses could be through clinical supervision, debriefing around critical incidents and resilience training. Clinical supervision has been shown to be an effective strategy for support allowing healthcare professionals to develop new skills, maintain standards and encourage personal and professional development [55]. Debriefing is another effective way of helping nurses to have a space to discuss and reflect on difficult incidents that happen on the ward. Research by Keene et al., looked at debriefing sessions to support healthcare professionals cope with a death of a patient, and findings on self-report measures showed that staff found debriefing helpful in managing their grief [56]. Finally, resilience training has been reported to be an effective strategy to help combat workplace stress [57] however training would need to be tailored to the environment that nurses work within and the different stressors they experience.

Psychological Training

Alongside offering spaces to reflect, training is needed around recognising the early warning signs of psychological distress, helping staff to seek help in a timely manner.

Specific group training around Cognitive Behavioural approaches would help staff to understand the links between our; physical sensations, behavior, thoughts, and feelings so to better formulate their difficulties [58]. The aim is to explore and recognise unhelpful behaviour and interpretations, to facilitate change and to promote adaptive ways of thinking and begin [59]. Developing bespoke training with a focus on specific psychological difficulties such as anxiety, depression and trauma would provide staff with a better understanding about what signs and symptoms they need to look out for. Finally, mindfulness training could enable staff to utilize this technique in times of distress. A systematic review by Suleiman-Martos looked at training in this approach among nurses indicating that it reduces levels of burnout and emotional burden [60].

Conclusion

This IPA, study exploring the lived experience of qualified nurses working in an acute palliative care unit, adds to the currently neglected literature. Qualified nurses when working within an acute academic palliative care unit, have often suffered in silence, experiencing uncontrollable external influences and being powerless in the face of the medical model they work within. Despite this, qualified nurses appear to overcome these difficulties with resilience, strength, and commitment to their professional responsibilities. Overall, highlighting the importance of the environment when nurses are providing end-of-life care. Qualified nurses should be offered various avenues of support to help them manage the psychological distress of working in palliative care. Nurses need education around psychological principles to help them to recognise early warning signs of distress. Further research is needed to explore the particular environmental factors that impact upon psychological wellbeing and how services can implement changes to better support staff.

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Appendices

Appendix A – Role and Skills Requirements (Please view green section for specialist palliative care nurse)

Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life (Skills for Health and Skills for Care, 2014) **Outcomes informed by Speciality Training Curriculum for Palliative Medicine** (Joint Royal Colleges of Physicians Training Board, 2014) **Five Priorities for Care** (The Leadership Alliance for Care of Dying People 2014)	Unregistered Support Worker in Health & Social Care	Nursing Associate	Pre-qualifying students Under supervision	Registrant providing palliative care approach or general palliative care	Registered Practitioner – Specialist Palliative Care	Senior Practitioner – Specialist Palliative Care	Advanced Practitioner – Specialist Palliative Care	**Evidence of Achievement For** (Tick Programme): Pre-qualifying Programmes Continuing Professional Development: Not accredited Undergraduate level Postgraduate level	**Action required for achievement of EoLC LO** Date & Signature
1.1 Communication Skills: The Practitioner will be able to:									
1.1a Communicate with a range of people on a range of matters in a form that is appropriate to them and the situation recognising need to talk openly and honestly.	■	■		■	■	■	■		
1.1b Develop and maintain communication with people about difficult and complex matters or situations related to end of life care.					■	■	■		
1.1c Present information in a range of formats, including written and verbal, as appropriate to the circumstances.	■	■		■	■	■	■		
1.1d Listen to individuals, their families and friends about their concerns related to the end of life and provide information and support.	■	■	■	■	■	■	■		
1.1e Work with people, their families and friends in a sensitive and flexible manner, demonstrating awareness of the impact of death, dying and bereavement, and recognising that their priorities and ability to communicate may vary over time.	■	■	■	■	■	■	■		
1.1f Work with colleagues to share information appropriately, taking account of issues of confidentiality, to ensure that people receive the best possible care.	■	■	■	■	■	■	■		
1.1g Ensure that information is clear, and non-jargonistic, so that it can be fully understood by others.	■	■		■	■	■	■		
1.1h Demonstrate knowledge of theories and evidence base for communication.		■	■	■	■	■	■		
1.1i Examine knowledge/research of the importance of breaking bad news and to develop strategies for the skills delivery of bad news.					■	■	■		

12

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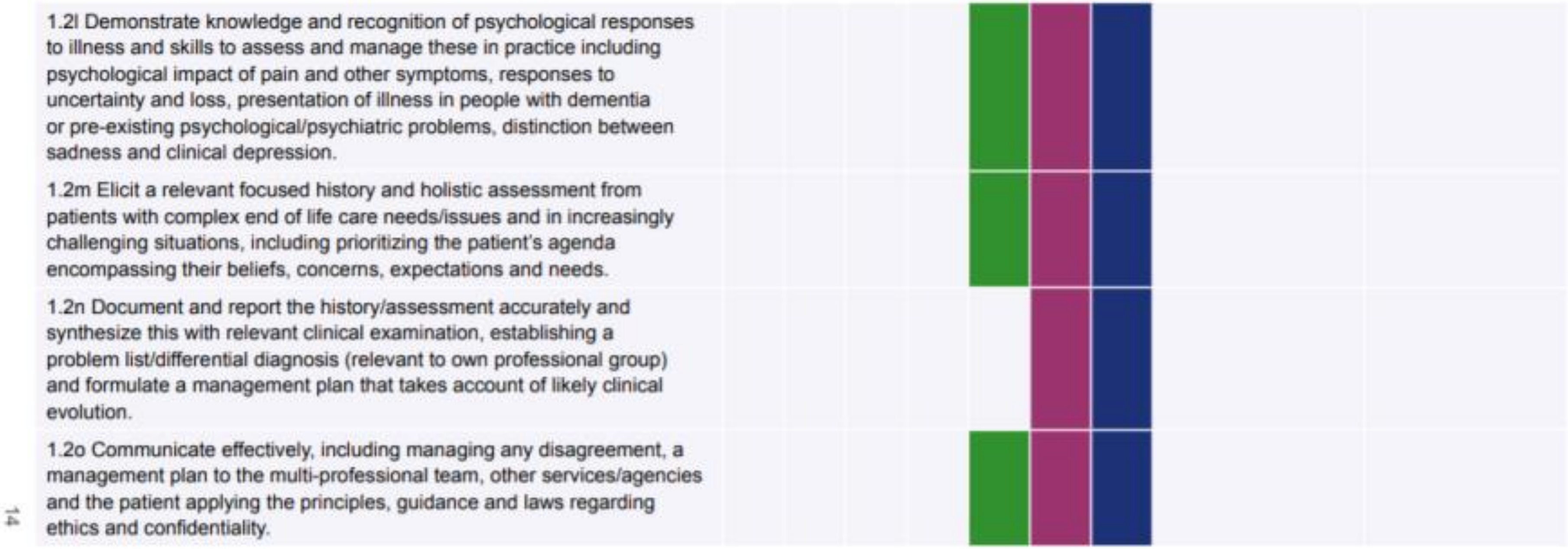
1.2 Assessment and Care Planning: The Practitioner will be able to:									
1.2a Work in a person-centred way, listening to and taking account of the wishes of the person and their carers. Recognise people as experts in their own lives.	■	■		■	■	■	■		
1.2b Understand the range of assessment tools, and ways of gathering information including conversation, and know their advantages and disadvantages.		■		■	■	■	■		
1.2c Assess pain and other symptoms in ways appropriate to your role, including using assessment tools, pain history, appropriate physical examination and relevant investigation. Know when to refer concerns to specialist colleagues.				■	■	■	■		
1.2d Undertake/contribute to multi-disciplinary assessment and information sharing, including speaking to colleagues as part of the assessment process, and ensuring that, where information is already available, the person is not asked to provide the same information repeatedly.	■	■	■	■	■	■	■		

1.2e Ensure that all assessments are holistic, including: i. Background information about the person's life ii. Personal strengths, aspirations and priorities iii. Religious or other belief, cultural and lifestyle factors iv. Current physical health and prognosis, including underlying health or other conditions v. Social, occupational, psychological and emotional and spiritual well-being vi. Religion and/or spiritual well-being, where appropriate. vii. Risk and risk management.	■	■	■	■	■	■	■
1.2f Ensure that the needs of carers, including children and young people, are taken into account and that carer support and, where appropriate, assessments are offered.		■		■	■	■	■
1.2g In partnership with others, review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is properly shared.	■	■	■	■	■	■	■
1.2h Communicate with a range of people on a range of matters in a form that is appropriate to them and the situation.	■	■		■	■	■	■
1.2i Explain the scientific basis and clinical manifestations of disease processes that are life limiting and integrate this knowledge in the assessment, diagnosis and management of patients with life limiting, progressive disease commonly encountered within own practice.				■	■	■	■
1.2j Analyse presentation of illnesses in people with dementia and other common psychiatric and psychological conditions including clinical depression.				■	■	■	■
1.2k Analyse theories and evidence relating to the psychological impact and responses to illness and loss, and integrate this knowledge in the assessment and management strategies within clinical practice.				■	■	■	■



1.2l Demonstrate knowledge and recognition of psychological responses to illness and skills to assess and manage these in practice including psychological impact of pain and other symptoms, responses to uncertainty and loss, presentation of illness in people with dementia or pre-existing psychological/psychiatric problems, distinction between sadness and clinical depression.					🟩	🟪	🟦		
1.2m Elicit a relevant focused history and holistic assessment from patients with complex end of life care needs/issues and in increasingly challenging situations, including prioritizing the patient's agenda encompassing their beliefs, concerns, expectations and needs.					🟩	🟪	🟦		
1.2n Document and report the history/assessment accurately and synthesize this with relevant clinical examination, establishing a problem list/differential diagnosis (relevant to own professional group) and formulate a management plan that takes account of likely clinical evolution.						🟪	🟦		
1.2o Communicate effectively, including managing any disagreement, a management plan to the multi-professional team, other services/agencies and the patient applying the principles, guidance and laws regarding ethics and confidentiality.					🟩	🟪	🟦		

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1.3 Symptom management, maintaining comfort and well being: The Practitioner will be able to:									
1.3a Be aware that symptoms have many causes, including the disease itself, its treatment, a concurrent disorder, including depression or anxiety, or other psychological or practical issues.	■	■	■	■	■	■	■		
1.3b Understand the significance of the individual's own perception of their symptoms to any intervention.	■	■	■	■	■	■	■		
1.3c Understand that the underlying causes of a symptom will have an impact upon how care should be delivered.		■	■	■	■	■	■		
1.3d Understand the range of therapeutic options available, including drugs, hormone therapy, physical therapies, counselling or other therapies, surgery, community or practical support.				■	■	■	■		
1.3e In partnership with others, including the individual, their family and friends, develop an EoLC plan which balances disease-specific treatment with other interventions and support that meet the needs of the individual and *addresses the five priorities of care identified by The Leadership Alliance for Care of Dying People (2014).*				■	■	■	■		
1.3f In partnership with others, implement, monitor and review the EoLC plan *to address the five priorities of care identified by The Leadership Alliance for Care of Dying People (2014).*	■	■	■	■	■	■	■		
1.3g Be aware of cultural issues that may impact on symptom management.	■	■	■	■	■	■	■		

1.3h Demonstrate knowledge, skills and understanding to manage symptoms and other clinical problems secondary to life-limiting progressive disease including: pain, gastro-intestinal symptoms, respiratory symptoms, genitourinary symptoms, musculoskeletal and skin problems, neurological and psychiatric problems, paraneoplastic syndromes, palliative care emergencies, treatment induced symptoms.					🟩	🟪	🟦		
1.3i Review and monitor interventions and management plans, including medications and non-medication based interventions, identifying indications, contraindications, side effects, drug interactions and dosage of commonly used drugs communicating appropriately to multi-professional team, patients (and carers).						🟪	🟦		
1.3j Demonstrate knowledge of treatment methods and use of drugs to treat patients with life limiting progressive disease – including relevant national guidelines and protocols, drug formularies in palliative care, legal and ethical issues relating to prescription of controlled drugs, problems of polypharmacy.					🟩	🟪	🟦		
1.3k Apply general principles of pharmacodynamics and pharmacokinetics and, for drugs commonly used in palliative and end of life care, explain: Routes of administration, absorption, metabolism, excretion, half-life, frequency of administration, adverse effects and their management, opioid switching, use of syringe drivers, interactions with other drugs, issues of tolerance addiction, dependence and discontinuation reactions dose adjustment in altered metabolism, organ failure, disease progression and in dying patients.						🟪	🟦		

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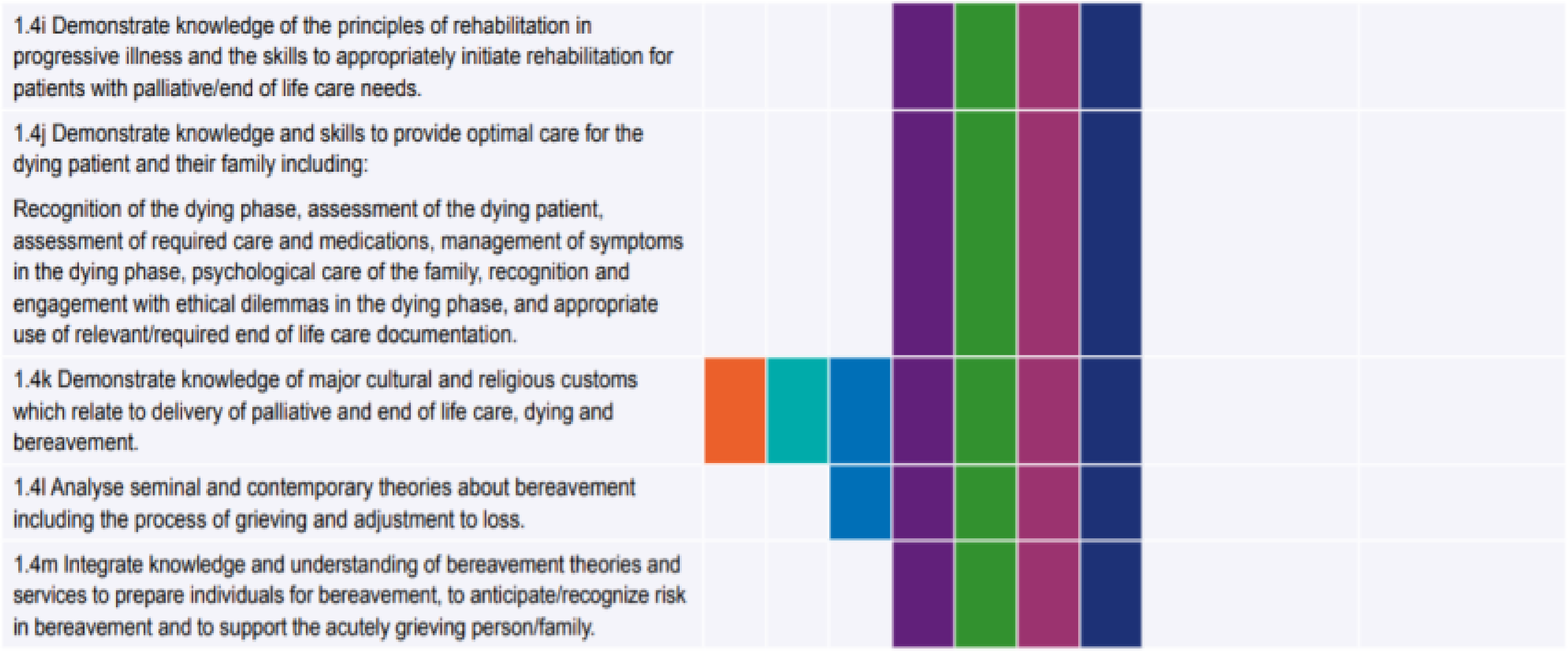
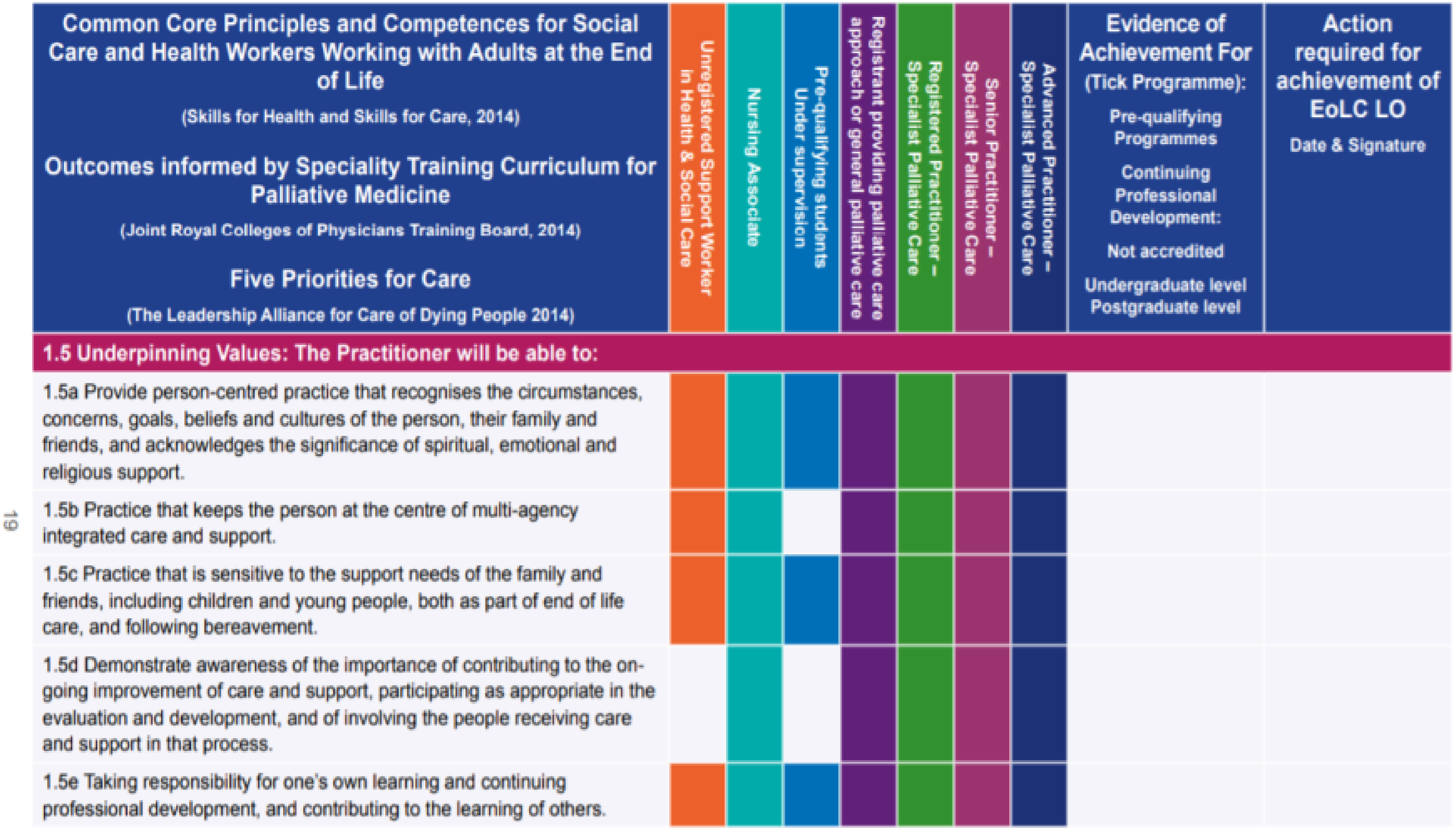
1.4 Advance Care Planning: The Practitioner will be able to:									
1.4a Demonstrate awareness and understanding of Advance Care Planning, and the times at which it would be appropriate.	■	■	■	■	■	■	■		
1.4b Demonstrate awareness and understanding of the legal status and implications of the Advance Care Planning process in accordance with the provisions of the Mental Capacity Act 2005.	■	■		■	■	■	■		
1.4c Show understanding of Informed Consent, and demonstrate the ability to give sufficient information in an appropriate manner.	■	■	■	■	■	■	■		
1.4d Use effective, sensitive communication skills when having Advance Care Planning discussions as part of on-going assessment and intervention.						■	■		
1.4e Work sensitively with families and friends to support them as the person decides upon their preferences and wishes during the Advance Care Planning process.	■	■	■	■	■	■	■		
1.4f Where appropriate, ensure that the wishes of the individual, as described in an Advance Care Planning statement, are shared (with permission) with other workers.		■		■	■	■	■		
1.4g When appropriate, know what the Advance Care Planning statement contains, and how this will impact upon a person's care and support.	■	■	■	■	■	■	■		
1.4h Define for own practice/service and provide appropriate supportive, palliative and end of life care in long term conditions in conjunction with patients and other members of the multi-professional team.				■	■	■	■		



1.4i Demonstrate knowledge of the principles of rehabilitation in progressive illness and the skills to appropriately initiate rehabilitation for patients with palliative/end of life care needs.				■	■	■	■		
1.4j Demonstrate knowledge and skills to provide optimal care for the dying patient and their family including: Recognition of the dying phase, assessment of the dying patient, assessment of required care and medications, management of symptoms in the dying phase, psychological care of the family, recognition and engagement with ethical dilemmas in the dying phase, and appropriate use of relevant/required end of life care documentation.				■	■	■	■		
1.4k Demonstrate knowledge of major cultural and religious customs which relate to delivery of palliative and end of life care, dying and bereavement.	■	■	■	■	■	■	■		
1.4l Analyse seminal and contemporary theories about bereavement including the process of grieving and adjustment to loss.			■	■	■	■	■		
1.4m Integrate knowledge and understanding of bereavement theories and services to prepare individuals for bereavement, to anticipate/recognize risk in bereavement and to support the acutely grieving person/family.				■	■	■	■		



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1.5 Underpinning Values: The Practitioner will be able to:									
1.5a Provide person-centred practice that recognises the circumstances, concerns, goals, beliefs and cultures of the person, their family and friends, and acknowledges the significance of spiritual, emotional and religious support.	■	■	■	■	■	■	■		
1.5b Practice that keeps the person at the centre of multi-agency integrated care and support.	■	■		■	■	■	■		
1.5c Practice that is sensitive to the support needs of the family and friends, including children and young people, both as part of end of life care, and following bereavement.	■	■	■	■	■	■	■		
1.5d Demonstrate awareness of the importance of contributing to the on-going improvement of care and support, participating as appropriate in the evaluation and development, and of involving the people receiving care and support in that process.		■		■	■	■	■		
1.5e Taking responsibility for one's own learning and continuing professional development, and contributing to the learning of others.	■	■	■	■	■	■	■		

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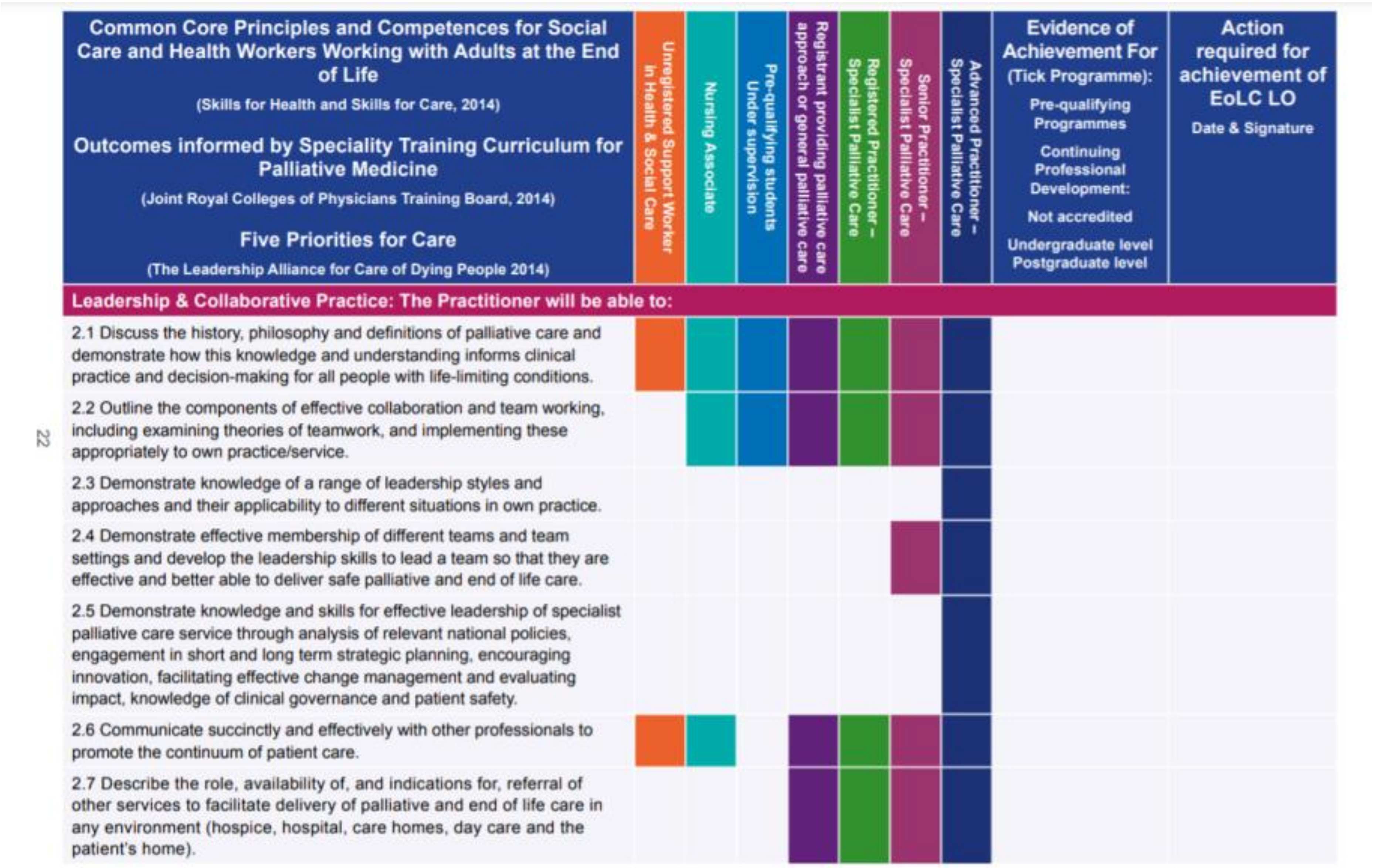
1.6 Knowledge: The Practitioner will be able to:									
1.6a Demonstrate awareness of own professional role and boundaries.	■	■	■	■	■	■	■		
1.6b Describe the roles of other practitioners you are working with.	■	■	■	■	■	■	■		
1.6c Explain professional codes of practice or conduct, including the range of common core principles, and their impact on practice.	■	■	■	■	■	■	■		
1.6d Explain relevant legislation and guidance, for example, the Mental Capacity Act (2005) and the Mental Health Act (2007) as they relate to end of life care		■		■	■	■	■		
1.6e Reflect on the impact of own beliefs on their practice	■	■	■	■	■	■	■		
1.6f Describe approaches to risk assessment, risk management, and risk taking.				■	■	■	■		
1.6g Describe approaches to, and theories of, change, loss and bereavement.		■	■	■	■	■	■		
1.6h Describe social models of care and person-centred approaches.	■	■	■	■	■	■	■		
1.6i Analyse the overall approach of person-centred, value-based practice and how this relates to ethics, law and decision-making in palliative and end of life care.				■	■	■	■		
1.6j Use an understanding of the theoretical basis for applied ethics in clinical practice, demonstrate application of these in ethical reasoning and decision-making in palliative and end of life care, with ability to justify own ethical position in relation to palliative care practice.				■	■	■	■		



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Leadership & Collaborative Practice: The Practitioner will be able to:									
2.1 Discuss the history, philosophy and definitions of palliative care and demonstrate how this knowledge and understanding informs clinical practice and decision-making for all people with life-limiting conditions.	■	■	■	■	■	■	■		
2.2 Outline the components of effective collaboration and team working, including examining theories of teamwork, and implementing these appropriately to own practice/service.		■	■	■	■	■	■		
2.3 Demonstrate knowledge of a range of leadership styles and approaches and their applicability to different situations in own practice.							■		
2.4 Demonstrate effective membership of different teams and team settings and develop the leadership skills to lead a team so that they are effective and better able to deliver safe palliative and end of life care.						■	■		
2.5 Demonstrate knowledge and skills for effective leadership of specialist palliative care service through analysis of relevant national policies, engagement in short and long term strategic planning, encouraging innovation, facilitating effective change management and evaluating impact, knowledge of clinical governance and patient safety.							■		
2.6 Communicate succinctly and effectively with other professionals to promote the continuum of patient care.	■	■		■	■	■	■		
2.7 Describe the role, availability of, and indications for, referral of other services to facilitate delivery of palliative and end of life care in any environment (hospice, hospital, care homes, day care and the patient's home).				■	■	■	■		

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Improving Quality & Developing Practice: The Practitioner will be able to:									
3.1 Work collaboratively at a strategic level with local, regional and national services/organisations to improve access to palliative/end of life services, develop palliative and end of life care practice, and lead change within practice/service delivery.							■		
3.2 Analyse national policies/guidelines for improving palliative and end of life care to inform proposals for the development of own service/organisation.						■	■		
3.3 Critically appraise own and other clinical practice to identify strategies to improve/enhance palliative and end of life care for individual patients and their carers.				■	■	■	■		
3.4 Demonstrate use of current best evidence in clinical decision making through knowledge/understanding of research methods and how to evaluate scientific publications using the principles of critical appraisal to distinguish levels of evidence and quality of evidence.			■	■	■	■	■		
3.5 Explain the processes necessary to initiate, plan, carry out and report/ present a project using sound investigative principles such as research study, systematic review, audit, service evaluation or guideline development.			■	■	■	■	■		
3.6 Contribute to research, audit, service evaluation and guideline development as part of team.	■	■		■	■	■	■		
3.7 Lead service improvement/quality improvement programmes within own service drawing on service user feedback/engagement where available/appropriate.							■		
3.8 Undertake the processes necessary to report/present a project, including research study, systematic review, audit, service improvement or guideline development for publication and/or conference presentation.							■		

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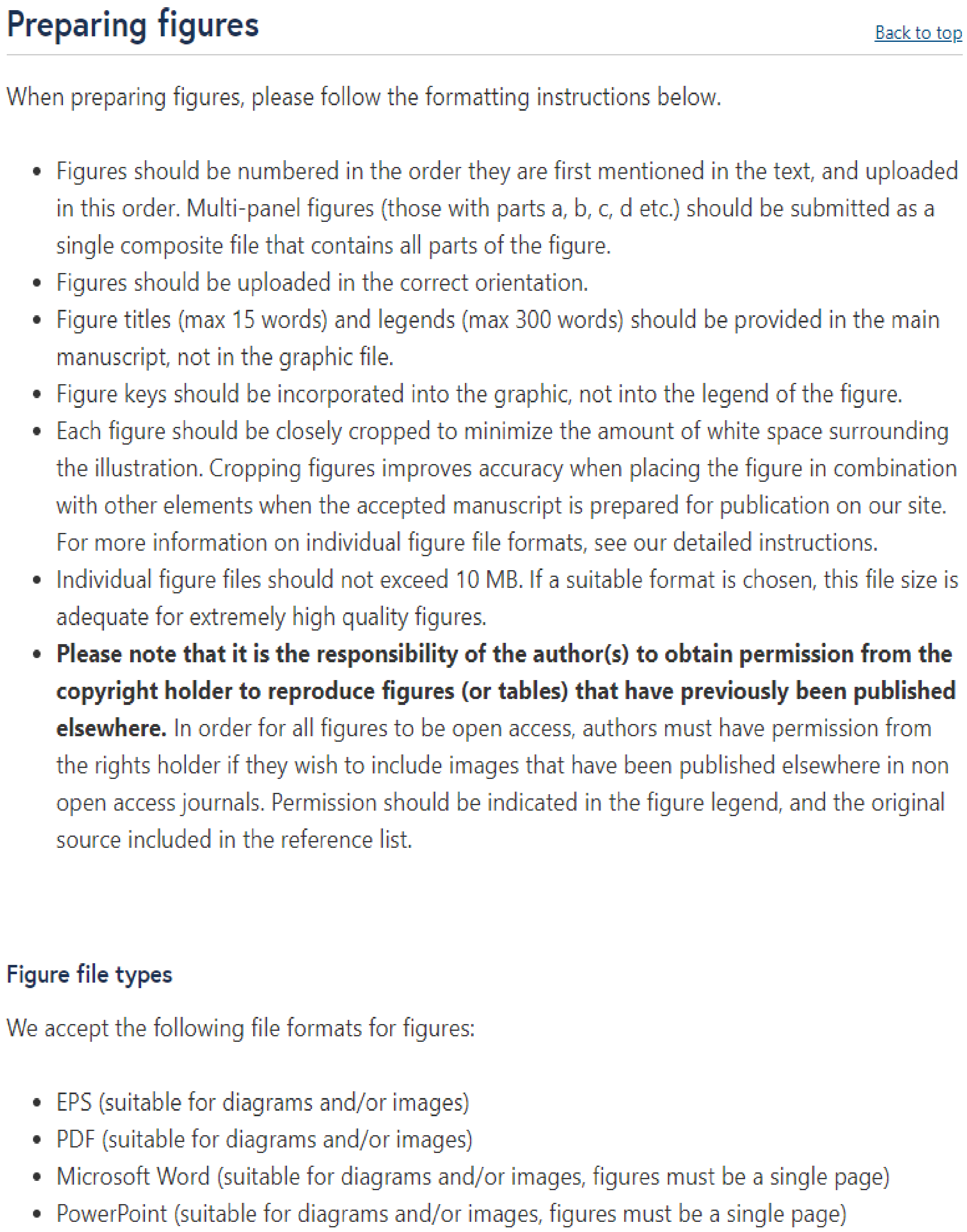
Developing Self & Others: The Practitioner will be able to:									
4.1 Demonstrate the attitudes and skills to maintain safe, evidence based and competent practice including an understanding of how to maximize own learning through continuing development or postgraduate education and supervision, and knowledge of the principles of adult and life-long learning.		■	■	■	■	■	■		
4.2 Deliver an education session to patients, families, professional colleagues at an appropriate level and using a range of teaching aids.				■	■	■	■		
4.3 Through understanding of relevant educational theories and principles, develop the ability to teach to a variety of audiences, assess quality of own teaching, plan and deliver a training programme with appropriate assessments and evaluation of learning.						■	■		
4.4 Recognise own knowledge and skills and their limitations, effect of personal loss or difficulties – being able to ask for help or hand over to others where necessary.	■	■	■	■	■	■	■		
4.5 Demonstrate support of professional colleagues, recognize the manifestations of stress on self and others, and being aware of where and when to look for support.	■	■	■	■	■	■	■		
4.6 Engage in activities that support openness about death, dying and bereavement with the public. For example Dying Matters Week.					■	■	■		

Appendix B – Author Guidelines for The Journal of BMC Palliative Care



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Back to top

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- Figures should be uploaded in the correct orientation.
- Figure titles (max 15 words) and legends (max 300 words) should be provided in the main manuscript, not in the graphic file.
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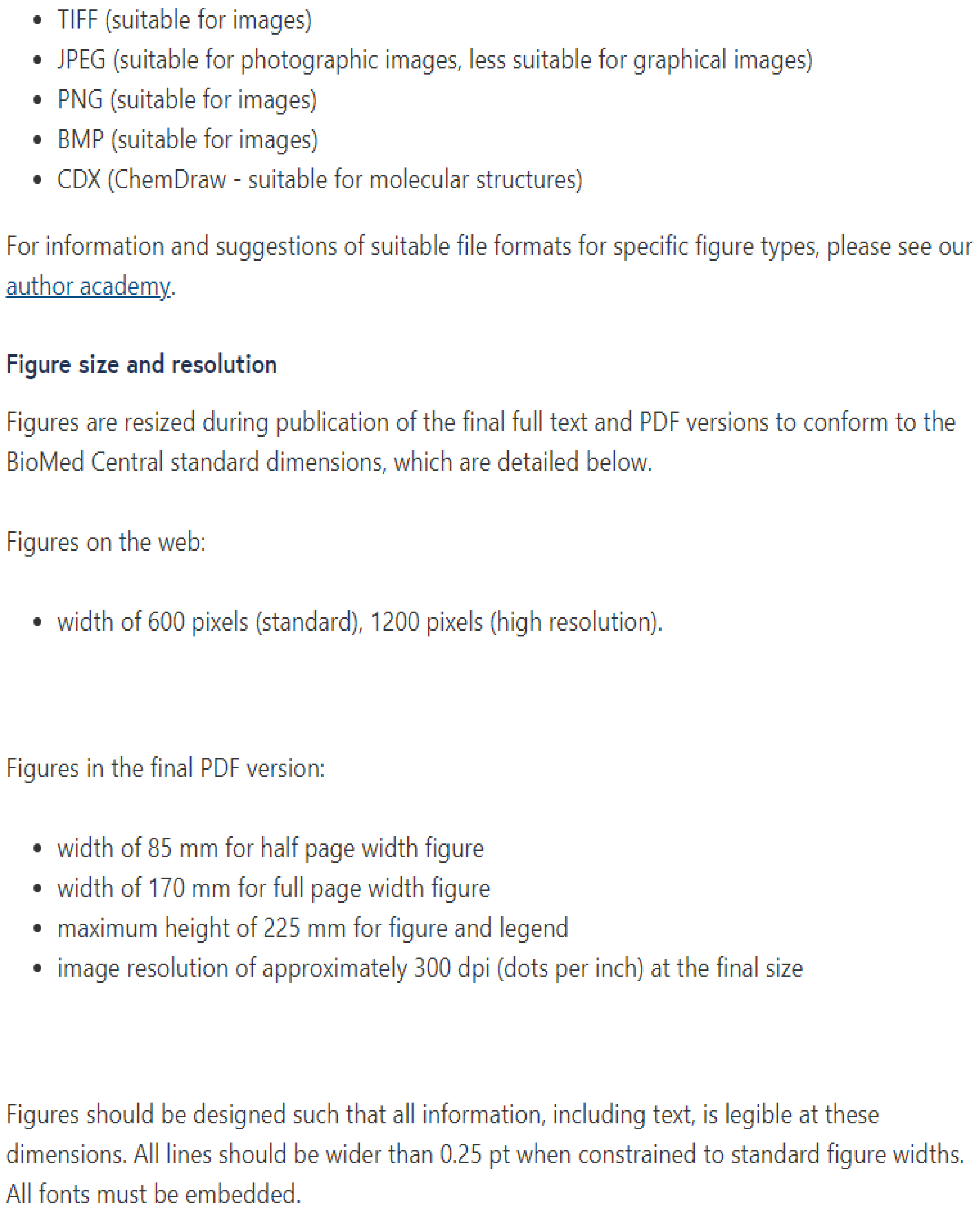

- TIFF (suitable for images)
- JPEG (suitable for photographic images, less suitable for graphical images)
- PNG (suitable for images)
- BMP (suitable for images)
- CDX (ChemDraw - suitable for molecular structures)

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- image resolution of approximately 300 dpi (dots per inch) at the final size

Figures should be designed such that all information, including text, is legible at these dimensions. All lines should be wider than 0.25 pt when constrained to standard figure widths. All fonts must be embedded.

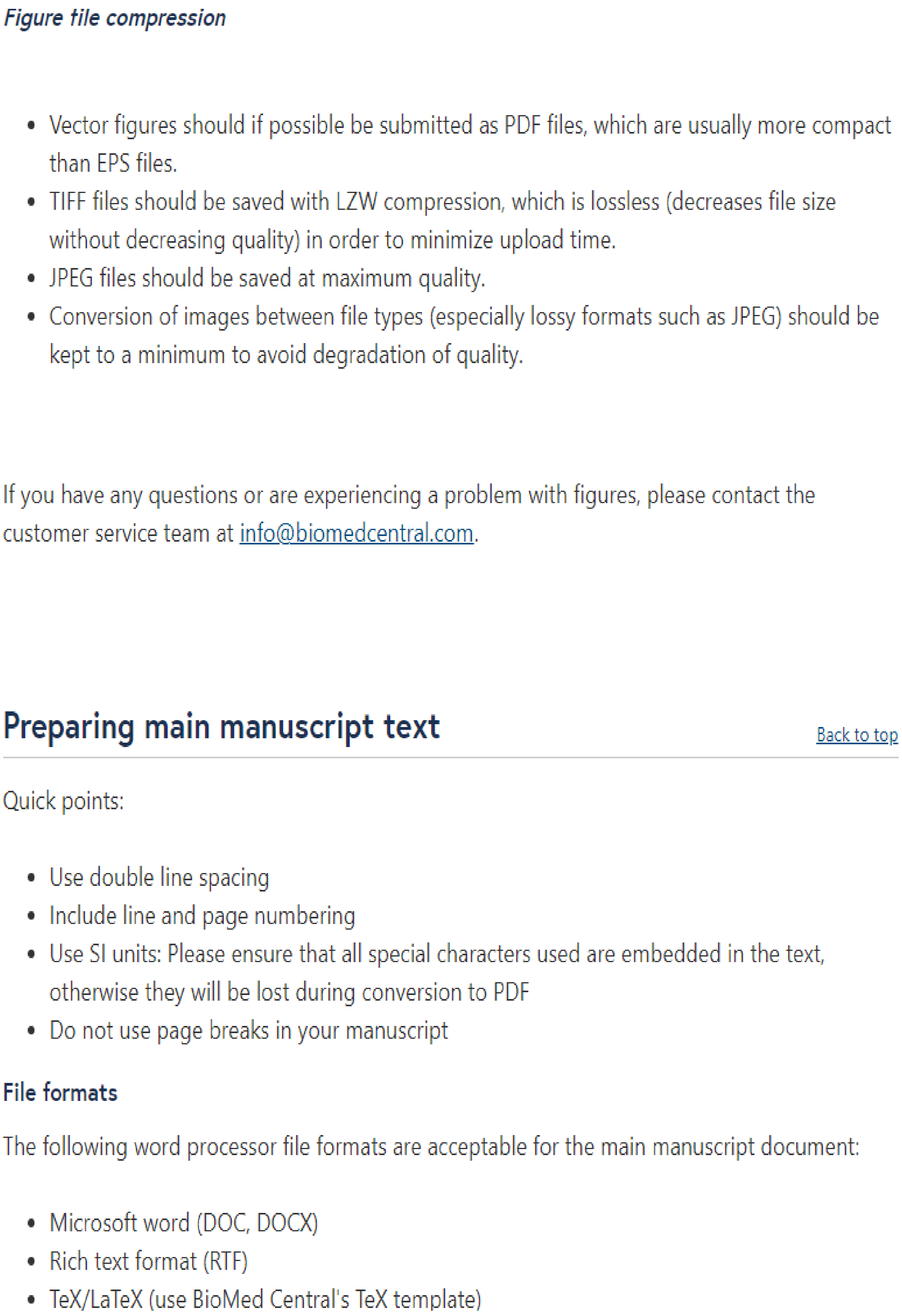


Figure file compression

- Vector figures should if possible be submitted as PDF files, which are usually more compact than EPS files.
- TIFF files should be saved with LZW compression, which is lossless (decreases file size without decreasing quality) in order to minimize upload time.
- JPEG files should be saved at maximum quality.
- Conversion of images between file types (especially lossy formats such as JPEG) should be kept to a minimum to avoid degradation of quality.

If you have any questions or are experiencing a problem with figures, please contact the customer service team at info@biomedcentral.com.

Preparing main manuscript text

Back to top

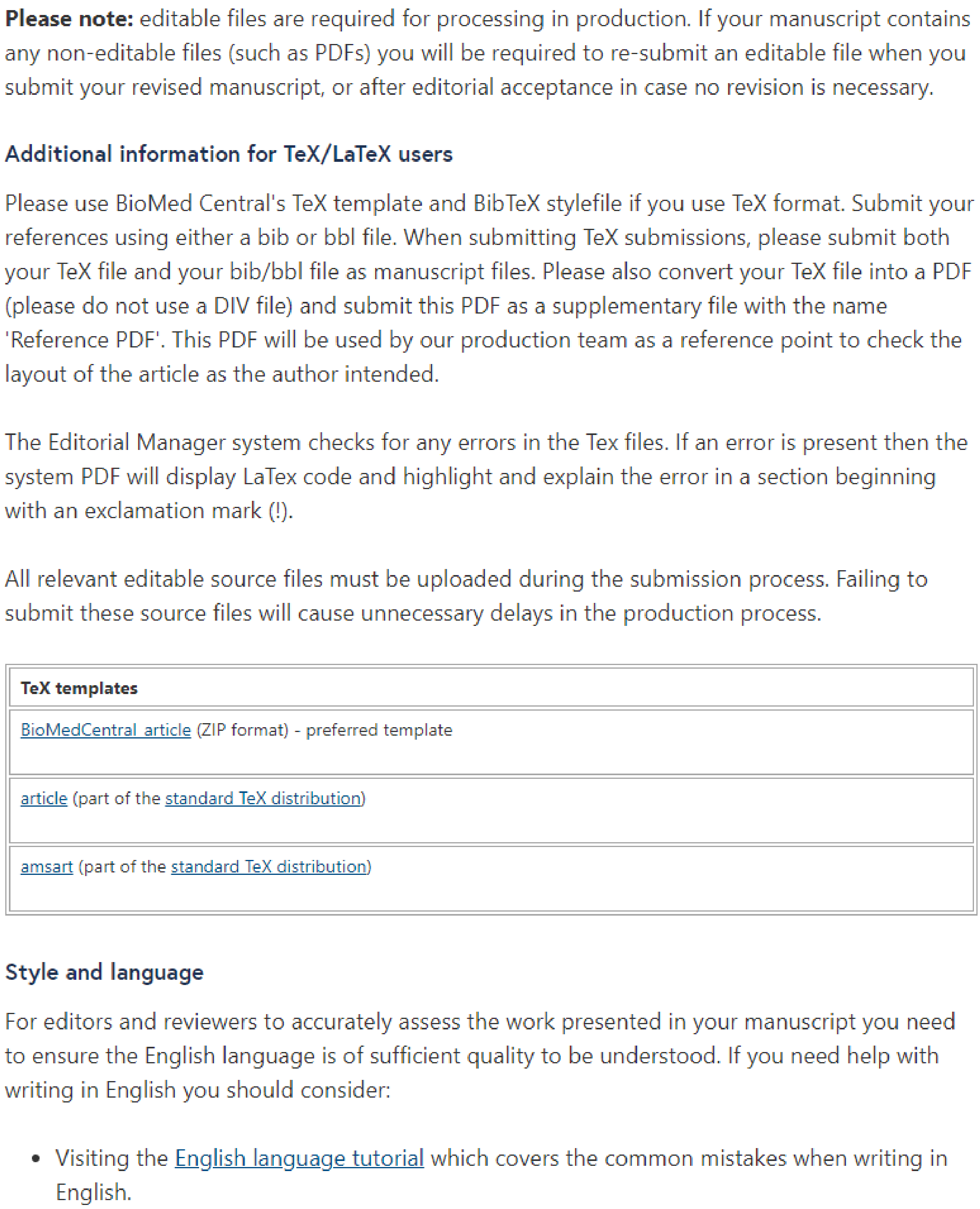
Quick points:

- Use double line spacing
- Include line and page numbering
- Use SI units: Please ensure that all special characters used are embedded in the text, otherwise they will be lost during conversion to PDF
- Do not use page breaks in your manuscript

File formats

The following word processor file formats are acceptable for the main manuscript document:

- Microsoft word (DOC, DOCX)
- Rich text format (RTF)
- TeX/LaTeX (use BioMed Central's TeX template)



Please note: editable files are required for processing in production. If your manuscript contains any non-editable files (such as PDFs) you will be required to re-submit an editable file when you submit your revised manuscript, or after editorial acceptance in case no revision is necessary.

Additional information for TeX/LaTeX users

Please use BioMed Central's TeX template and BibTeX stylefile if you use TeX format. Submit your references using either a bib or bbl file. When submitting TeX submissions, please submit both your TeX file and your bib/bbl file as manuscript files. Please also convert your TeX file into a PDF (please do not use a DIV file) and submit this PDF as a supplementary file with the name 'Reference PDF'. This PDF will be used by our production team as a reference point to check the layout of the article as the author intended.

The Editorial Manager system checks for any errors in the Tex files. If an error is present then the system PDF will display LaTex code and highlight and explain the error in a section beginning with an exclamation mark (!).

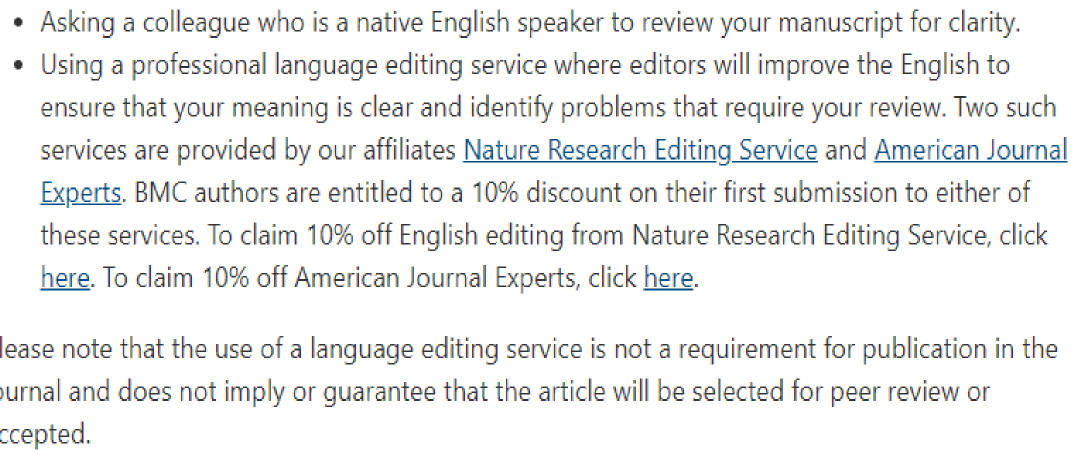
All relevant editable source files must be uploaded during the submission process. Failing to submit these source files will cause unnecessary delays in the production process.

TeX templates
BioMedCentral_article (ZIP format) - preferred template
article (part of the standard TeX distribution)
amsart (part of the standard TeX distribution)

Style and language

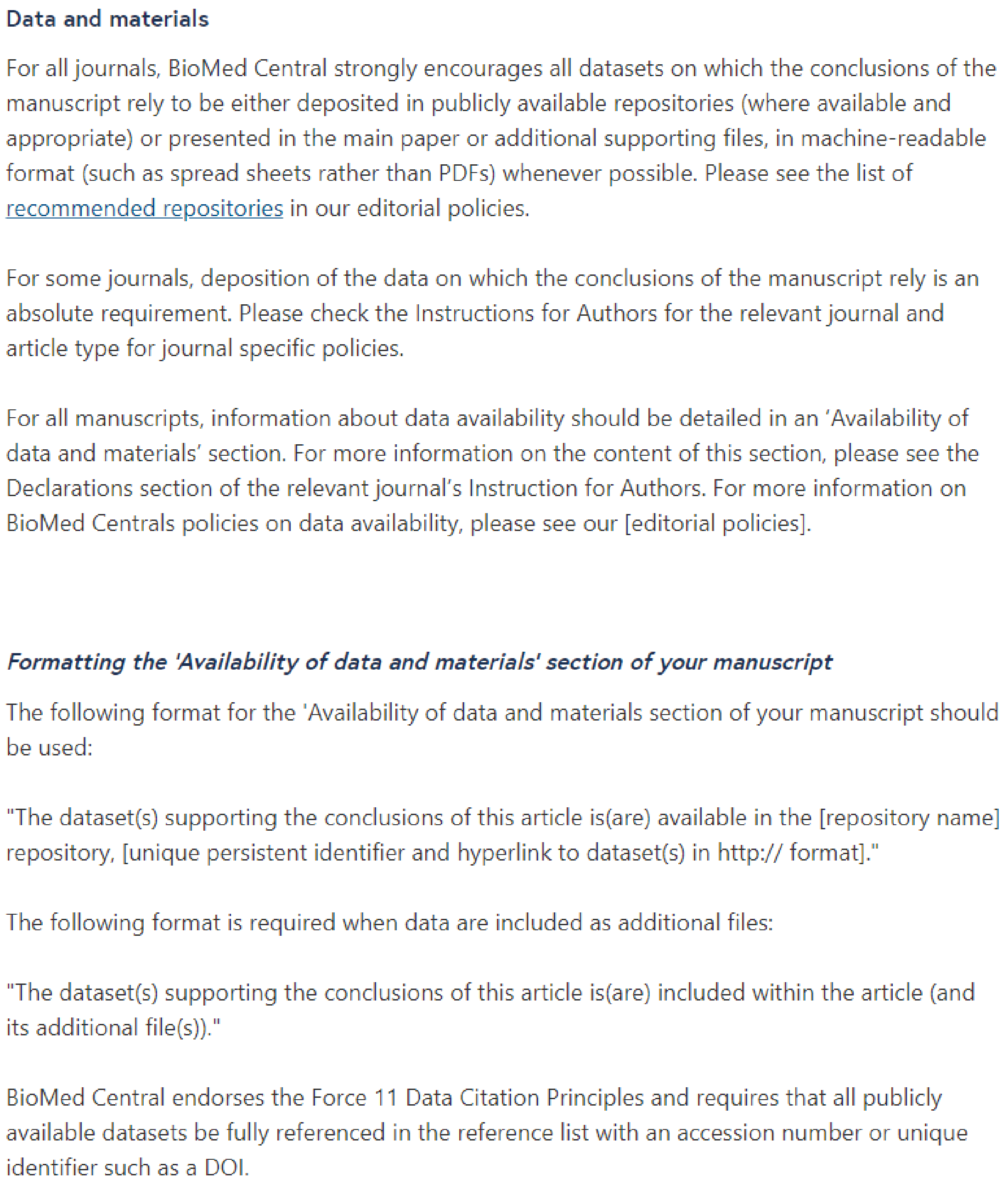
For editors and reviewers to accurately assess the work presented in your manuscript you need to ensure the English language is of sufficient quality to be understood. If you need help with writing in English you should consider:

- Visiting the English language tutorial which covers the common mistakes when writing in English.



- Asking a colleague who is a native English speaker to review your manuscript for clarity.
- Using a professional language editing service where editors will improve the English to ensure that your meaning is clear and identify problems that require your review. Two such services are provided by our affiliates Nature Research Editing Service and American Journal Experts. BMC authors are entitled to a 10% discount on their first submission to either of these services. To claim 10% off English editing from Nature Research Editing Service, click here. To claim 10% off American Journal Experts, click here.

Please note that the use of a language editing service is not a requirement for publication in the journal and does not imply or guarantee that the article will be selected for peer review or accepted.



Data and materials

For all journals, BioMed Central strongly encourages all datasets on which the conclusions of the manuscript rely to be either deposited in publicly available repositories (where available and appropriate) or presented in the main paper or additional supporting files, in machine-readable format (such as spread sheets rather than PDFs) whenever possible. Please see the list of recommended repositories in our editorial policies.

For some journals, deposition of the data on which the conclusions of the manuscript rely is an absolute requirement. Please check the Instructions for Authors for the relevant journal and article type for journal specific policies.

For all manuscripts, information about data availability should be detailed in an ‘Availability of data and materials’ section. For more information on the content of this section, please see the Declarations section of the relevant journal’s Instruction for Authors. For more information on BioMed Centrals policies on data availability, please see our [editorial policies].

Formatting the 'Availability of data and materials' section of your manuscript

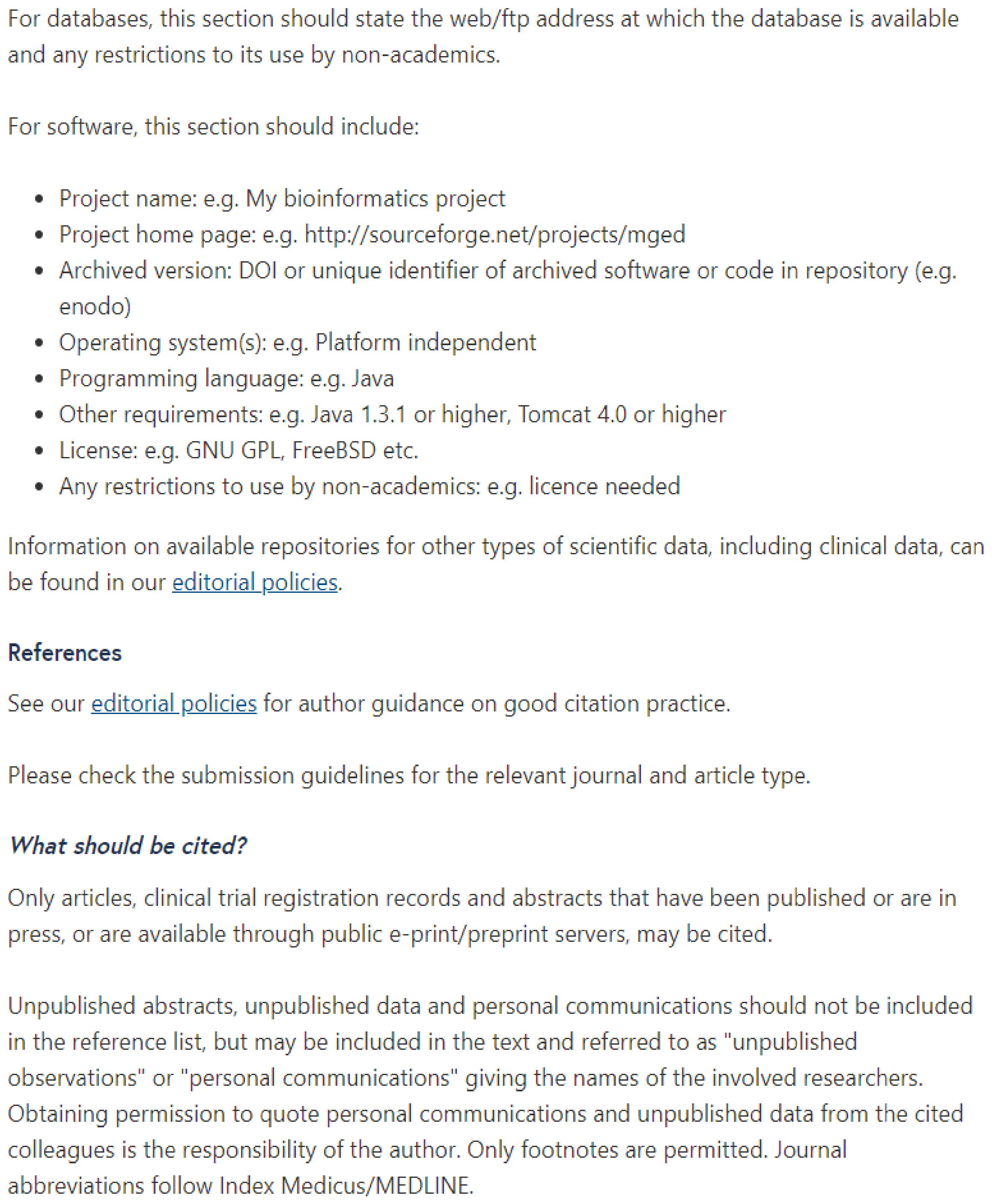
The following format for the 'Availability of data and materials section of your manuscript should be used:

"The dataset(s) supporting the conclusions of this article is(are) available in the [repository name] repository, [unique persistent identifier and hyperlink to dataset(s) in http:// format]."

The following format is required when data are included as additional files:

"The dataset(s) supporting the conclusions of this article is(are) included within the article (and its additional file(s))."

BioMed Central endorses the Force 11 Data Citation Principles and requires that all publicly available datasets be fully referenced in the reference list with an accession number or unique identifier such as a DOI.



For databases, this section should state the web/ftp address at which the database is available and any restrictions to its use by non-academics.

For software, this section should include:

- Project name: e.g. My bioinformatics project
- Project home page: e.g. http://sourceforge.net/projects/mged
- Archived version: DOI or unique identifier of archived software or code in repository (e.g. enodo)
- Operating system(s): e.g. Platform independent
- Programming language: e.g. Java
- Other requirements: e.g. Java 1.3.1 or higher, Tomcat 4.0 or higher
- License: e.g. GNU GPL, FreeBSD etc.
- Any restrictions to use by non-academics: e.g. licence needed

Information on available repositories for other types of scientific data, including clinical data, can be found in our editorial policies.

References

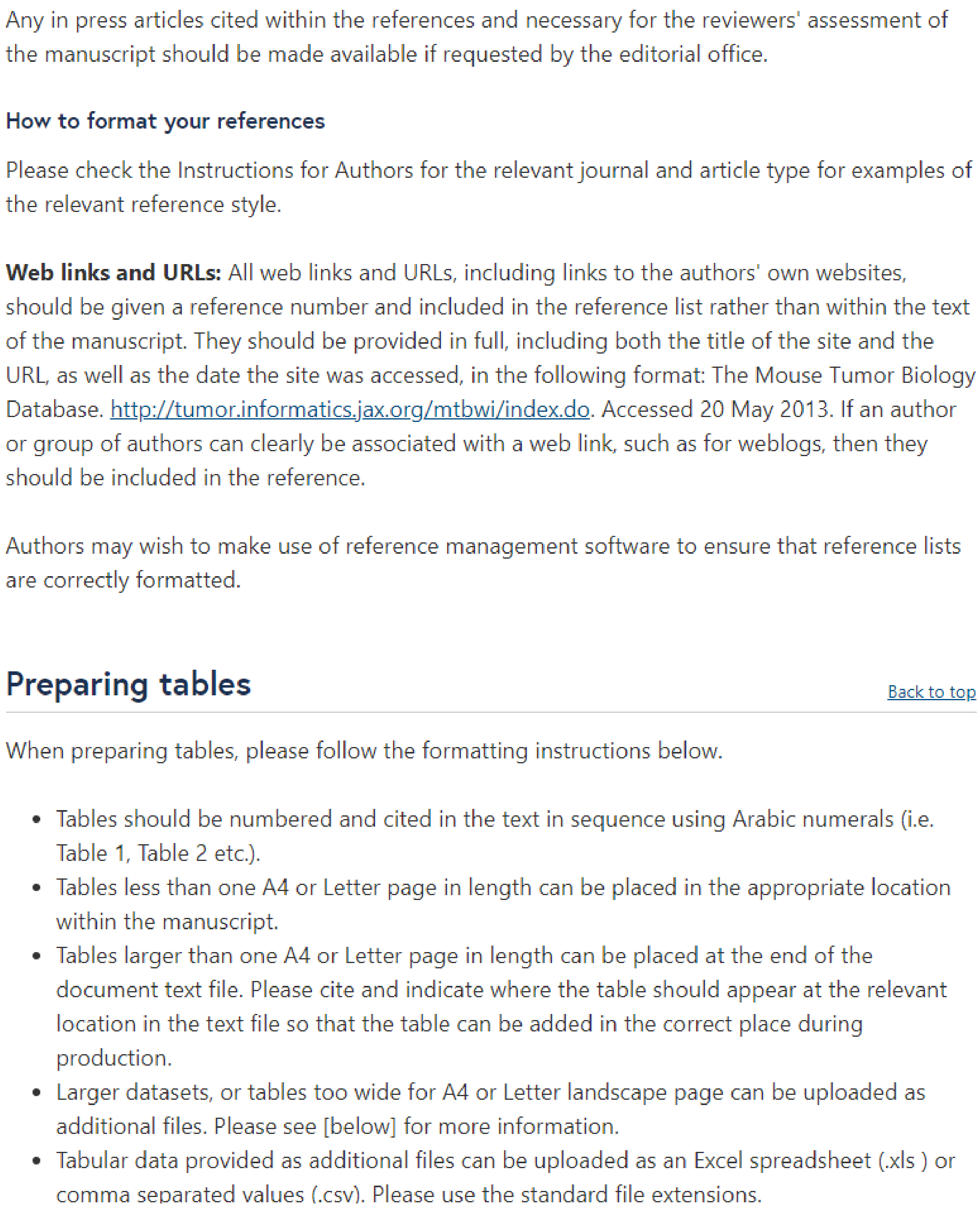
See our editorial policies for author guidance on good citation practice.

Please check the submission guidelines for the relevant journal and article type.

What should be cited?

Only articles, clinical trial registration records and abstracts that have been published or are in press, or are available through public e-print/preprint servers, may be cited.

Unpublished abstracts, unpublished data and personal communications should not be included in the reference list, but may be included in the text and referred to as "unpublished observations" or "personal communications" giving the names of the involved researchers. Obtaining permission to quote personal communications and unpublished data from the cited colleagues is the responsibility of the author. Only footnotes are permitted. Journal abbreviations follow Index Medicus/MEDLINE.



Any in press articles cited within the references and necessary for the reviewers' assessment of the manuscript should be made available if requested by the editorial office.

How to format your references

Please check the Instructions for Authors for the relevant journal and article type for examples of the relevant reference style.

Web links and URLs: All web links and URLs, including links to the authors' own websites, should be given a reference number and included in the reference list rather than within the text of the manuscript. They should be provided in full, including both the title of the site and the URL, as well as the date the site was accessed, in the following format: The Mouse Tumor Biology Database. http://tumor.informatics.jax.org/mtbwi/index.do. Accessed 20 May 2013. If an author or group of authors can clearly be associated with a web link, such as for weblogs, then they should be included in the reference.

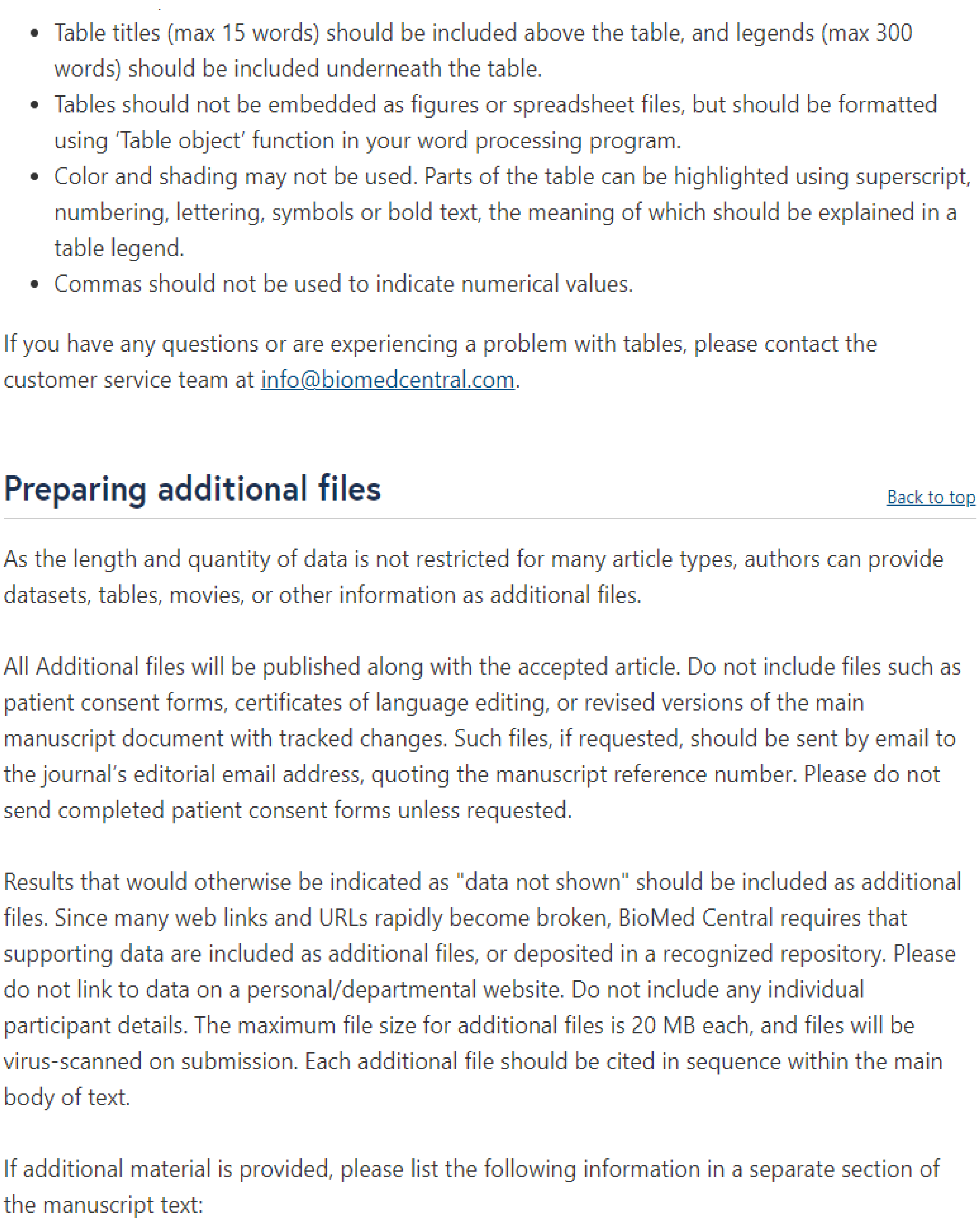
Authors may wish to make use of reference management software to ensure that reference lists are correctly formatted.

Preparing tables

Back to top

When preparing tables, please follow the formatting instructions below.

- Tables should be numbered and cited in the text in sequence using Arabic numerals (i.e. Table 1, Table 2 etc.).
- Tables less than one A4 or Letter page in length can be placed in the appropriate location within the manuscript.
- Tables larger than one A4 or Letter page in length can be placed at the end of the document text file. Please cite and indicate where the table should appear at the relevant location in the text file so that the table can be added in the correct place during production.
- Larger datasets, or tables too wide for A4 or Letter landscape page can be uploaded as additional files. Please see [below] for more information.
- Tabular data provided as additional files can be uploaded as an Excel spreadsheet (.xls) or comma separated values (.csv). Please use the standard file extensions.



- Table titles (max 15 words) should be included above the table, and legends (max 300 words) should be included underneath the table.
- Tables should not be embedded as figures or spreadsheet files, but should be formatted using 'Table object' function in your word processing program.
- Color and shading may not be used. Parts of the table can be highlighted using superscript, numbering, lettering, symbols or bold text, the meaning of which should be explained in a table legend.
- Commas should not be used to indicate numerical values.

If you have any questions or are experiencing a problem with tables, please contact the customer service team at info@biomedcentral.com.

Preparing additional files

Back to top

As the length and quantity of data is not restricted for many article types, authors can provide datasets, tables, movies, or other information as additional files.

All Additional files will be published along with the accepted article. Do not include files such as patient consent forms, certificates of language editing, or revised versions of the main manuscript document with tracked changes. Such files, if requested, should be sent by email to the journal's editorial email address, quoting the manuscript reference number. Please do not send completed patient consent forms unless requested.

Results that would otherwise be indicated as "data not shown" should be included as additional files. Since many web links and URLs rapidly become broken, BioMed Central requires that supporting data are included as additional files, or deposited in a recognized repository. Please do not link to data on a personal/departmental website. Do not include any individual participant details. The maximum file size for additional files is 20 MB each, and files will be virus-scanned on submission. Each additional file should be cited in sequence within the main body of text.

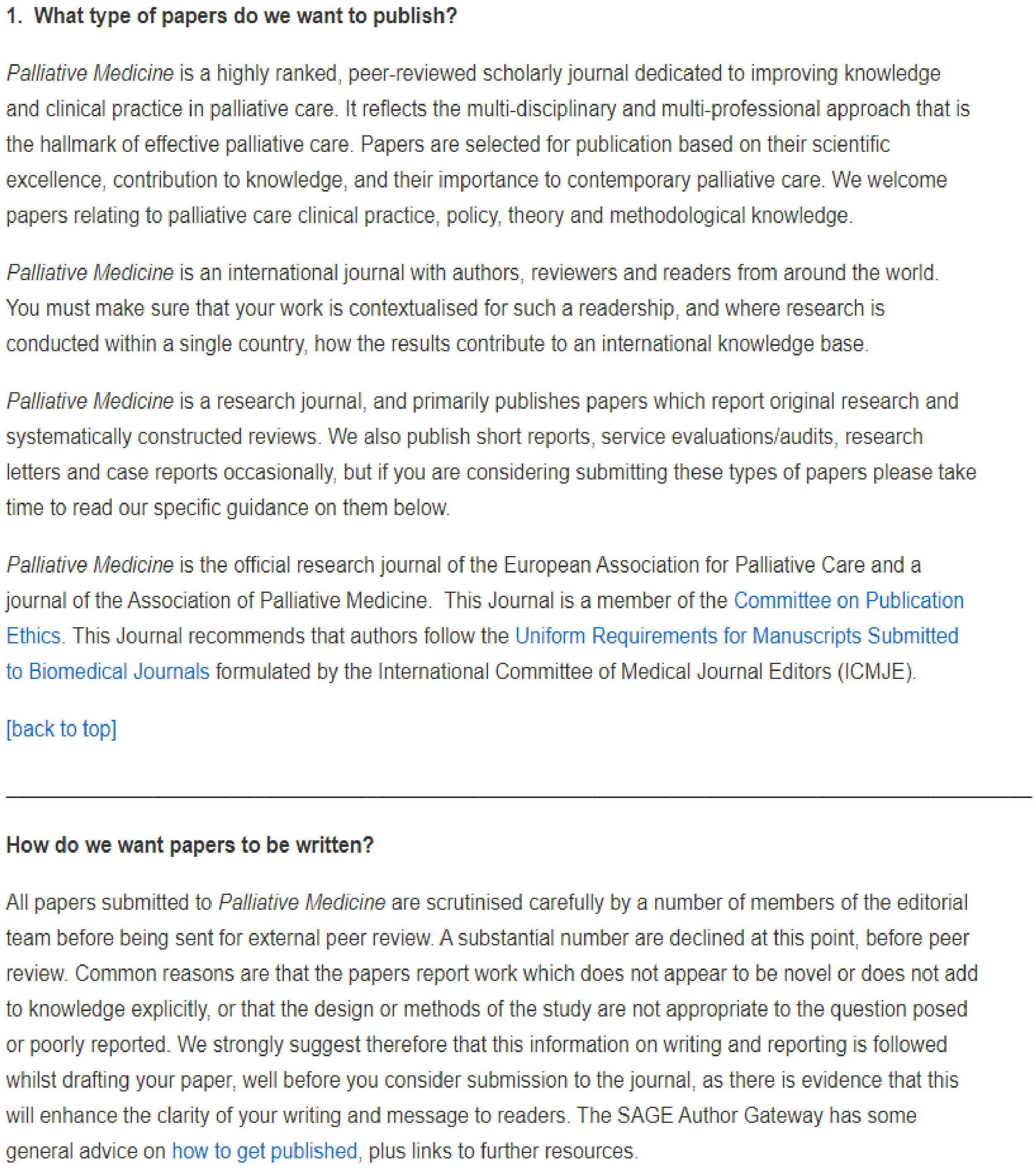
If additional material is provided, please list the following information in a separate section of the manuscript text:

- File name (e.g. Additional file 1)
- File format including the correct file extension for example .pdf, .xls, .txt, .pptx (including name and a URL of an appropriate viewer if format is unusual)
- Title of data
- Description of data

Additional files should be named "Additional file 1" and so on and should be referenced explicitly by file name within the body of the article, e.g. 'An additional movie file shows this in more detail [see Additional file 1]'.

For further guidance on how to use Additional files or recommendations on how to present particular types of data or information, please see How to use additional files.

Appendix C - Author Guidelines for The Journal of Palliative Care



1. What type of papers do we want to publish?

Palliative Medicine is a highly ranked, peer-reviewed scholarly journal dedicated to improving knowledge and clinical practice in palliative care. It reflects the multi-disciplinary and multi-professional approach that is the hallmark of effective palliative care. Papers are selected for publication based on their scientific excellence, contribution to knowledge, and their importance to contemporary palliative care. We welcome papers relating to palliative care clinical practice, policy, theory and methodological knowledge.

Palliative Medicine is an international journal with authors, reviewers and readers from around the world. You must make sure that your work is contextualised for such a readership, and where research is conducted within a single country, how the results contribute to an international knowledge base.

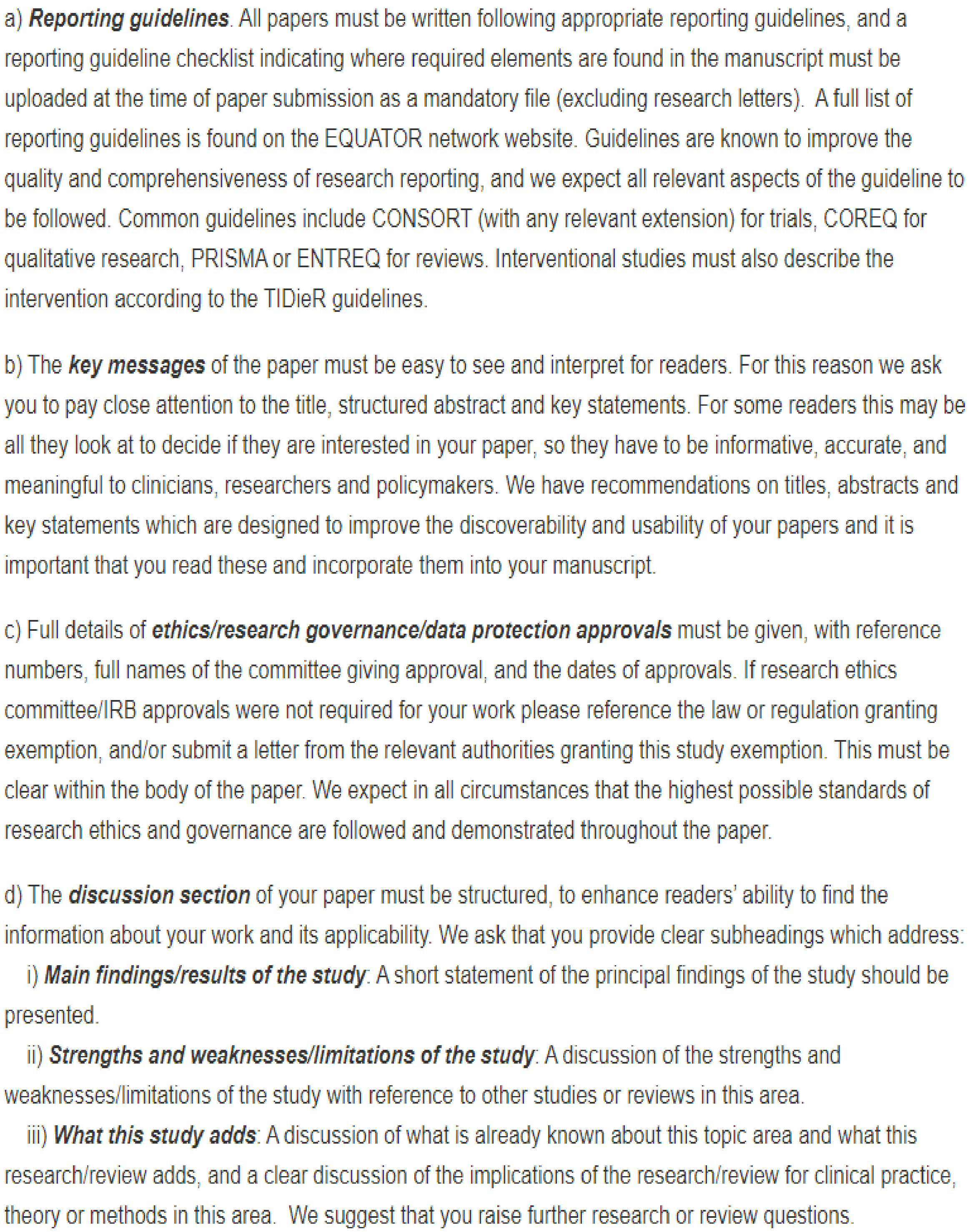
Palliative Medicine is a research journal, and primarily publishes papers which report original research and systematically constructed reviews. We also publish short reports, service evaluations/audits, research letters and case reports occasionally, but if you are considering submitting these types of papers please take time to read our specific guidance on them below.

Palliative Medicine is the official research journal of the European Association for Palliative Care and a journal of the Association of Palliative Medicine. This Journal is a member of the Committee on Publication Ethics. This Journal recommends that authors follow the Uniform Requirements for Manuscripts Submitted to Biomedical Journals formulated by the International Committee of Medical Journal Editors (ICMJE).

[back to top]

How do we want papers to be written?

All papers submitted to *Palliative Medicine* are scrutinised carefully by a number of members of the editorial team before being sent for external peer review. A substantial number are declined at this point, before peer review. Common reasons are that the papers report work which does not appear to be novel or does not add to knowledge explicitly, or that the design or methods of the study are not appropriate to the question posed or poorly reported. We strongly suggest therefore that this information on writing and reporting is followed whilst drafting your paper, well before you consider submission to the journal, as there is evidence that this will enhance the clarity of your writing and message to readers. The SAGE Author Gateway has some general advice on how to get published, plus links to further resources.



a) ***Reporting guidelines***. All papers must be written following appropriate reporting guidelines, and a reporting guideline checklist indicating where required elements are found in the manuscript must be uploaded at the time of paper submission as a mandatory file (excluding research letters). A full list of reporting guidelines is found on the EQUATOR network website. Guidelines are known to improve the quality and comprehensiveness of research reporting, and we expect all relevant aspects of the guideline to be followed. Common guidelines include CONSORT (with any relevant extension) for trials, COREQ for qualitative research, PRISMA or ENTREQ for reviews. Interventional studies must also describe the intervention according to the TIDieR guidelines.

b) The ***key messages*** of the paper must be easy to see and interpret for readers. For this reason we ask you to pay close attention to the title, structured abstract and key statements. For some readers this may be all they look at to decide if they are interested in your paper, so they have to be informative, accurate, and meaningful to clinicians, researchers and policymakers. We have recommendations on titles, abstracts and key statements which are designed to improve the discoverability and usability of your papers and it is important that you read these and incorporate them into your manuscript.

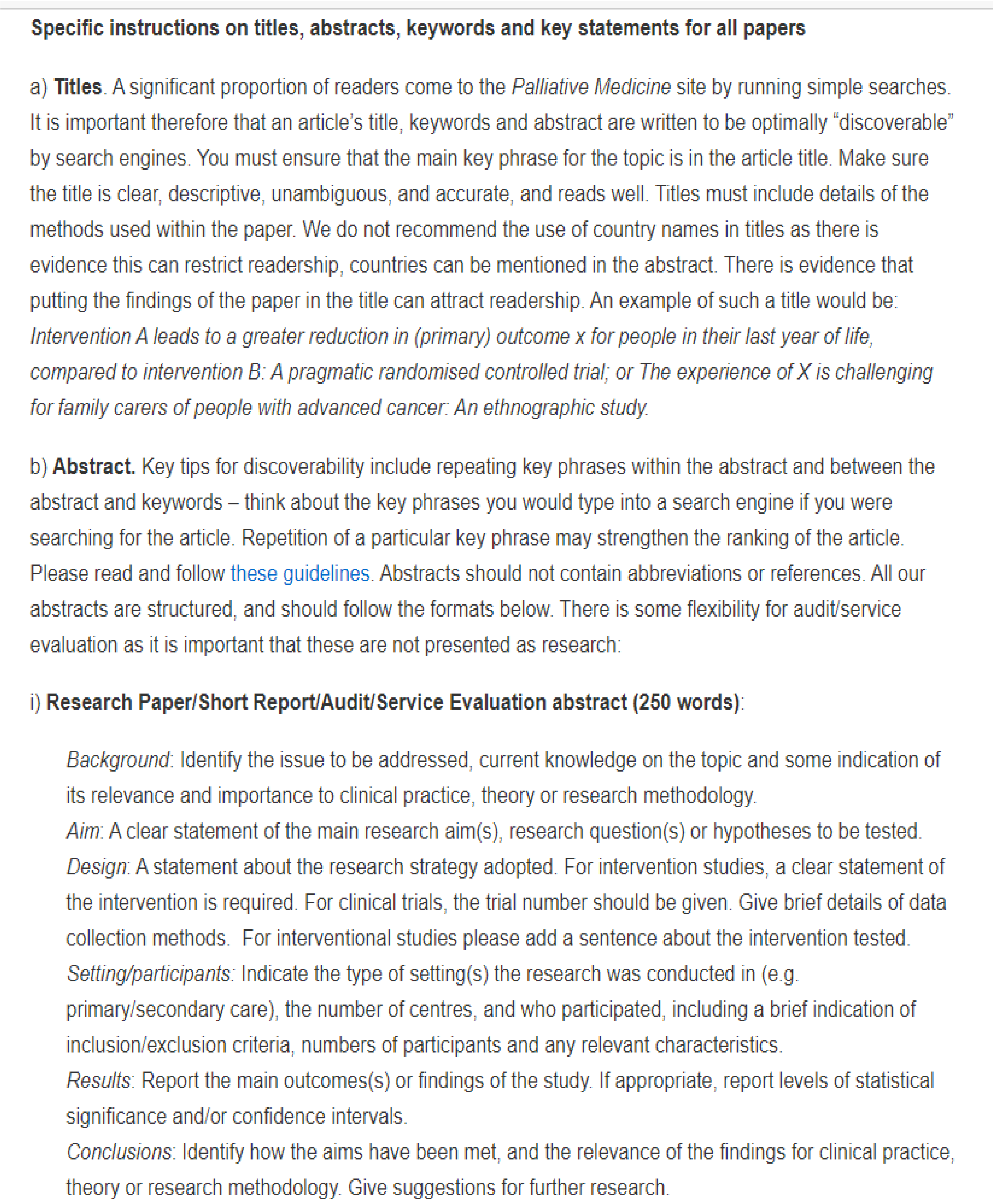
c) Full details of ***ethics/research governance/data protection approvals*** must be given, with reference numbers, full names of the committee giving approval, and the dates of approvals. If research ethics committee/IRB approvals were not required for your work please reference the law or regulation granting exemption, and/or submit a letter from the relevant authorities granting this study exemption. This must be clear within the body of the paper. We expect in all circumstances that the highest possible standards of research ethics and governance are followed and demonstrated throughout the paper.

d) The ***discussion section*** of your paper must be structured, to enhance readers' ability to find the information about your work and its applicability. We ask that you provide clear subheadings which address:

i) ***Main findings/results of the study***: A short statement of the principal findings of the study should be presented.

ii) ***Strengths and weaknesses/limitations of the study***: A discussion of the strengths and weaknesses/limitations of the study with reference to other studies or reviews in this area.

iii) ***What this study adds***: A discussion of what is already known about this topic area and what this research/review adds, and a clear discussion of the implications of the research/review for clinical practice, theory or methods in this area. We suggest that you raise further research or review questions.



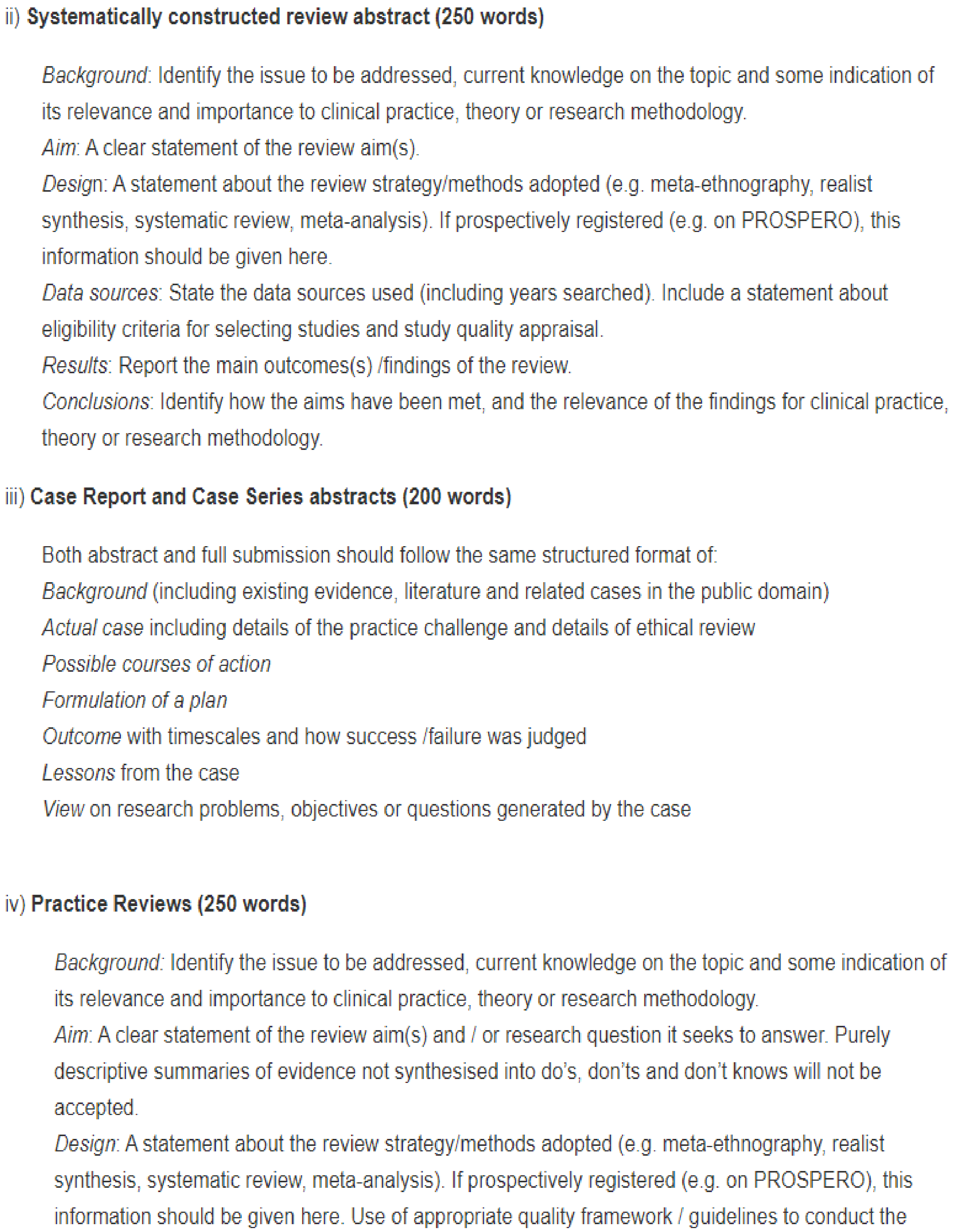
Specific instructions on titles, abstracts, keywords and key statements for all papers

a) **Titles**. A significant proportion of readers come to the *Palliative Medicine* site by running simple searches. It is important therefore that an article's title, keywords and abstract are written to be optimally "discoverable" by search engines. You must ensure that the main key phrase for the topic is in the article title. Make sure the title is clear, descriptive, unambiguous, and accurate, and reads well. Titles must include details of the methods used within the paper. We do not recommend the use of country names in titles as there is evidence this can restrict readership, countries can be mentioned in the abstract. There is evidence that putting the findings of the paper in the title can attract readership. An example of such a title would be: *Intervention A leads to a greater reduction in (primary) outcome x for people in their last year of life, compared to intervention B: A pragmatic randomised controlled trial; or The experience of X is challenging for family carers of people with advanced cancer: An ethnographic study.*

b) **Abstract.** Key tips for discoverability include repeating key phrases within the abstract and between the abstract and keywords – think about the key phrases you would type into a search engine if you were searching for the article. Repetition of a particular key phrase may strengthen the ranking of the article. Please read and follow these guidelines. Abstracts should not contain abbreviations or references. All our abstracts are structured, and should follow the formats below. There is some flexibility for audit/service evaluation as it is important that these are not presented as research:

i) **Research Paper/Short Report/Audit/Service Evaluation abstract (250 words)**:

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.
Aim: A clear statement of the main research aim(s), research question(s) or hypotheses to be tested.
Design: A statement about the research strategy adopted. For intervention studies, a clear statement of the intervention is required. For clinical trials, the trial number should be given. Give brief details of data collection methods. For interventional studies please add a sentence about the intervention tested.
Setting/participants: Indicate the type of setting(s) the research was conducted in (e.g. primary/secondary care), the number of centres, and who participated, including a brief indication of inclusion/exclusion criteria, numbers of participants and any relevant characteristics.
Results: Report the main outcomes(s) or findings of the study. If appropriate, report levels of statistical significance and/or confidence intervals.
Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology. Give suggestions for further research.



ii) **Systematically constructed review abstract (250 words)**

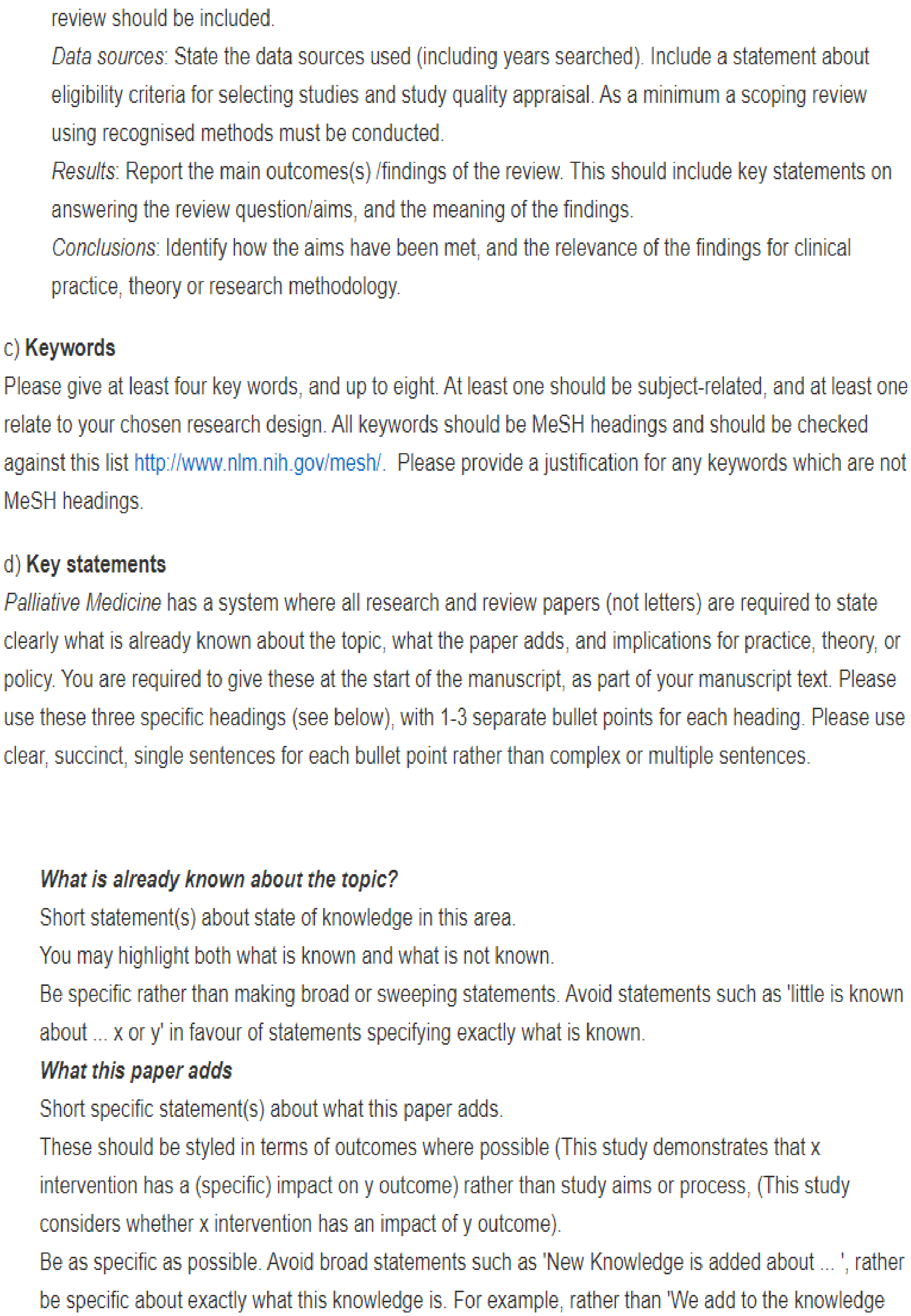
Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.
Aim: A clear statement of the review aim(s).
Design: A statement about the review strategy/methods adopted (e.g. meta-ethnography, realist synthesis, systematic review, meta-analysis). If prospectively registered (e.g. on PROSPERO), this information should be given here.
Data sources: State the data sources used (including years searched). Include a statement about eligibility criteria for selecting studies and study quality appraisal.
Results: Report the main outcomes(s) /findings of the review.
Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology.

iii) **Case Report and Case Series abstracts (200 words)**

Both abstract and full submission should follow the same structured format of:
Background (including existing evidence, literature and related cases in the public domain)
Actual case including details of the practice challenge and details of ethical review
Possible courses of action
Formulation of a plan
Outcome with timescales and how success /failure was judged
Lessons from the case
View on research problems, objectives or questions generated by the case

iv) **Practice Reviews (250 words)**

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.
Aim: A clear statement of the review aim(s) and / or research question it seeks to answer. Purely descriptive summaries of evidence not synthesised into do's, don'ts and don't knows will not be accepted.
Design: A statement about the review strategy/methods adopted (e.g. meta-ethnography, realist synthesis, systematic review, meta-analysis). If prospectively registered (e.g. on PROSPERO), this information should be given here. Use of appropriate quality framework / guidelines to conduct the



review should be included.

Data sources: State the data sources used (including years searched). Include a statement about eligibility criteria for selecting studies and study quality appraisal. As a minimum a scoping review using recognised methods must be conducted.

Results: Report the main outcomes(s) /findings of the review. This should include key statements on answering the review question/aims, and the meaning of the findings.

Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology.

c) **Keywords**

Please give at least four key words, and up to eight. At least one should be subject-related, and at least one relate to your chosen research design. All keywords should be MeSH headings and should be checked against this list http://www.nlm.nih.gov/mesh/. Please provide a justification for any keywords which are not MeSH headings.

d) **Key statements**

Palliative Medicine has a system where all research and review papers (not letters) are required to state clearly what is already known about the topic, what the paper adds, and implications for practice, theory, or policy. You are required to give these at the start of the manuscript, as part of your manuscript text. Please use these three specific headings (see below), with 1-3 separate bullet points for each heading. Please use clear, succinct, single sentences for each bullet point rather than complex or multiple sentences.

What is already known about the topic?

Short statement(s) about state of knowledge in this area.

You may highlight both what is known and what is not known.

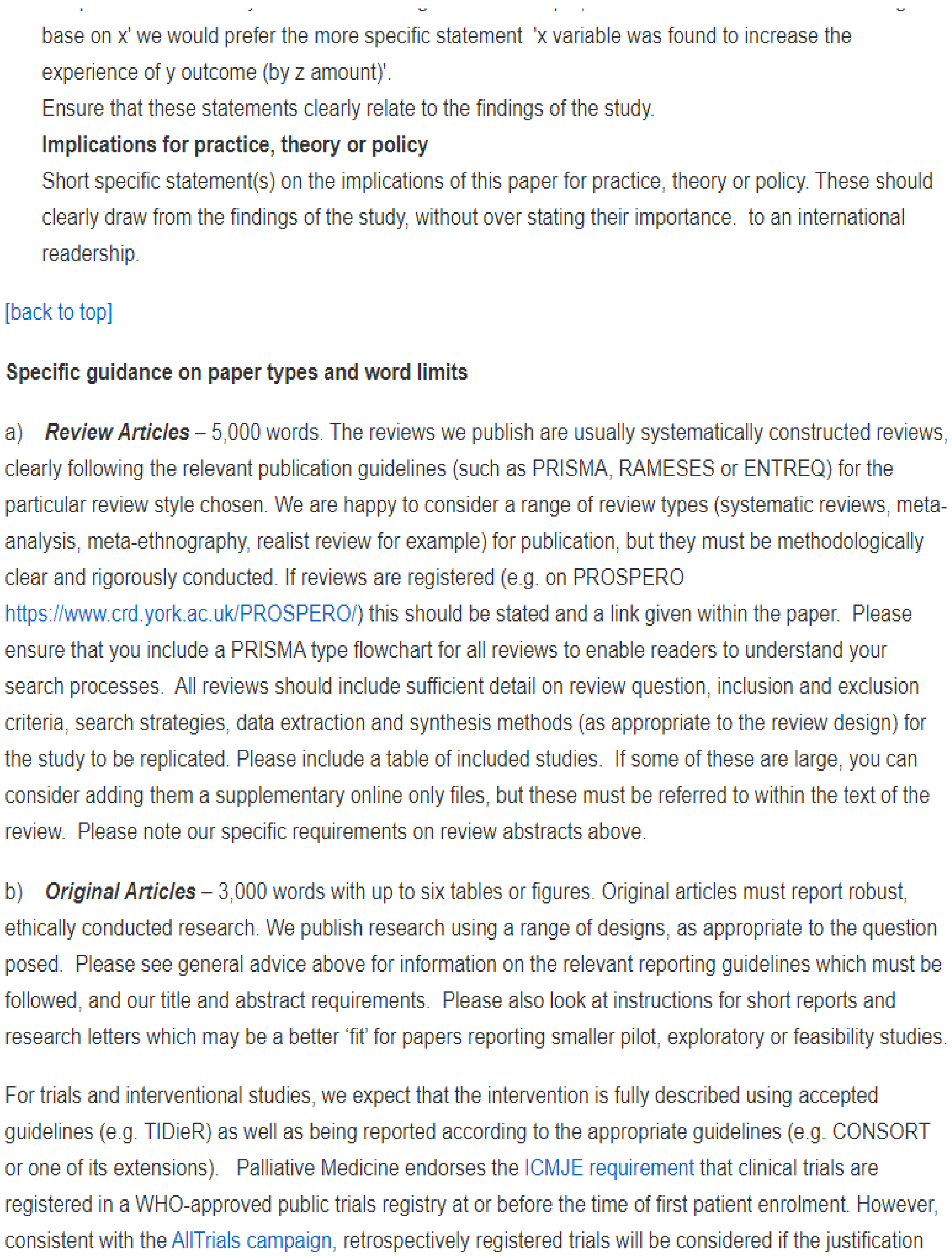
Be specific rather than making broad or sweeping statements. Avoid statements such as 'little is known about ... x or y' in favour of statements specifying exactly what is known.

What this paper adds

Short specific statement(s) about what this paper adds.

These should be styled in terms of outcomes where possible (This study demonstrates that x intervention has a (specific) impact on y outcome) rather than study aims or process, (This study considers whether x intervention has an impact of y outcome).

Be as specific as possible. Avoid broad statements such as 'New Knowledge is added about ... ', rather be specific about exactly what this knowledge is. For example, rather than 'We add to the knowledge



base on x' we would prefer the more specific statement 'x variable was found to increase the experience of y outcome (by z amount)'.

Ensure that these statements clearly relate to the findings of the study.

Implications for practice, theory or policy

Short specific statement(s) on the implications of this paper for practice, theory or policy. These should clearly draw from the findings of the study, without over stating their importance. to an international readership.

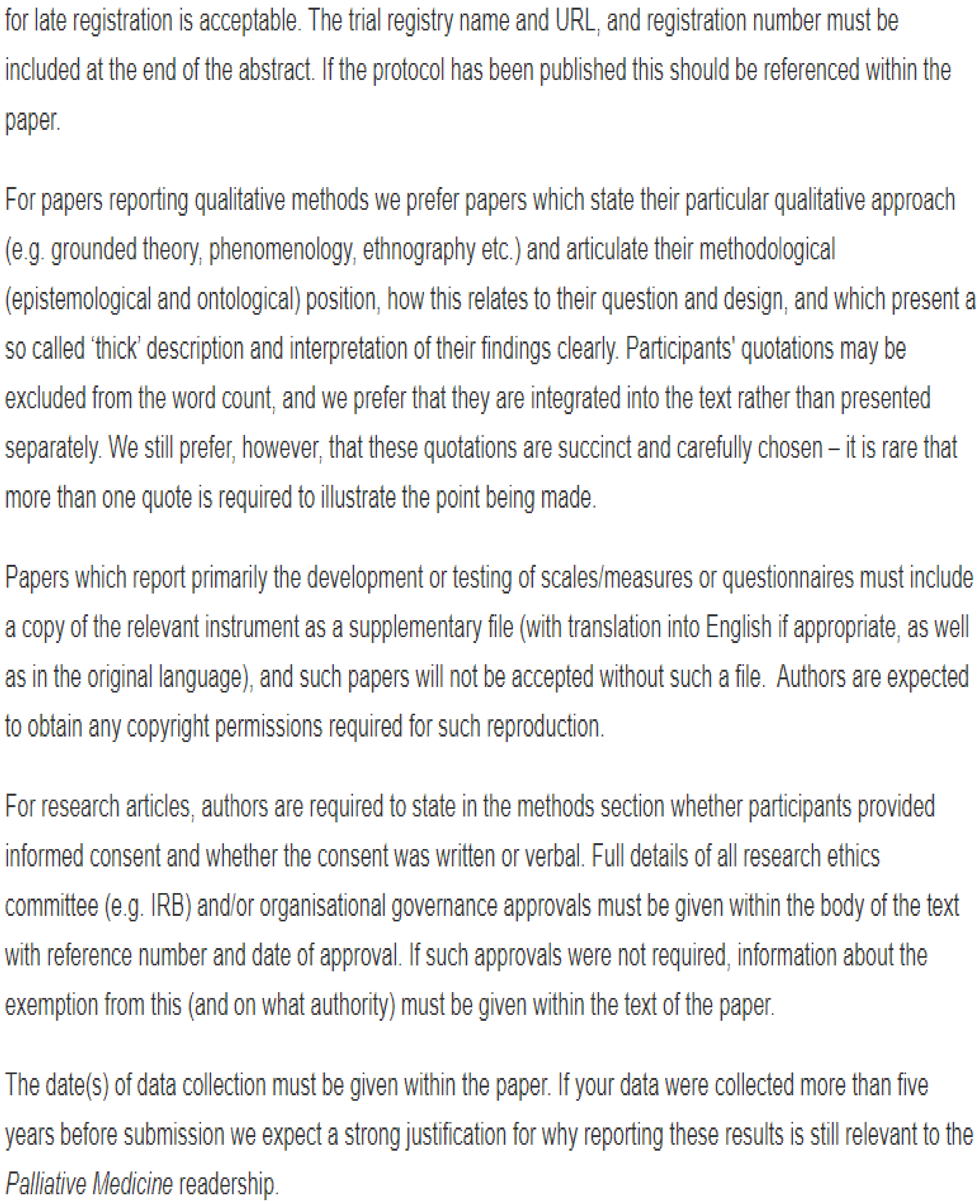
[back to top]

Specific guidance on paper types and word limits

a) ***Review Articles*** – 5,000 words. The reviews we publish are usually systematically constructed reviews, clearly following the relevant publication guidelines (such as PRISMA, RAMESES or ENTREQ) for the particular review style chosen. We are happy to consider a range of review types (systematic reviews, meta-analysis, meta-ethnography, realist review for example) for publication, but they must be methodologically clear and rigorously conducted. If reviews are registered (e.g. on PROSPERO https://www.crd.york.ac.uk/PROSPERO/) this should be stated and a link given within the paper. Please ensure that you include a PRISMA type flowchart for all reviews to enable readers to understand your search processes. All reviews should include sufficient detail on review question, inclusion and exclusion criteria, search strategies, data extraction and synthesis methods (as appropriate to the review design) for the study to be replicated. Please include a table of included studies. If some of these are large, you can consider adding them a supplementary online only files, but these must be referred to within the text of the review. Please note our specific requirements on review abstracts above.

b) ***Original Articles*** – 3,000 words with up to six tables or figures. Original articles must report robust, ethically conducted research. We publish research using a range of designs, as appropriate to the question posed. Please see general advice above for information on the relevant reporting guidelines which must be followed, and our title and abstract requirements. Please also look at instructions for short reports and research letters which may be a better 'fit' for papers reporting smaller pilot, exploratory or feasibility studies.

For trials and interventional studies, we expect that the intervention is fully described using accepted guidelines (e.g. TIDieR) as well as being reported according to the appropriate guidelines (e.g. CONSORT or one of its extensions). Palliative Medicine endorses the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment. However, consistent with the AllTrials campaign, retrospectively registered trials will be considered if the justification



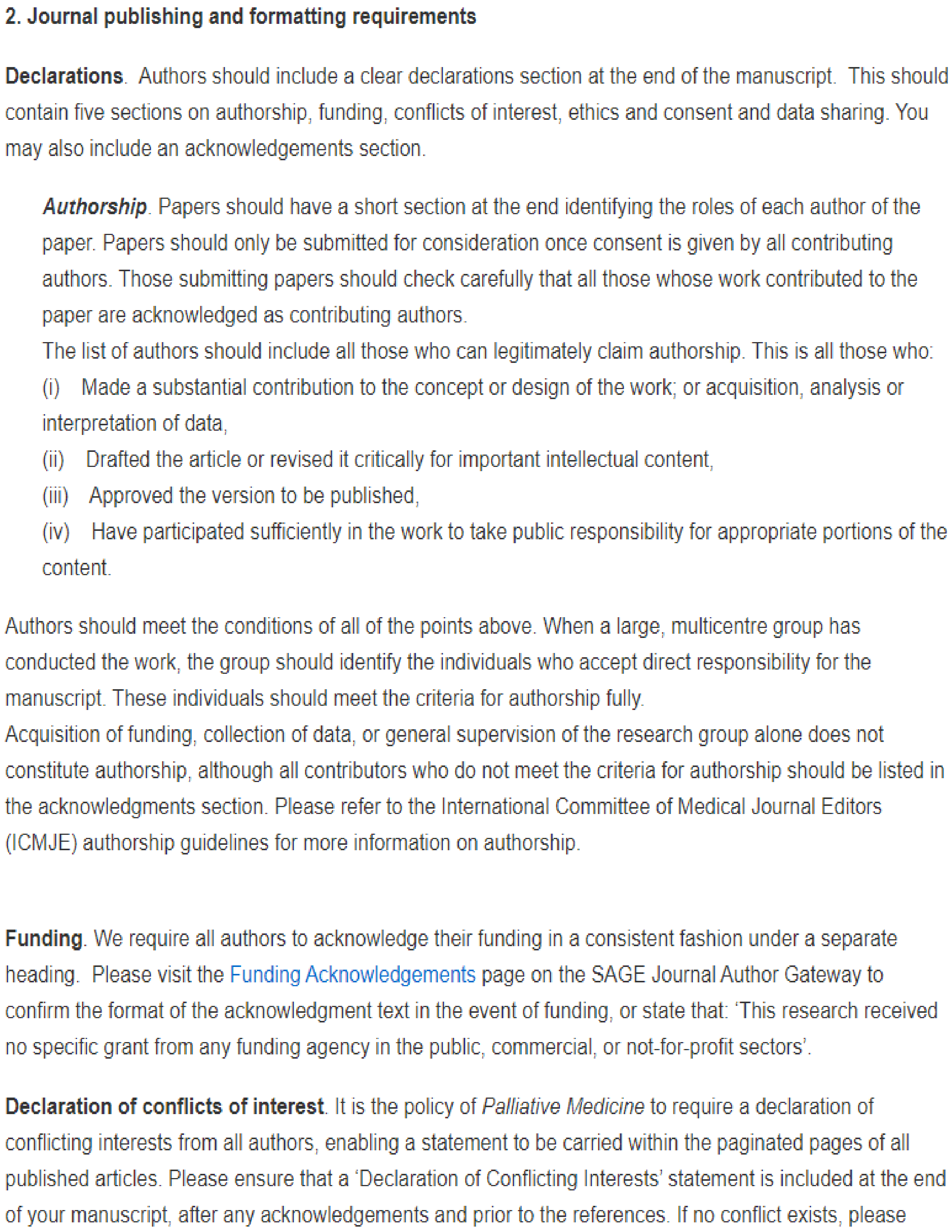
for late registration is acceptable. The trial registry name and URL, and registration number must be included at the end of the abstract. If the protocol has been published this should be referenced within the paper.

For papers reporting qualitative methods we prefer papers which state their particular qualitative approach (e.g. grounded theory, phenomenology, ethnography etc.) and articulate their methodological (epistemological and ontological) position, how this relates to their question and design, and which present a so called 'thick' description and interpretation of their findings clearly. Participants' quotations may be excluded from the word count, and we prefer that they are integrated into the text rather than presented separately. We still prefer, however, that these quotations are succinct and carefully chosen – it is rare that more than one quote is required to illustrate the point being made.

Papers which report primarily the development or testing of scales/measures or questionnaires must include a copy of the relevant instrument as a supplementary file (with translation into English if appropriate, as well as in the original language), and such papers will not be accepted without such a file. Authors are expected to obtain any copyright permissions required for such reproduction.

For research articles, authors are required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal. Full details of all research ethics committee (e.g. IRB) and/or organisational governance approvals must be given within the body of the text with reference number and date of approval. If such approvals were not required, information about the exemption from this (and on what authority) must be given within the text of the paper.

The date(s) of data collection must be given within the paper. If your data were collected more than five years before submission we expect a strong justification for why reporting these results is still relevant to the *Palliative Medicine* readership.



2. Journal publishing and formatting requirements

Declarations. Authors should include a clear declarations section at the end of the manuscript. This should contain five sections on authorship, funding, conflicts of interest, ethics and consent and data sharing. You may also include an acknowledgements section.

> ***Authorship***. Papers should have a short section at the end identifying the roles of each author of the paper. Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should check carefully that all those whose work contributed to the paper are acknowledged as contributing authors.
>
> The list of authors should include all those who can legitimately claim authorship. This is all those who:
>
> (i) Made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data,
>
> (ii) Drafted the article or revised it critically for important intellectual content,
>
> (iii) Approved the version to be published,
>
> (iv) Have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Authors should meet the conditions of all of the points above. When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should meet the criteria for authorship fully.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

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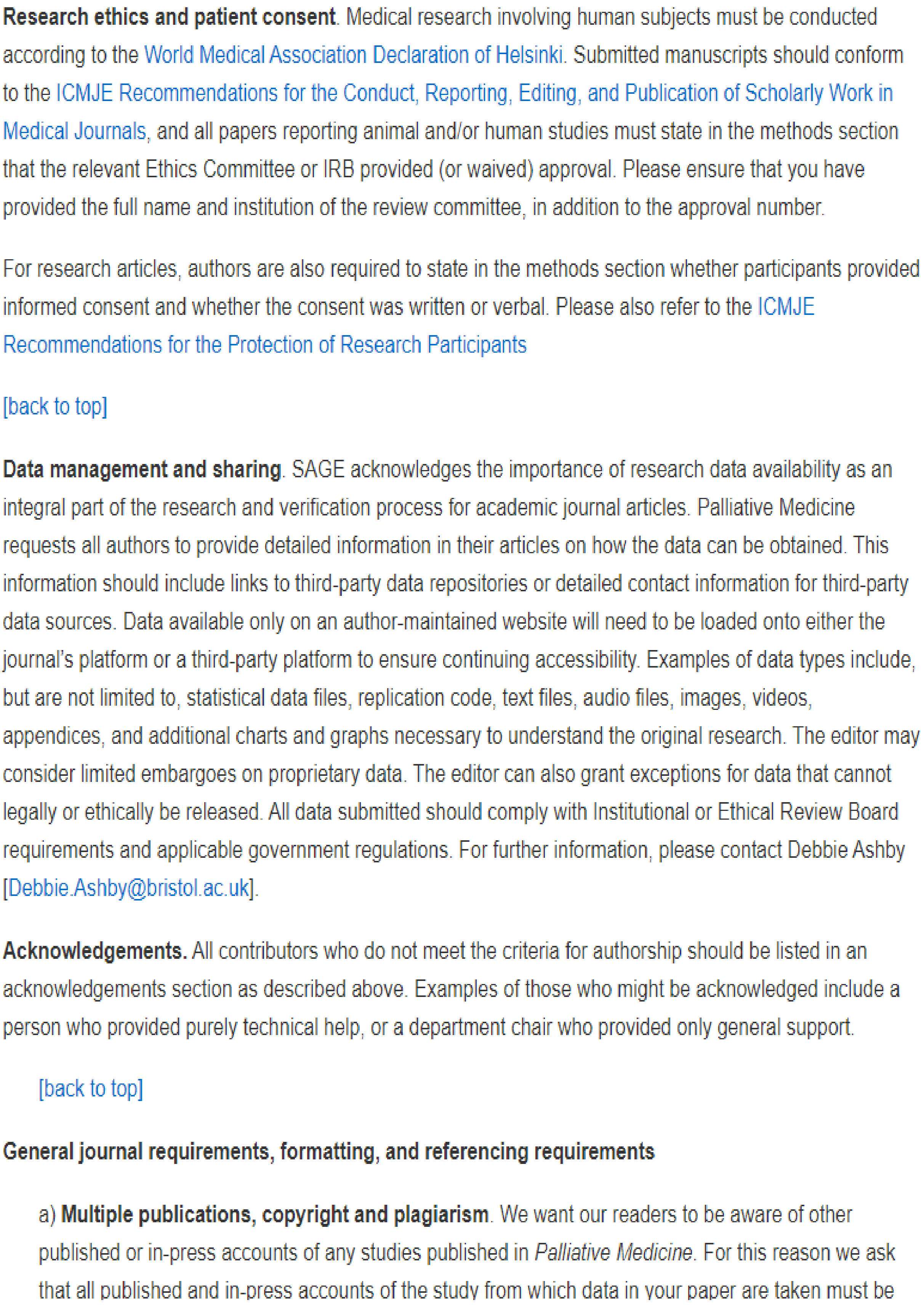

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[back to top]

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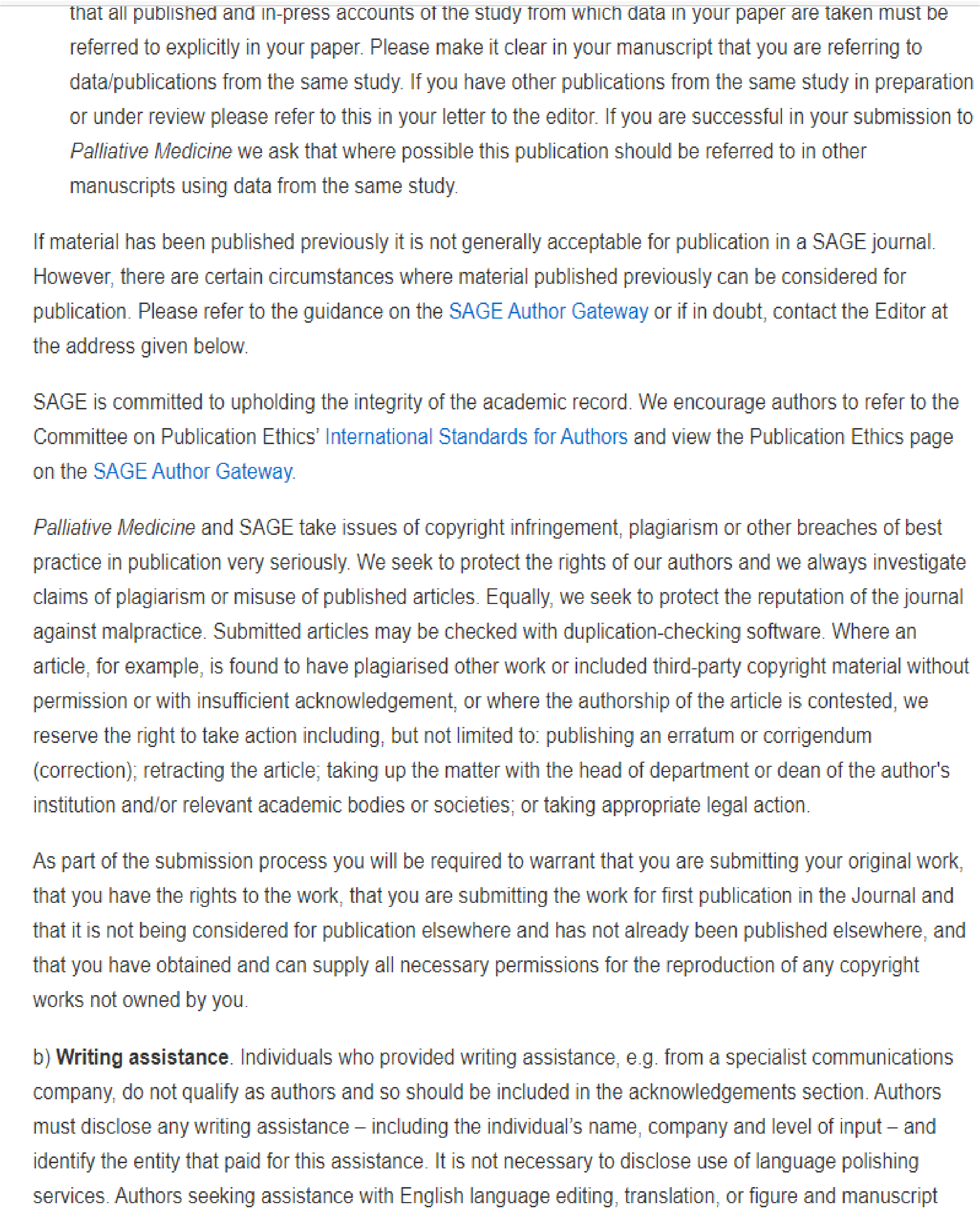

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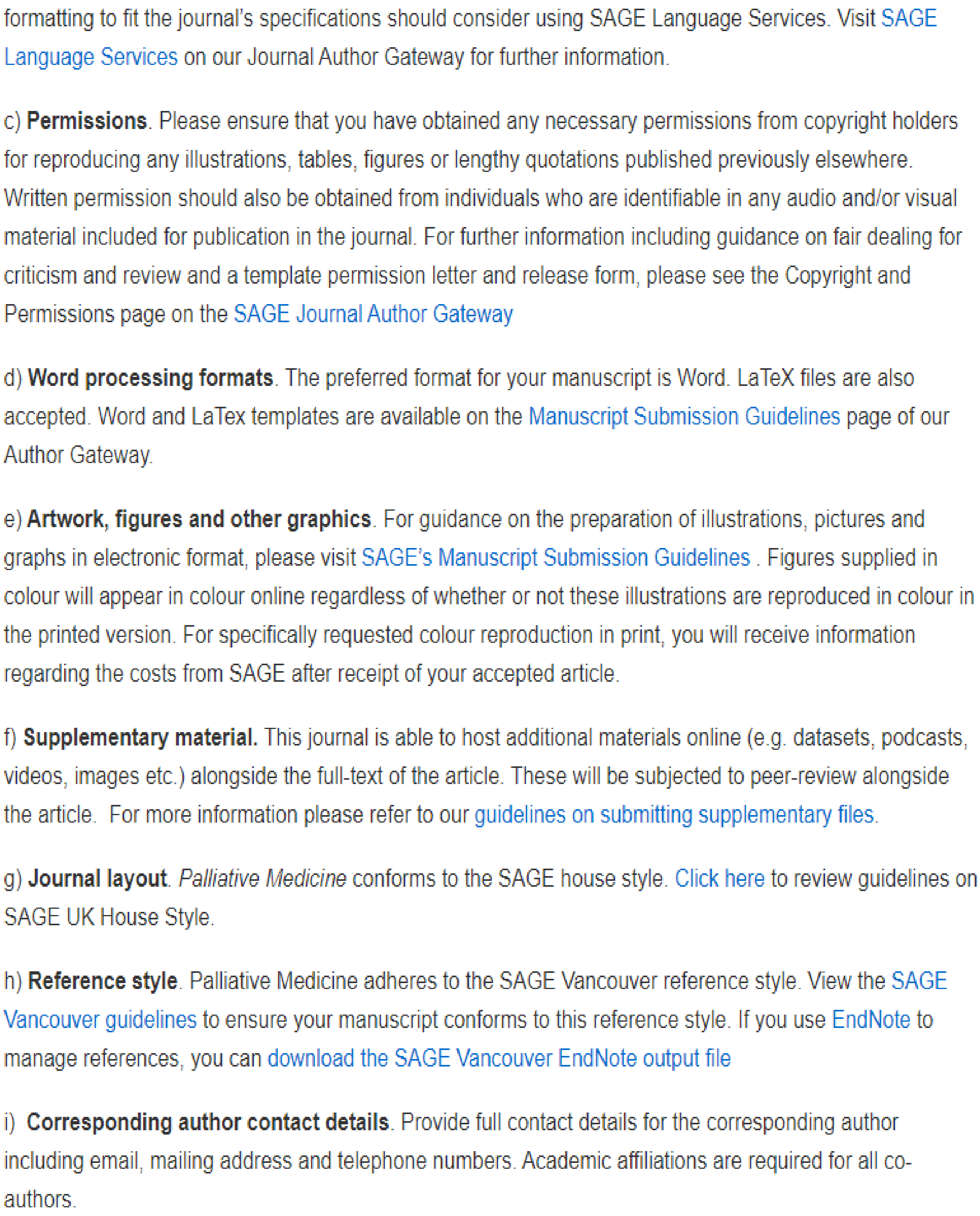

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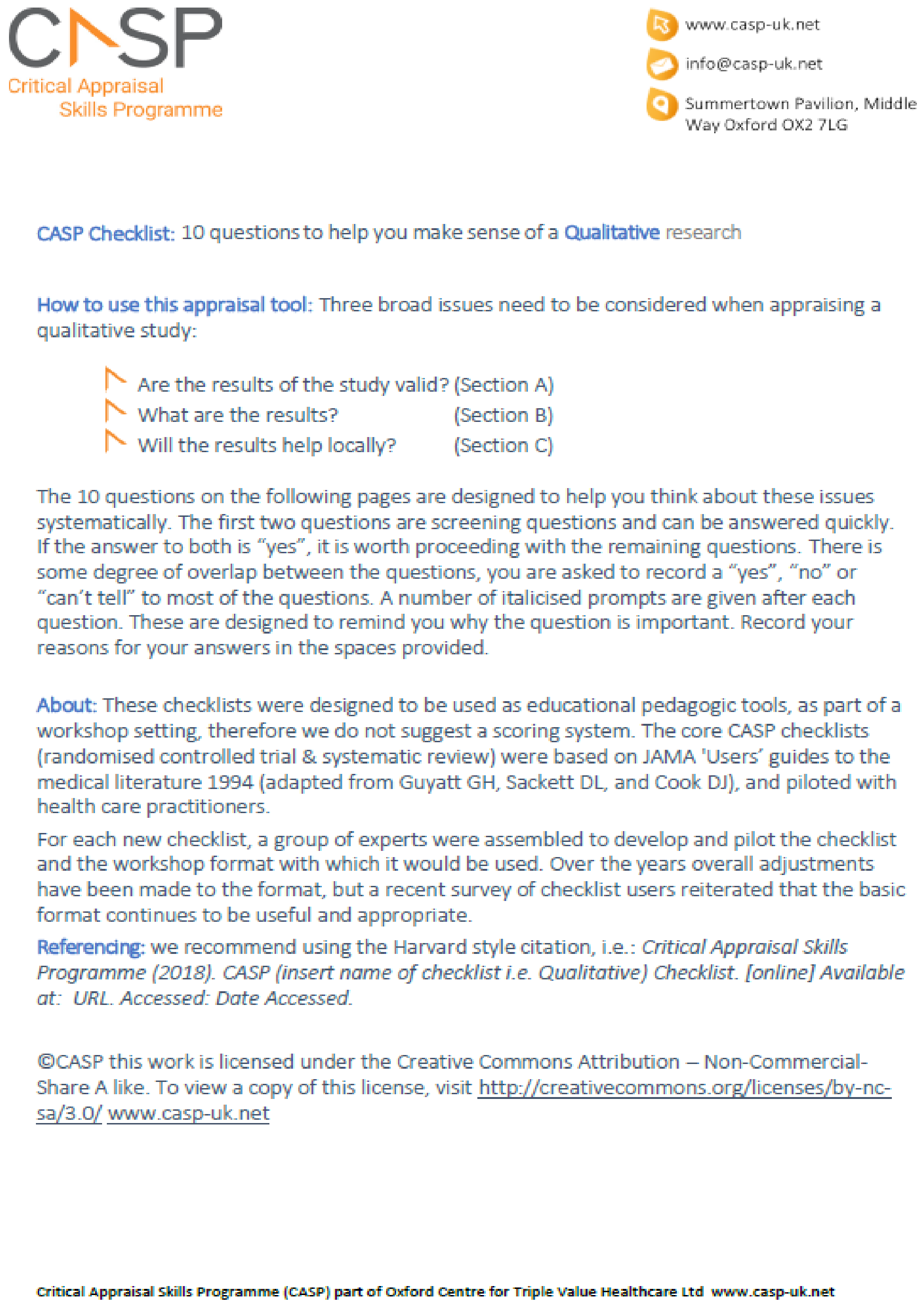
Appendix D – Example Search Strategy

PSYCHinfo:

1. “Palliative care”
2. “End-of-Life Care”
3. “Advanced Disease”
4. 1 OR 2 OR 3
5. Experience*
6. Understanding
7. Perspective*
8. View*
9. 5 OR 6 OR 7 OR 8
10. Hospital*
11. Hospice*
12. “Academic Medical”
13. Inpatient*
14. Primary
15. Secondary
16. Tertiary
17. Acute
18. Community
19. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18
20. "health?care professional*"
21. nurse*
22. “general practitioner*”
23. “Health?care worker*”
24. 20 OR 21 OR 22 OR 23
25. 4 OR 9 AND 19 AND 24
26. 4 OR 9 AND 19 AND 24 [DT 2010 – 2020]

Total papers found: **468**

Appendix E – CASP Quality Assessment Tool



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

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:

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:

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:

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

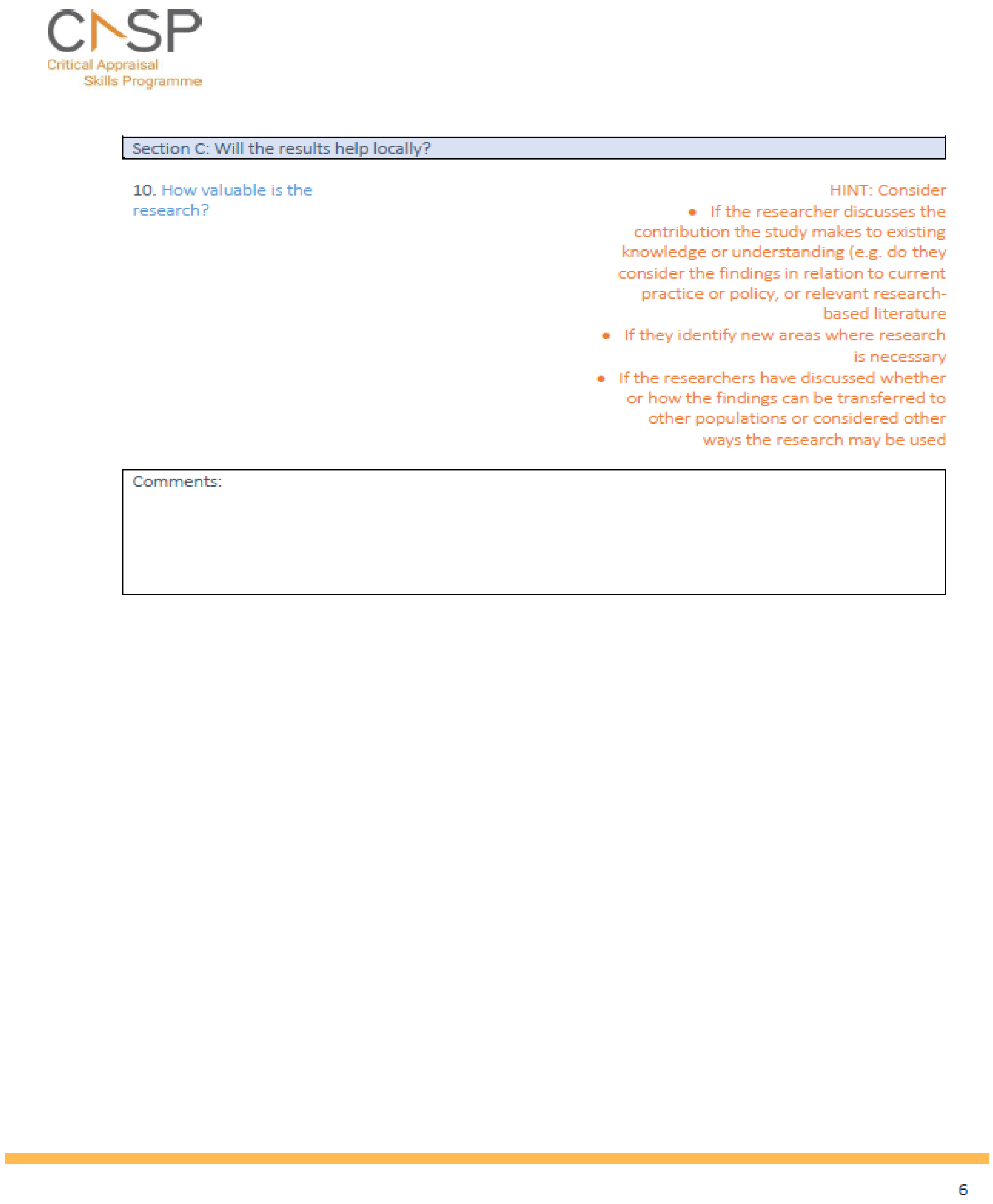
Comments:

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 F –Reflective Journal

Reflective Diary

Date	Notes
October 2018	During October 2018 was when I was due to submit my research project initial idea and supervisor preferences. This was extremely difficult as it was hard to know what project you wanted to do. Especially considering you had to do this for the next 3 years. It felt really early on within my training to be thinking about something I would be submitting at the end of the course. I knew I had a keen interest in palliative care due to personal and professional experiences so went with something I was passionate about.
November 2018	I then completed a one-page protocol about my research so that my potential supervisor. This was then shown to the supervisor's wider research team to confirm whether this would be a project that they would be interested in get involved with. At the time this felt very early to be doing such a proposal however, when reflecting back it has really helped me to get to grips with the literature when I had to write my research proposal for submission.
Early January 2019	I then had to present my research to my clinical skills group. This was very scary as I had not long developed the project and did not had lots of information to present. I had watched the third years and second years the weeks before and they were much further ahead than I was and it felt unrealistic to think that I would ever be able to get to that stage as I had only just started to think about my research proposal to send to the research committee. The presentation went well and the feedback was really positive which made me feel better that my project.
Late January 2019	Around this time, I started to meet with my allocated research team. We started to develop my idea further to see what our aims of the research would be and what methodological approach I would use. This was to help get a better idea of what to write in my proposal. At this time, I felt like I did not have any idea where to start and in meetings was being asked questions, I honestly did not know the answer too. I remember sitting there feeling like I was completely incompetent and that I did not deserve to be sitting in that room with three very competent professionals. I think this was the impostor syndrome kicking in. I left that meeting with lots of questions and things to read and understand and it just felt like a massive task. We then met a few times before the hand in of the research proposal and my supervisors provided me with feedback around my write up.
February 2019	I had started to draft up a research table including all the literature that was important this took me hours. I synthesised each paper into a manageable about so I could take it to a research meeting to show my supervisors and get their opinions on each paper. This was something that took me a long time to do but was also something I found extremely useful because it meant that I knew the literature very well and when it came to answering questions, I had the answers.

May 2019	I submitted my research proposal on this date and felt happy with the work I had produced. I thought that I would get a few comments back from the reviewers, however I felt on the whole it would be ok. I had just felt relieved that I had handed the work in and it was one less thing to worry about alongside placement and other university coursework.
June 2019 – March 2020	I received amendments for my research proposal. The committee was happy with the research but wanted more information regarding various aspects of the methodology. The questioned whether the methodology was correct for the study and asked me to provide more detail. I felt ok at this point as I knew I would have amendments to do but overall, the study would get through. I then completed the amendments and sent them back to reviewed, however from resubmitting in July until March 2020 I had to keep resubmitting my proposal as the reviewers were not happy with the amendments and kept asking for further amendments and clarification. Due to this is caused me to fall behind as I still had to submit my ethical approval and this was something that was going to be very time consuming as I have two ethical panels to go through (university and REC) and university sponsorship. Eventually I passed through the committee review and had to start looking at getting sponsorship.
April 2020	**<u>Empirical Paper</u>** I submitted to sponsorship and received approval relatively quickly allowing me to then to submit my university ethics form which I had started to populate while waiting for my sponsorship approval. I did this as I knew at this stage, I was behind and needed to get moving with my ethics and the approval process can take a number of months and I was aware that I was now into my second year of training. Once submitting my ethics approval, the world was faced with the COVID-19 pandemic and this delayed the university ethics from getting back to me for a while. I was very concern at this point that I would not be able to continue with my research project due to the fact that I was interviewing nurses in palliative care who were extremely busy due to the high death rate and pressures of COVID-19. I then had to think about how to amend my research to be compatible with social distancing guidelines and lockdown restrictions. End of April I received university ethical approval. I had to make for COVID-19 and had the amendments approved by the committee as well and the sponsorship. I then submitted my IRAS form. **<u>Systematic Review</u>** At this point I decided to start work on my systematic review. I started doing my scoping searches and then developed my review protocol and submitted this to Prospero which was approved 3 weeks later.
May 2020	**<u>Empirical Paper</u>** I received approval from the REC which allowed me to then provide all the documentation to the hospital I was recruiting from so that I could have authority to recruit. This took a long time as the study had to be registered with the SPARK team at the hospital as it may have relevance to COVID-19. I then received the approval from the trust within a few weeks allowing me to then start my recruitment. Recruitment was then arranged with the ward to start and during this time lockdown restrictions had started to be lifted and

	social contacted was allowed as long as people wore the appropriate PPE equipment and remained two meters apart etc. Going through recruitment during this time was stressful and caused me to worry about whether anyone would still be interested to take part in the study given the current climate. **Systematic Review** Alongside working on my empirical paper, I started to conduct my searches for my systematic review. I started to go through the papers excluding the ones that did not meet my inclusion criteria. I then got it down to the last 13 papers and started to go through each paper using the CASP tool. I found doing the searches extremely stressful trying to make sure I had the correct search terms was something I spent time on so to make sure that they were exactly what I needed them to be.
June 2020 – July 2020	**Empirical Paper** I then started recruitment face to face as a risk assessment was completed and lockdown was lifted allowing me to conduct the interviews the way I had initially wanted. This was a massive relief as I worried that I would have missed various information had I had to interview virtually. Each nurse that was interviewed spoke about the COVID-19 pandemic and how it had impacted on their ability to do their job. It was also interested throughout to note how they found it difficult to talk about their ways of coping with such difficult emotions and experiences they had on the ward. They found it much easier to speak about the emotions of others such as patients and family members. Even so, they were able to highlight the need for psychological support for staff. When interviewing the nurses there was two groups one group who was very open and transparent and another group who were more difficult to engage and struggle with various questions causing their interviews to be shorter in length. All nurses really appreciated the research and were interested in the findings and wanted to know how the findings may be beneficial. The team was only small and interviews took place over a number of weeks which could have allowed staff members to talk about their experiences and in turn influenced how the other interviews then when thereafter. This is something to bear in mind for limitations of the study. **Systematic Review** I also started the beginning of my write up for my systematic review populating what I had done so far. I found the searches incredibly difficult as I had never done a systematic review before however when writing this up it helped me to get my head around the searches, I had done so I felt comfortable redoing them closer to submission.

August 2020 – December 2020	**Empirical Paper** Once the interviews had been carried out, I spent time then transcribing and started the analysis. During the transcription process I was able to familiarise myself with each interview, this was extremely time consuming so I was only able to transcribe some of the interviews myself. I did feel that the interviews I transcribed myself allowed me to have a deeper insight and helped me to develop my initial notes. I went through each interview and jotted down conceptual, descriptive and linguistic themes. This I found difficult at first because I found that I often wanted to start adding too much of my interpretation and in doing this took more time coding and making draft notes separate for anything I felt was my interpretation. I then developed my emergent themes and found that I wanted to have minimal emergent themes, however after seeking some guidance realised the more information the better even if it did look overwhelming at this point. I again went through each transcript individually giving space between starting one transcript and finishing another to prevent myself from looking for themes across the transcripts. I used supervision to help me to notice when I was starting to look across transcripts to prevent any investigator bias. Eventually I then had my emergent themes. Getting to this stage felt like a life time and was a lot more time consuming than I had anticipated. I realised at this point there was a software called NVivo that could have helped with process but felt that it was too late to start learning and using this software, so I continued with the analysis manually. **Systematic Review** Systematic review analysis was completed during this time. I went through each paper results/findings section to line-by-line code each paper. This felt time consuming because at this point, I was also starting my empirical paper analysis and often found myself getting confused. I then separated my time better between empirical and systematic review work helping me to decompartmentalise the two papers. I was not sure whether to do this by hand or to use a computer software when trying to do my analysis. I used Excel in the end as it allowed me to play around with the data better and save it safely. I saved the emergent themes for each paper and started to group them looking for descriptive and analytical themes. I found this a really enjoyable part of the systematic review process and found looking for names for themes to be something very clear.
January 2021 – February 2021	**Empirical Paper** Once I had my emergent themes, I copied them from the transcripts to an excel document. Each participant had their own excel tab and this allowed me to then cluster the emergent themes together for each participant. Visually, I grouped themes in coloured and then devised a heading for each cluster. After doing this for each participant then looked across participants developing overarching themes. I utilised Excel through the process and then came to my sub themes and main themes also using this approach.

	Again, this process was daunting there was so much data and it felt impossible to condense it down into something that I could write about. I struggled to come up with names for themes as I wanted to make sure it had the phenomenological element and double hermeneutic approach. I met with my supervisory team to discuss themes and names for themes together so that those who had reviewed the transcripts could review the themes to make sure it encapsulated their understanding of the information. **Systematic Review** Systematic review analysis was finalised and supervisors reviewed the analysis. I then continued with the rest of the write up and completed the searches again to check for any further studies that could be included within the systematic review which may have been published more recently. No additional studies were included within the systematic review. I felt doing the searches again allowed me to get to grips with the searches and feel more confident performing them.
March 2021 – April 2021	**Empirical Paper** I now had my first draft of my systematic review paper and was awaiting feedback from my supervisors. During this time, I had a meeting to discuss my empirical paper analysis. Initially I had 7 themes which I felt could have been collapsed further into three high order themes. Together with my supervisors we reflected on keeping 7 themes versus having them collapse into three main themes. We decided to go with three main themes as this allowed us to encompass all the different aspects found within the transcripts but allowed us to further put on our phenomenological view into the higher order themes reflecting a better IPA analysis. I found during this time that I struggled to know when I had done enough analysis and often used my supervisors as a way to reflect on this to prevent the loss of meaning within the data. **Systematic Review** I continued to amend the write up from feedback from supervisors and made sure to format this write up to the specific journal we were writing for. Several drafts needed to get make sure write up is ready for submission. It was hard trying to write the paper in a style suitable for a medical journal and how they would expect papers to be written. This is where my supervisors helped me to refine my writing style and format the document using Vancouver referencing, something I had not used before.
April 2021 – May 2021	**Systematic Review and Empirical Papers** During this time, I started to write my introductory chapter and organise my appendices. It was hard with the appendices to know how much to include without providing information that would be deemed to be unnecessary. I spent time trying to make my introduction provide a clear background to the research while trying to make sure that it was not too lengthy. I also spent time tweaking my position statement and adding to my diary to make sure I was capturing all aspects of my journey.

	I continued to make amendments to the write up getting this ready for submission and reflecting on my journey with research. I could not believe that I was on the home straight and June was quickly approaching. I felt relieved yet scared of submitting and then thought of Viva was something I was consciously trying to avoid thinking about. Given the COVID-19 pandemic I did not think that this piece of work would be submitted on time and to think that I may make the deadline is something I am immensely proud of.
May 2021 – June 2021	**Systematic review and Empirical Papers** During this time, I continued to make amendments and get my thesis ready for submission. I am incredibility grateful for my friends, family and supervisory team for helping me through this process and I cannot believe I am ending this diary by saying my thesis was submitted on time!

Appendix G – Quotes Reflecting Descriptive Themes

Analytical and descriptive themes	***Participant quotations and/or author interpretations***
Palliative Care Standards	
Idealised View	*"It is an honour to be the person taking care if a dying resident" (*Cagle et al., 2017) Staff members reported feeling that they helped by being responsive to the patients need for supportive care… *"going the extra mile." (*Cagle et al., 2017) *"After that we got refreshments for the family and I made a tent out of blankets over the back of the recliner… to keep them occupied in the time of stress…"* (Cagle et al., 2017) *…it was a privilege to be allowed to share in and have an impact on the last intimate moments of a patients journey in life.* (Oliveira et al., 2017)
"Doing our best"	*"… I truly knew we did everything in our power to make the residents final moments as comfortable as possible." (*Cagle et al., 2017) *"Dying patients need one-to-one care and sometimes that can be hard when you have other residents."* (Cagle et al., 2017)
Willingness to learn	*"I learnt a lot about how to simultaneously bring physical comfort to the dying person and emotional comfort to the family…" (*Cagle et al., 2017) *"… I find it much easier to observe the right things, and I have to work less with myself on interpersonal relations…" (*Devik, Enmarker & Hellzen, 2019) *"I really learnt a lot through that patient experience…"* (Oliveira et al., 2017) *Most participants believed that EOLC was something that could not be taught full in a classroom or read in a book but needed to be experienced. (*Oliveira et al., 2017) *Distance and staffing deficits impacted on the nurse's accessing education. (*Rabbetts, Harrington & Breaden, 2018)
The Role of a Nurse – A Split Role	
Nurse Qualities	*"It did something to me… to see how lonely and lost she was… it just felt good to be there for her."* (Devik, Enmarker & Hellzen, 2019) *"It is really a matter of, yes… I always say that being a nurse is a little bit like being an actress. I think, sort of, that you can almost get caught up… yes you take on another role in some ways…" (*Johansson & Lindahl, 2011) When nurses were in patients' room, they understood and witnessed their vulnerability and sensed their imminent death. (Karlsson, Kasen & Warna-Furu, 2017) Having an open mind attitude and adopting an empathetic approach was key… (Penz & Duggleby, 2011)

Patients' Needs	*"Keeping the patient comfortable – maintaining family involvement."* (Cagle et al., 2017) *"I think some of the patients have stopped expecting anything…. Some patients just want the 'mission complete'…"* (Devik, Enmarker & Hellzen, 2019) …each patient is unique, so the nurses described how they provided personalised and singular care tailored to the preferences, wishes and needs of each patient. (Parola et al., 2018) *"I always value what he wants to do. If he wants to take a shower, he does."* (Parola et al., 2018)
Families As well	*"Being there for family support."* (Cagle et al., 2017) *"When the patient that is clearly passing soon had family that become irrational and try to blame us for what is happening and not understanding why we cannot stop the inevitable."* (Cagle et al., 2017) Conflict between family members can also distract from the supportive care that patients need. (Cagle et al., 2017) *"The patient was taking her last breaths and the family was fighting in the patient's room over her belongings."* (Cagle et al., 2017) *"Families will have their own goals and expectations. Physicians will have their own goals and expectations. And nurses are kind of suck in the middle."* (Oliveira et al., 2017)
Weighing up the Pros and Cons	
Benefits of the Job	*"It was a positive experience to offer comfort and education to the family when they had fears… It is comfort to me as well as the patient and family to provide end of life care."* (Cagle et al., 2017) *"It caught me off guard… I have never witnessed that before… this man's hope for and strong will to die in his own home. No sign of fear – he was just so determined."* (Devik, Enmarker & Hellzen, 2019) However, caring for the terminally ill and their families means getting a lot back in return, which mean experiencing affirmation and stimulation in the work. (Johansson & Lindahl, 2011) *"I guess simply if you don't have hope, it's really hard to continue on…"* (Penz & Duggleby, 2011)
Consequences of the Job	*"Feeling like 'my hands are tied' during times when there are families in conflict over treatment…"* (Cagle et al., 2017) *"When an alert patient on hospice had a sudden condition change… She died before the hospice services were able to make it to the facility".* (Cagle et al., 2017) *"No matter how hard I tried, it was never enough for him. I felt annoyed and helpless because I always fell short."* (Devik, Enmarker & Hellzen, 2019) *"Palliative care in very demanding as you have to go from happiness to deep sorrow, very great tragedy… Caring for palliative patients is, like going up and down the whole time… at the same time it takes so much out of you."* (Johansson & Lindahl, 2011)

	When nurses are unable to give patient and their loved ones what they need, it is unsatisfactory and gives rise to a 'feeling of inadequacy. (Johansson & Lindahl, 2011) Nurses faced with questions about what was right and wrong for treatment of suffering at end of life. (Karlsson, Kasen & Warna-Furu, 2017)
The Pain of Saying Farewell	
Inner Dialogue/ Conflict	*"My resident fought death, yelling and cursing as he was passing… I've never forgotten this resident…"* (Cagle et al., 2017) However, caring interactions do not happen incidentally, and the nurses are well-aware of the framework that guides their professional actions. (Devik, Enmarker & Hellzen, 2019) This dialogue exists as a negotiation between the patients' expressions and the nurses' own feelings and their actual caring actions. (Devik, Enmarker & Hellzen, 2019) *"… So, you don't get too close and personal, because, I feel that's not good… there we must, or I must restrict myself in the relationship... so I can give them professional support."* (Johansson & Lindahl, 2011) The emotions in the room were manifestations of life's vulnerability. (Karlsson, Kasen & Warna-Furu, 2017) *"[the nurse] can see that she has extreme pain, and [the nurse] really tries, but she does not want to take pain relievers… then goes home with a lump in her stomach that 'Why didn't I do more?' or 'What more could I have done?"* (Karlsson, Kasen & Warna-Furu, 2017) *Thoughts and reflections about suffering … caused nurses views on life and death to undergo constant re-evaluation.* *"I think that everyone who works with this reflects on their own death or that something could happen." (*Karlsson, Kasen & Warna-Furu, 2017)
Emotional Coping	*"His housing conditions were really bad… dirt and trash all over, but the man was so reflective and shared so many interested details about his life at sea…"* (Devik, Enmarker & Hellzen, 2019) *"We have a lot of humour, A lot."* (Zheng, Lee & Bloomer, 2017) *"...At times I find we laugh a lot in the office when we are together."* (LaToya & Harris, 2013) *"the darker the humour the funnier"* (Zheng, Lee & Bloomer, 2017) *"It's interesting how dark we get, the more tired and fried we are."* (LaToya & Harris, 2013) *"during the long commute, there is time to think, and if you give yourself that time, you can decompress. I find that very therapeutic." (*LaToya & Harris, 2013) *At times their emotions cannot be held back, and they need to find another way to express.* (*Karlsson, Kasen & Warna-Furu, 2017)* *They hold back tears, anger and fear when caring for patients. (Karlsson, Kasen & Warna-Furu, 2017)*

	“.... Stop pull yourself together and the go into the room very quietly. That’s part of your nursing being able to switch…” (Oliveira et al., 2017) *The nurses mention making attempts at emotional distancing as a protection strategy.* (Parola et al., 2018) *They needed to disconnect mental and emotionally at times to maintain their own stability…”* (White & Meeker, 2019)
Physical Coping	*“…and sometimes, you deliberately avoid getting involved because there is not enough time deal with any struggles.”* (Devik, Enmarker & Hellzen, 2019) *“I just delivered the medicines and took the blood samples as ordered; I didn’t have to go there every day…”* (Devik, Enmarker & Hellzen, 2019) *“Get into existential questions, spiritual questions, where I’m very careful, where I do not really dare…”* (Johansson & Lindahl, 2011) *Setting boundaries, which means distancing oneself from or avoiding patient death either emotionally or physically was paramount to coping with the death of patients.* (Zheng, Lee & Bloomer, 2017)
Nurses – the pillar of support *Collaboration*	Good care was often provided by, or in concert with hospice services. (Cagle et al., 2017) They are more inclined to regard their responsibility as a shared one, shared with the other nurses who are also visiting the patient. (Devik, Enmarker & Hellzen, 2019) *“Your chaplain and your social worker are always there and you can go and you know gain some support.”* (LaToya & Harris, 2013)
Relationships	*“The hardest part of taking care of a dying resident is the heartache that follows. We grow attached to people and sometimes it can cause grief.”* (Cagle et al., 2017) *“…you meet new people and some… they just pass by… While others they make a stronger impression that affects you.”* (Devik, Enmarker & Hellzen, 2019) To be simultaneously responsible for patients with diverse acute illnesses and the terminally ill hinders deeper relationships between those concerned… (Johansson & Lindahl, 2011)
Communication	Being able to communicate well with patients, families and other care providers was another prevailing positive theme... (Cagle et al., 2017) *“… had a family that did not want their mom given morphine despite she had every sign and symptom of pain, they refused to let us treat her. I talked to them until I cried. It was no use…”* (Zheng, Lee & Bloomer, 2017)

Supporting Fellow Nurses	…it became clear through the discussions that most viewed the relationships with their co-workers as much more than a professional connection. (LaToya & Harris, 2013) *"…the relationship with my co-workers is 100% different than those I have had in a previous nurse role…"* (LaToya & Harris, 2013) *"There are always situations that raise doubts in me… I turn to the team… we need to speak to each other."* (Parola et al., 2018)
Organisational Issues *Navigating the system*	*"Also, it is about the only time a CAN feels appreciated and noticed."* (Cagle et al., 2017) *"… In order to manage a long list of patients you can't ask everyone how they really are… we have to take care of the tasks that are expected from us."* (Devik, Enmarker & Hellzen, 2019) *"You have got your patient right here…. then you got the family and everyone else… and where's nursing?"* (Oliveira et al., 2017) *"You know listen to the nurses… you know, they don't care." (*Oliveira et al., 2017) *"Fighting a lot of prejudices… fighting to be part of a team…"* (Oliveira et al., 2017) *"Resigning myself to the system"* (Penz & Duggleby, 2011)
What Governance?	A number of staff indicated that they would welcome staff support groups that were no specific to grief but allowed them to informally dialogue about any topic. (LaToya & Harris, 2013) There was consensus that having someone to talk to whether on-site or via telephone, would be beneficial on a particularly stressful or painful day… (LaToya & Harris, 2013) The nurses participating… found that there were limited opportunities to talk about feelings, about the finality of death, the experience of loss and grief resulting in the nurses feeling very alone. (Rabbetts, Harrington & Breaden, 2018)

Appendix H – Tracy's (2010) eight key markers of quality in qualitative research.

How this research has met the eight key markers for quality in qualitative research.

Key Markers	Means through which criteria were achieved
Worthy topic	• Study's relevance was supported by the palliative care clinical team • Supported by the existing literature in the field
Rich rigor	• Relevance of the findings in relation to existing theoretical constructs (e.g., burnout) • Significant sample size for qualitative phenomenological research • In-depth interview by trainee clinical psychologist • Discussion with supervisory team
Sincerity	• Transparency with regards to the methods (recruitment, interview coding etc.) • Recognition of the researcher's subjectivity, keeping reflective diary • Recognition of study limitations
Credibility	• Substantive citations from diverse participants • Crystallization (with supervisory team)
Resonance	• Evocation representations • Transferable findings • Result validation within the clinical team
Significant contribution	• Conceptually/ theoretically • Clinical contribution/ transferability

Ethics	• Procedural ethics (approved by university board of ethics) • Situational ethics (interviews conducted by trainee clinical psychologist) • Relational ethics (included all participants who showed interest; availability of researcher)
Meaningful coherence	• Question/ paradigm/ design and analysis in line with IPA • Coherence between literature, data and interpretations

Appendix I&J - Participant Debrief Form and Distress Protocol

The lived experience of qualified nurses working within an Academic Specialist Palliative Care Unit within the acute care setting: a phenomenological study.

STUDY SPECIFIC DEBRIEF SUMMARY & DISTRESS PROTOCOL

Debrief Summary

This document highlights the background around why this study has been conducted and the key aims of what the study is aiming to look at alongside the objectives. This document also provides evidence for services that you are able to contact if you feel you need further support if this interview has brought up any uncomfortable feelings or thoughts.

Research evidence clearly shows that individuals approaching the end of their life benefit from support by Palliative Care (PC) services (Powell, Froggatt & Giga, 2019; World Health Organisation, 2018). However, population and mortality statistics from England and Wales (2006-2014) indicate that if mortality rates increase at the current level, then 160,000 more people will need PC by 2040 (Etkind et al., 2017). The quoted figures indicate that there will be additional demands on the National Health Service (NHS) and pressure on the delivery of PC. Healthcare systems need to adapt in preparation to the changing demographic picture and increase in the number of deaths from chronic illness (Etkind et al., 2017).

Working in an environment such as PC presents both clinical and personal challenges, requiring professionals to make difficult clinical and ethical decisions, alongside supporting patients, families and other staff. In addition to existing challenges of working in the NHS, the increasing demand for PC provision may produce additional stressors for staff, for example, limited time with patients and families, more complex health conditions and differing disease profiles. The effect of these additional stressors may be variable, but may precipitate negative outcomes such as; stress, burnout and compassion fatigue. Specialist PC is considered a stressful profession, with clear evidence of the risks of psychological morbidity and burnout (Pereira, Teixeira, Carvalho, & Hernández-Marrero, 2016).

The World Health Organisation (WHO) has called for increased examination of the impact of work-related stress, identifying work-related stress as a major public health concern (Commission on Social Determinants of Health, 2008). In 2015-2016, the prevalence of work-related stress, anxiety and depression in the UK accounted for 37% of work-related health issues. Factors that cause workplace stress have remained constant over time and include issues with workload, lack of support from managers and organisational change (Health & Safety Executive, 2018). Furthermore, these issues are prevalent in many other countries and care settings, (Sizmur & Raleigh, 2018) with nurses reporting similar issues in their workplaces regardless of how their country's healthcare system is organised (Aiken et al., 2001).

The WHO has noted growing concern about the disproportionate prevalence of stress in the healthcare workforce. A report by the WHO highlighted that nurses had a higher rate of stress (3010 cases per 100,000) when compared to skilled tradesmen (550 cases per 100,000) (Health & Safety Executive, 2018). The consequences of excessive and prolonged stress can lead to burnout. Given the depleting and struggling workforce within the NHS and the struggle to meet demands of the healthcare system, staff maybe at greater risk of burnout (McVicar, 2016). The number of vacancies in the UK National Health Service (NHS) has doubled in the past three years, with the number of people entering the profession significantly lower than those leaving (Royal College of Nursing, 2017). Further, it is predicted that there will be a global shortage of nurses within the next 10–20 years (Moloney, Boxall, Parsons, & Cheung, 2018) and it is therefore imperative to ensure measures are taken to understand and ameliorate the stresses nurses may face to protect against stress induced ill-health and absences.

The quality of care experienced by patients is negatively affected when staff are stressed (Dawson, 2014), as staff that are over-stretched and over-worked may be more prone to error. Johnson et al. (2017) found that when healthcare professionals' ability to cope is compromised, the distress associated with perceived failure undermines resilience. This leads to negative outcomes such as shame, depression and anxiety, which in turn increases the likelihood of further distress and so the cycle continues. While many recognise the stressors that are inherent in generic nursing, some claim that PC is especially stressful due to working with terminally ill patients, their families and dealing with frequent losses (Grafton, & Coyne, 2012; Herrington, Knowlton, & Tucker, 2012; McAllister, & McKinnon, 2009; The Point of Care Foundation, 2015).

Summary

Studies have demonstrated that PC is an especially stressful area to work in, however; there may be many factors that moderate work-based stressors to protect specialist PC staff from experiencing stress, burnout or compassion fatigue. Most studies included within the systematic reviews outlined within this proposal are based within either oncology or hospice settings. This indicates a gap in the literature to look at how providing PC works within an acute hospital setting, where focus of care is different (cure in Oncology/care in palliative medicine), staff/patient ratios are different, and patient symptomology is likely to be significantly more complex and challenging for staff.

Research is needed to explore nurses lived experience of working APCU in an acute setting as there is no current meaningful evidence in this area due to the relatively recent establishment of such units. Such data and analysis, providing an-depth understanding of the "lived-experience" of nurses, and the meanings that they attribute to the care they provide, will be crucial in establishing parameters for safeguarding staff and potentially identifying approaches to assist staff in coping with the challenges of this particular setting.

Study Objectives

Aim: To provide an in-depth understanding of the lived experience of nurses working in an acute palliative care unit, how they apply meaning to their role and examine how meanings may impact upon psychological well-being.

The Study Objectives are to:

1. To understand lived experience of providing care to dying patients (Phenomenolgy)
2. To identify the interpretation of the experience of providing care to dying patients (Hermeneutics)
3. To identify the experiences particular to palliative care nurses in providing care (Idiography)
4. Develop a phenomenologically rich interpretative account of the relationship between nurses' experiences, end of life care and experience of delivering care within an APCU.

If you feel you need more support please contact any of the following support services:

You can self-refer to IAPT Talk Liverpool (if you live in the Liverpool area) online via https://www.talkliverpool.nhs.uk/ or via phone 0151 228 300

You can self-refer to IAPT Access Sefton (if you live within the Sefton area) online via https://www.insighthealthcare.org/our-services/talking-therapies/find-a-service/access-sefton/ or by phone 0300 303 2708

You can self-refer to IAPT Halton (if you live within the Halton area) online via https://www.mhm.org.uk/talking-matters-warrington or by phone 01925 401720

You can self-refer to IAPT Knowsley (if you live within the Knowsley area) online via https://www.nwbh.nhs.uk/think-wellbeing-knowsley or by phone 0151 430 1707

Further Information

If you would like any further information about this study please contact:

Dr Stephen Mason

Research & Development Lead (Mon-Wed)
Methods (Thurs-Fri)
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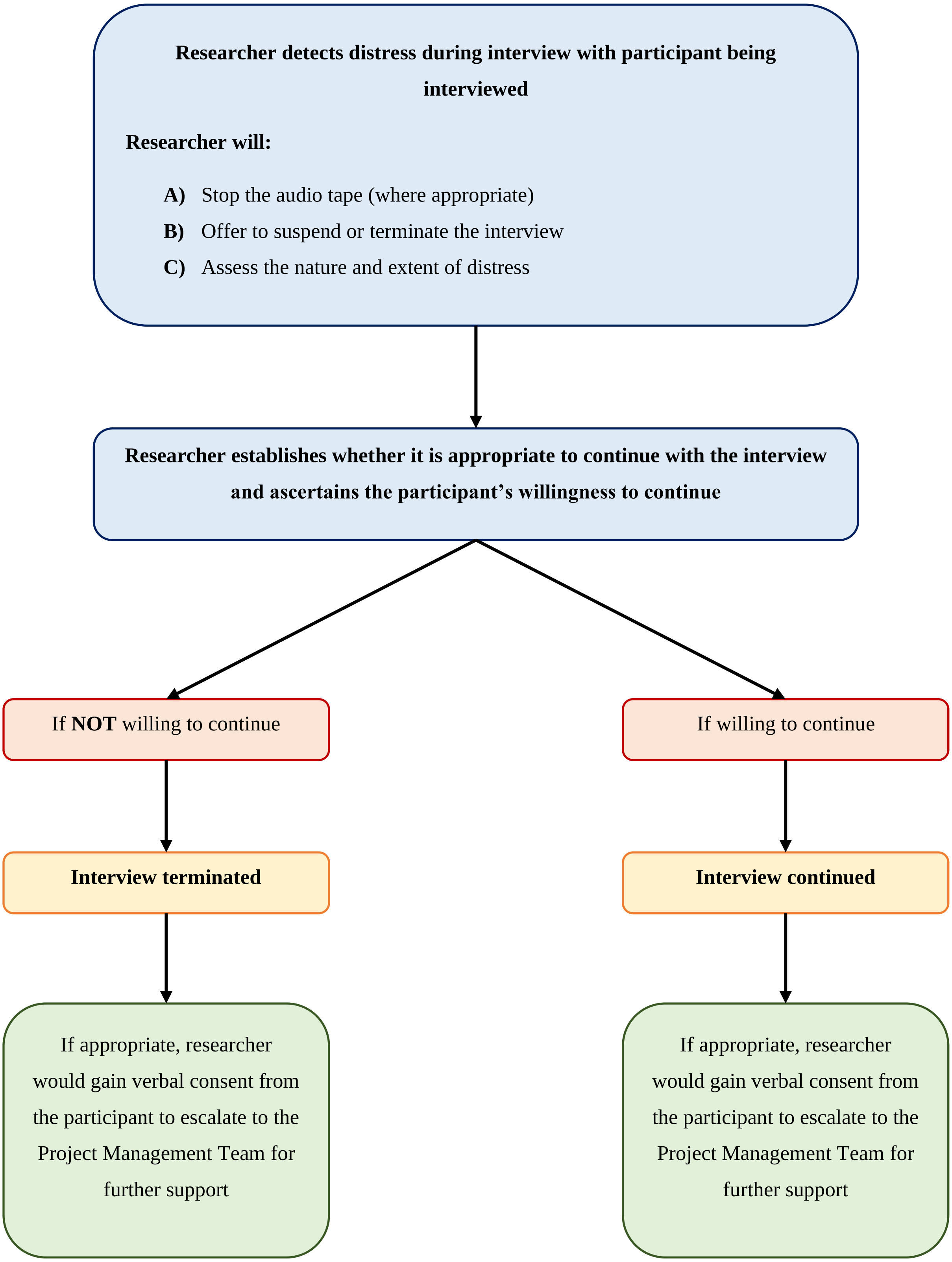
W: **www.liverpool.ac.uk/medicine**

Distress Protocol:



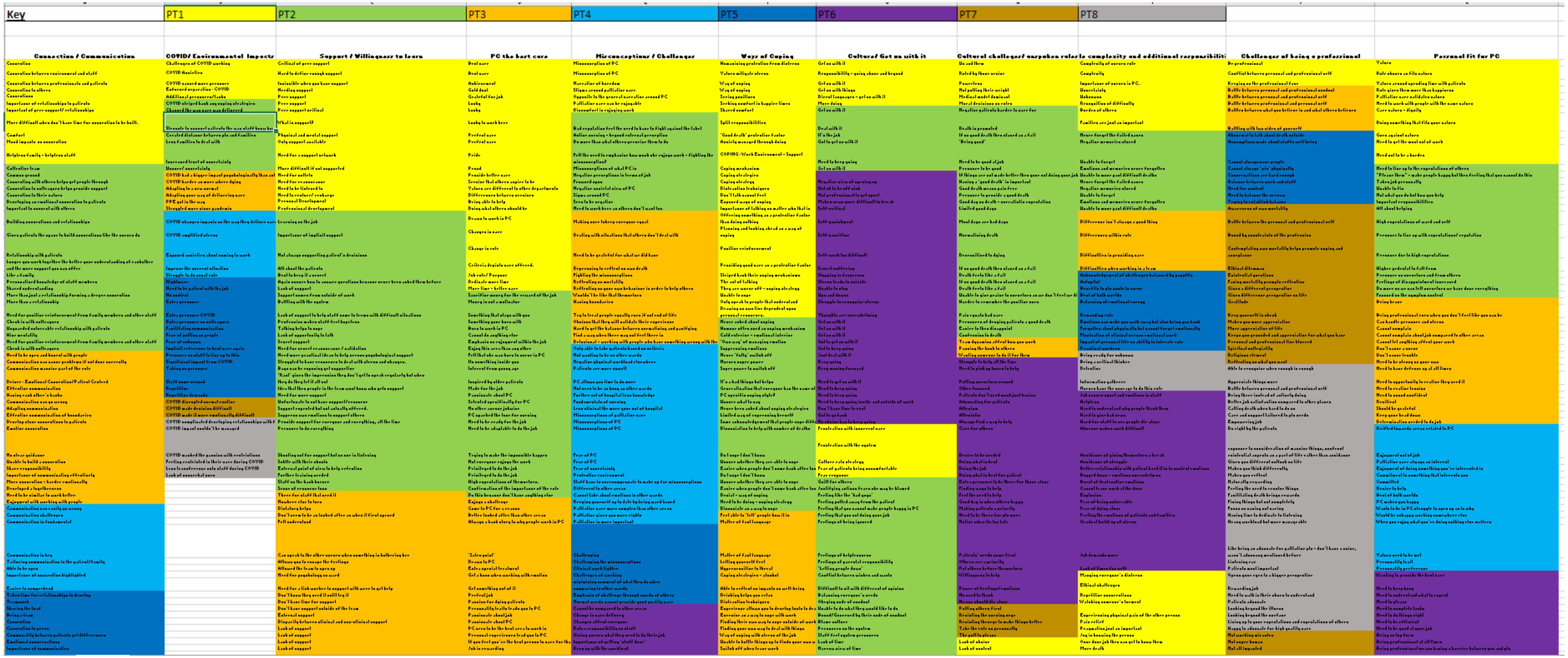
Appendix K – Participant Theme Map

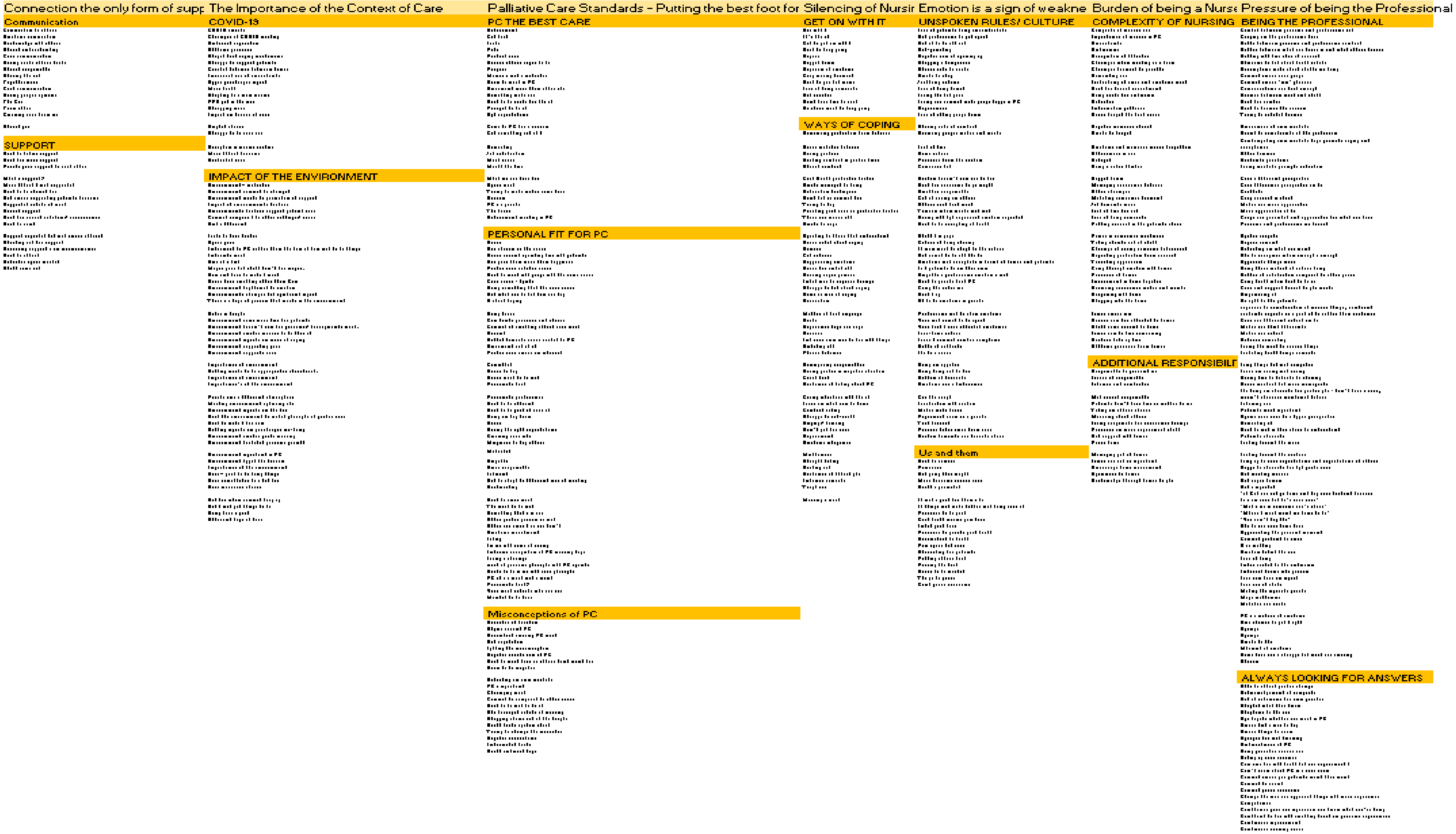
Connection	Ways of Coping	Negative Emotions Associated with Role	Palliative Care Standards	COVID-19	Need for Support
Connection	Humanising protection from distress	Anticipatory Anxiety	Best care	Challenges of COVID working	Critical of peer support
Connection between environment and staff	Values mitigate stress	Delayed emotional response	Best care	COVID Anxieties	Hard to define enough support
Connection between professionals and patients	Way of coping	Difficulty with emotions	Achievement	COVID caused more pressure	Invincible when you have support
Connection to others	Way of coping	Emotional detachment	Gold dust	Enforced separation - COVID	Needing support
Connections	Seeing positives	Emotional exhaustion	Grateful for job	Additional pressures/tasks	Peer support
Importance of relationships to patients	Seeking comfort in happier times	Emotional Labour	Lucky		Peer support
Important of peer support/ relationships	Shared comfort	Emotional torment	Lucky		Peer support critical
More difficult when don't have time for connection to be built.	Split responsibilities	Emotionally draining	Lucky to work here		What is support?
Comfort	'Good death' protective factor	Exhausting emotionally	Perfect care		Physical and mental support
Mood impacts on connection	Anxiety managed through doing	Futility of trying to avoid emotional involvement	Perfect care		Only support available
Helpless family – helpless staff	COPING - Work Environment – Support	Impossibility to not get heavily involved/invested	Pride		Need for a support network
	Coping mechanism	Looking for positives in negative situation	Proud		More difficult if not supported
	Coping strategies	Prolonged distress	Provide better care		Need for outlets
	Coping strategy	Cannot be negative	Service that others aspire to be		Need for reassurance
	Distraction techniques	Processing delayed	Values are different to other departments		Need to be listened to
	Don't talk cannot feel	When broken theres no way back	Differences between services		Need to restore/ recharge
	Exposed ways of coping	Issues of not speaking	Being able to help		Personal Development
	Importance of talking no matter who that is	Critical of self	Doing what others should be		Professional development
	Offering something as a protective factor than doing nothing	Negative self talk when unable to manage pain	Drawn to work in PC		
	Planning and looking ahead as a way of coping		Changes in care		
	Positive reinforcement		Change in role		
	Providing good care as a protective factor		Criteria depicts care offered.		
	Striped back their coping mechanisms		Job role/ Purpose		
	The act of talking		Dedicate more time		
	They are worse off – coping strategy		More time = better care		
	Unable to cope				
	Only speak to people that understand				
	Drawing on own line dependent upon personal resources.				

Cultural Difficulties	Get on with it	Whats missing	Misconceptions of Palliative Care	Benefits of the job	Environmental Factors
Frustration with incorrect care	Get on with it	Lack of choice	Misconception of PC	Rewarding	Environment = motivator
Frustration with the system	Get on with it	Lack of control	Misconception of PC	Rewarding	Environment cannot be changed
Cultural barriers	Get on with things	Lack of control	Narrative of boredom	Rewarding work	
Fear of patients being uncomfortable	Direct languages – get on with it	Lack of control over workload	Stigma around palliative care	Emphasis on rewards of the job	
Fear response	More doing	Lack of identity at first	Opposite to the general narrative around PC	Job satisfaction	
		Lack of shared values	Palliative care can be enjoyable	Making a difference	
		Lack of space to grieve	Discomfort in enjoying work	Unhappy if worked elsewhere	
		Lack of support		Motivated	
		Lack of support – more difficult			
		Lack of understanding about own emotions			
		Lack of understanding of support offered			
		Pressure to have answers			

Personal Fit	Maintaining professionalism	Complexity of nurses role	Organisational issues	Additional responsibilites	Challenges of the job
Values	Be professional	Complexity of nurses role	Us and them	Responsibility – going above and beyond	Manging everyone's distress
Role chosen as fits values	Conflict between personal and professional self	Complexity	Ruled by those senior	Responsibility to present well	Ethical challenges
Values around spending time with patients	Keeping on the professional face	Importance of nurses in PC.	Powerless	Responsible for the ward	Repetitive converstions
Role gives them more than happiness		Uncertainty	Not pulling their weight	Listener and comforter	Watching someone's torment
Palliative care validates values		Unknowns	Medical model dominant	Guilt of families – managing this	Effective communication
Need to work with people with the same values		Recognition of difficulty	Moral decisions vs rules	Helping when people are limited	Experiencing physical pain of the other person
Care values – dignity		Burden of others		Fulfilling patient's wishes	Pain relief
Doing something that fits your values		Cruel / unfair / not acceptable.		Equality and equity of personal responsibility/duty	Pragmatics just as important
Goes against values		Families are just as important		Multi layered responsibility	Joy in knowing the person
Need to get the most out of work				Unable to let that happen	Once done job then can get to know them
Need not to be a burden					More death

Appendix L- Print Screenshot of Individual and Group Analysis Process





Connection the only form of supp

Communication

SUPPORT

The Importance of the Context of Care

COVID-19

IMPACT OF THE ENVIRONMENT

Palliative Care Standards - Putting the best foot for

PC THE BEST CARE

PERSONAL FIT FOR PC

Misconceptions of PC

Silencing of Nursir

GET ON WITH IT

WAYS OF COPING

Emotion is a sign of weakne

UNSPOKEN RULES/ CULTURE

Us and them

Burden of being a Nurse

COMPLEXITY OF NURSING

ADDITIONAL RESPONSIBILIT

Pressure of being the Professional

BEING THE PROFESSIONAL

ALWAYS LOOKING FOR ANSWERS

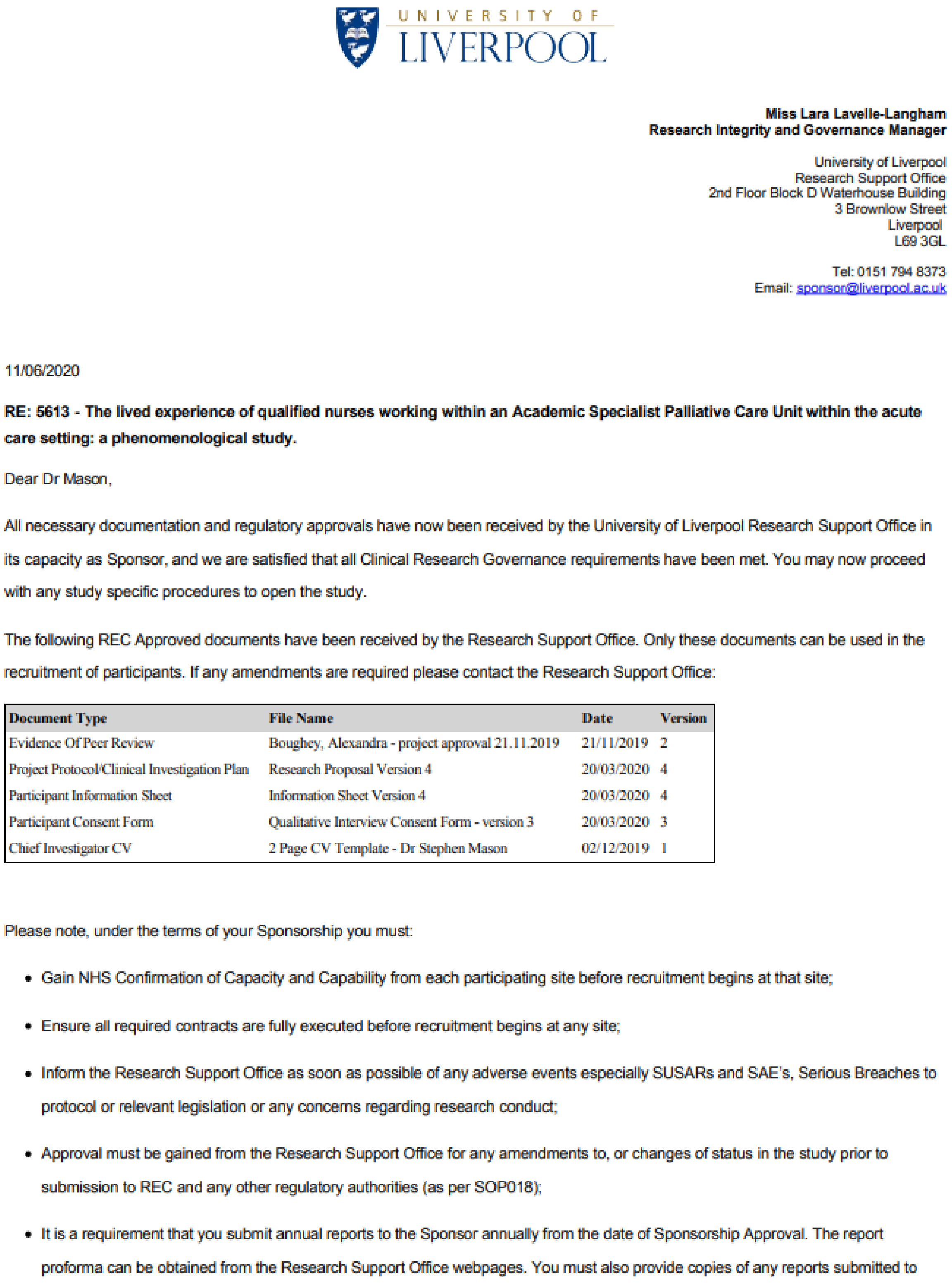
Appendix M – Key Themes and Sub Themes Shown Across Participants

Overview of themes			**Participants**							
Key Themes	**Sub Themes**		**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
The Pressure to Provide 'Perfect Care'	The Importance of the Context of Care	COVID-19	**X**	**X**	**X**	**X**	**X**		**X**	**X**
		Impact of the Environment		**X**		**X**	**X**	**X**	**X**	**X**
	Palliative Care Standards: Putting the best foot forward	Palliative Care the best care	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
		Personal fit for Palliative care	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
		Misconceptions of Palliative Care	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
Get on with it in Silence	Connection the only form of support	Communication	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
		What support?	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
	Silencing of Nursing	Get on with it	**X**	**X**	**X**	**X**		**X**	**X**	
		Ways of Coping	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
	Emotion is a sign of weakness	Unspoken Rules/ Culture		**X**	**X**	**X**	**X**	**X**	**X**	**X**
		Us and Them	**X**	**X**	**X**	**X**		**X**		**X**
'Bargaining' with the System	Burden of being a Nurse	Complexity of Nursing Role	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
		Additional Nursing Responsibilities				**X**		**X**		**X**
	Pressure of being the Professional	How to do a professional	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
		Always looking for answers		**X**		**X**		**X**	**X**	**X**

Appendix N – Example of How the Theme of 'Palliative Care Standards' was Developed

Line by Line Codes	Descriptive Themes	Analytical Theme
Honour to do job	Idealised View	Palliative Care Standards
Providing best possible care		
Going above and beyond		
Providing unique care		
Job comes first		
Special care		
Providing perfect care		
Giving one's self to the job		
Holistic Care		
Privilege to work		
Grateful for job		
Honour to share someone's death		
Going the extra mile		
Juggling everything	"Doing our best"	
Cannot do it all		
It's the job		
Cannot always provide care		
Holding everything		
Trying to please everyone		
Couldn't do anymore		
Giving best you can		
Strive to please		
Need to carry on		
Wanting to help		
Demanding		
Continuous learning	Willingness to Learn	
Need for more education and support		
Educating others		
Knowledge is power		
Need to keep up to date		
Developing strength		
Cannot be taught learn on the job		
Openness to learn		
Need experience of dying before		
Harder when newly qualified		

Appendix O – University of Liverpool Sponsorship Approval



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Tel: 0151 794 8373
Email: sponsor@liverpool.ac.uk

11/06/2020

RE: 5613 - The lived experience of qualified nurses working within an Academic Specialist Palliative Care Unit within the acute care setting: a phenomenological study.

Dear Dr Mason,

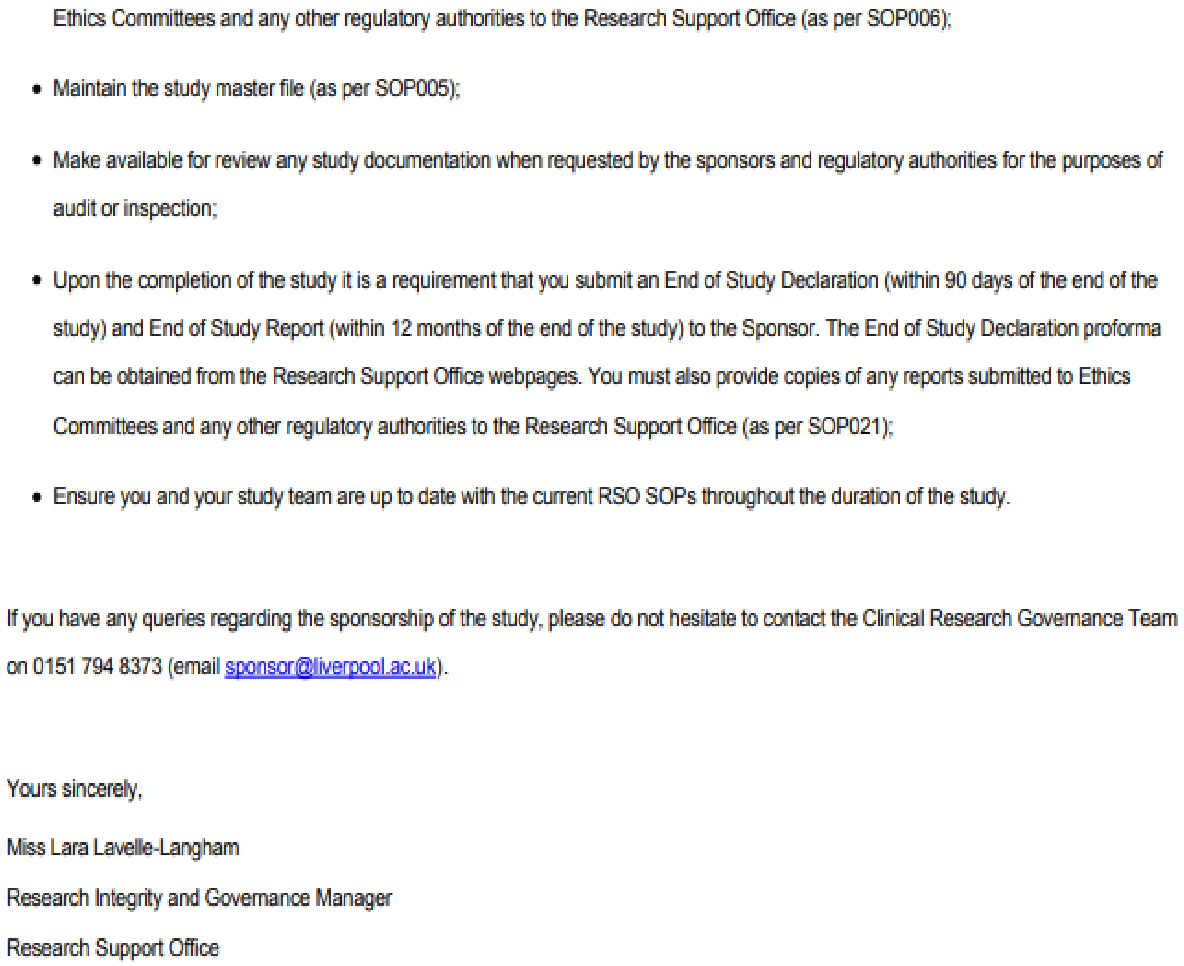
All necessary documentation and regulatory approvals have now been received by the University of Liverpool Research Support Office in its capacity as Sponsor, and we are satisfied that all Clinical Research Governance requirements have been met. You may now proceed with any study specific procedures to open the study.

The following REC Approved documents have been received by the Research Support Office. Only these documents can be used in the recruitment of participants. If any amendments are required please contact the Research Support Office:

Document Type	File Name	Date	Version
Evidence Of Peer Review	Boughey, Alexandra - project approval 21.11.2019	21/11/2019	2
Project Protocol/Clinical Investigation Plan	Research Proposal Version 4	20/03/2020	4
Participant Information Sheet	Information Sheet Version 4	20/03/2020	4
Participant Consent Form	Qualitative Interview Consent Form - version 3	20/03/2020	3
Chief Investigator CV	2 Page CV Template - Dr Stephen Mason	02/12/2019	1

Please note, under the terms of your Sponsorship you must:

- Gain NHS Confirmation of Capacity and Capability from each participating site before recruitment begins at that site;
- Ensure all required contracts are fully executed before recruitment begins at any site;
- Inform the Research Support Office as soon as possible of any adverse events especially SUSARs and SAE's, Serious Breaches to protocol or relevant legislation or any concerns regarding research conduct;
- Approval must be gained from the Research Support Office for any amendments to, or changes of status in the study prior to submission to REC and any other regulatory authorities (as per SOP018);
- It is a requirement that you submit annual reports to the Sponsor annually from the date of Sponsorship Approval. The report proforma can be obtained from the Research Support Office webpages. You must also provide copies of any reports submitted to



Ethics Committees and any other regulatory authorities to the Research Support Office (as per SOP006);

- Maintain the study master file (as per SOP005);
- Make available for review any study documentation when requested by the sponsors and regulatory authorities for the purposes of audit or inspection;
- Upon the completion of the study it is a requirement that you submit an End of Study Declaration (within 90 days of the end of the study) and End of Study Report (within 12 months of the end of the study) to the Sponsor. The End of Study Declaration proforma can be obtained from the Research Support Office webpages. You must also provide copies of any reports submitted to Ethics Committees and any other regulatory authorities to the Research Support Office (as per SOP021);
- Ensure you and your study team are up to date with the current RSO SOPs throughout the duration of the study.

If you have any queries regarding the sponsorship of the study, please do not hesitate to contact the Clinical Research Governance Team on 0151 794 8373 (email sponsor@liverpool.ac.uk).

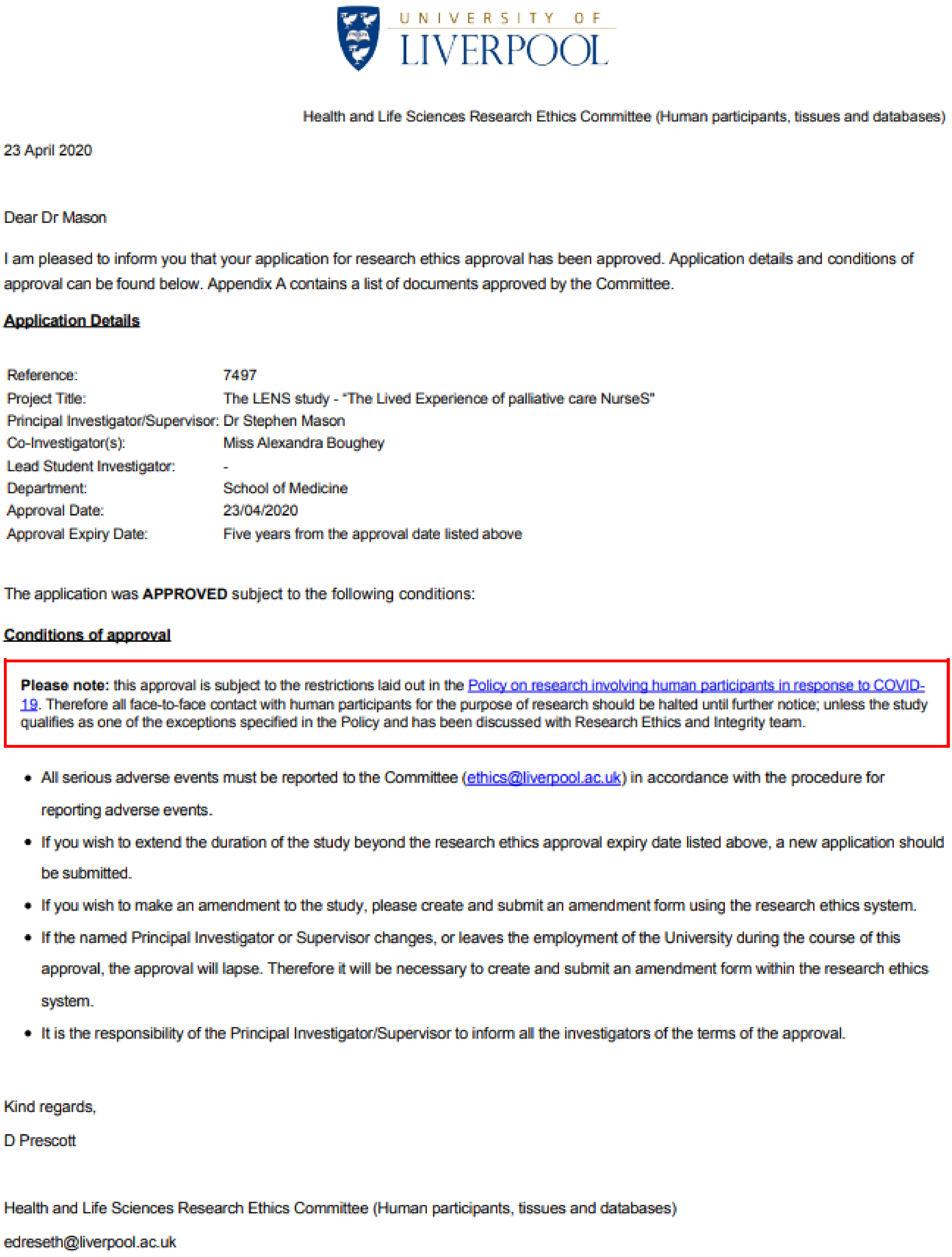
Yours sincerely,

Miss Lara Lavelle-Langham

Research Integrity and Governance Manager

Research Support Office

Appendix P - University of Liverpool Ethical Approval



UNIVERSITY OF LIVERPOOL

Health and Life Sciences Research Ethics Committee (Human participants, tissues and databases)

23 April 2020

Dear Dr Mason

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:	7497
Project Title:	The LENS study - "The Lived Experience of palliative care NurseS"
Principal Investigator/Supervisor:	Dr Stephen Mason
Co-Investigator(s):	Miss Alexandra Boughey
Lead Student Investigator:	-
Department:	School of Medicine
Approval Date:	23/04/2020
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.

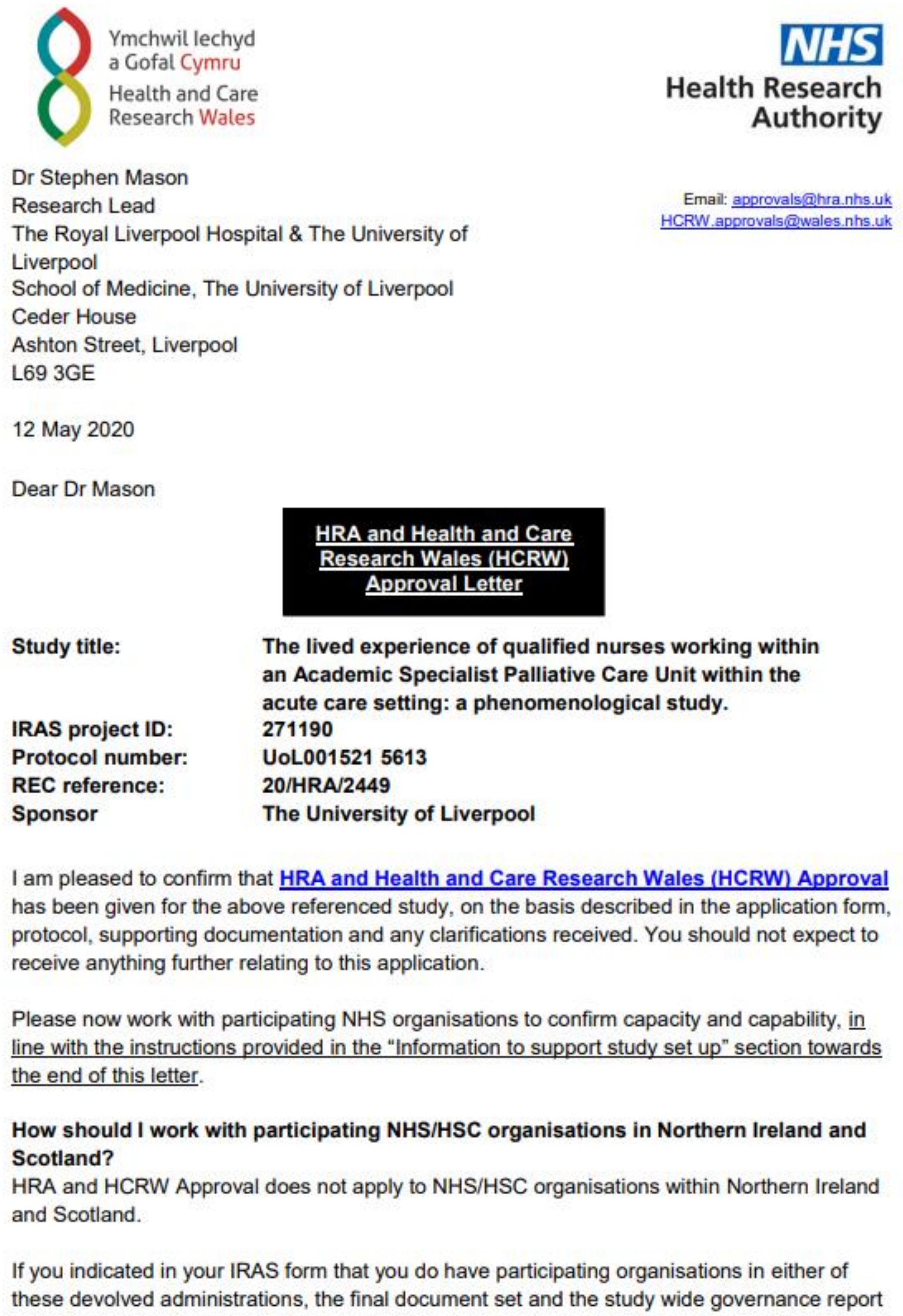
Kind regards,

D Prescott

Health and Life Sciences Research Ethics Committee (Human participants, tissues and databases)

edreseth@liverpool.ac.uk

Appendix Q - HRA Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Dr Stephen Mason
Research Lead
The Royal Liverpool Hospital & The University of Liverpool
School of Medicine, The University of Liverpool
Ceder House
Ashton Street, Liverpool
L69 3GE

12 May 2020

Dear Dr Mason

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **The lived experience of qualified nurses working within an Academic Specialist Palliative Care Unit within the acute care setting: a phenomenological study.**
IRAS project ID: **271190**
Protocol number: **UoL001521 5613**
REC reference: **20/HRA/2449**
Sponsor **The University of Liverpool**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The *"After HRA Approval – guidance for sponsors and investigators"* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

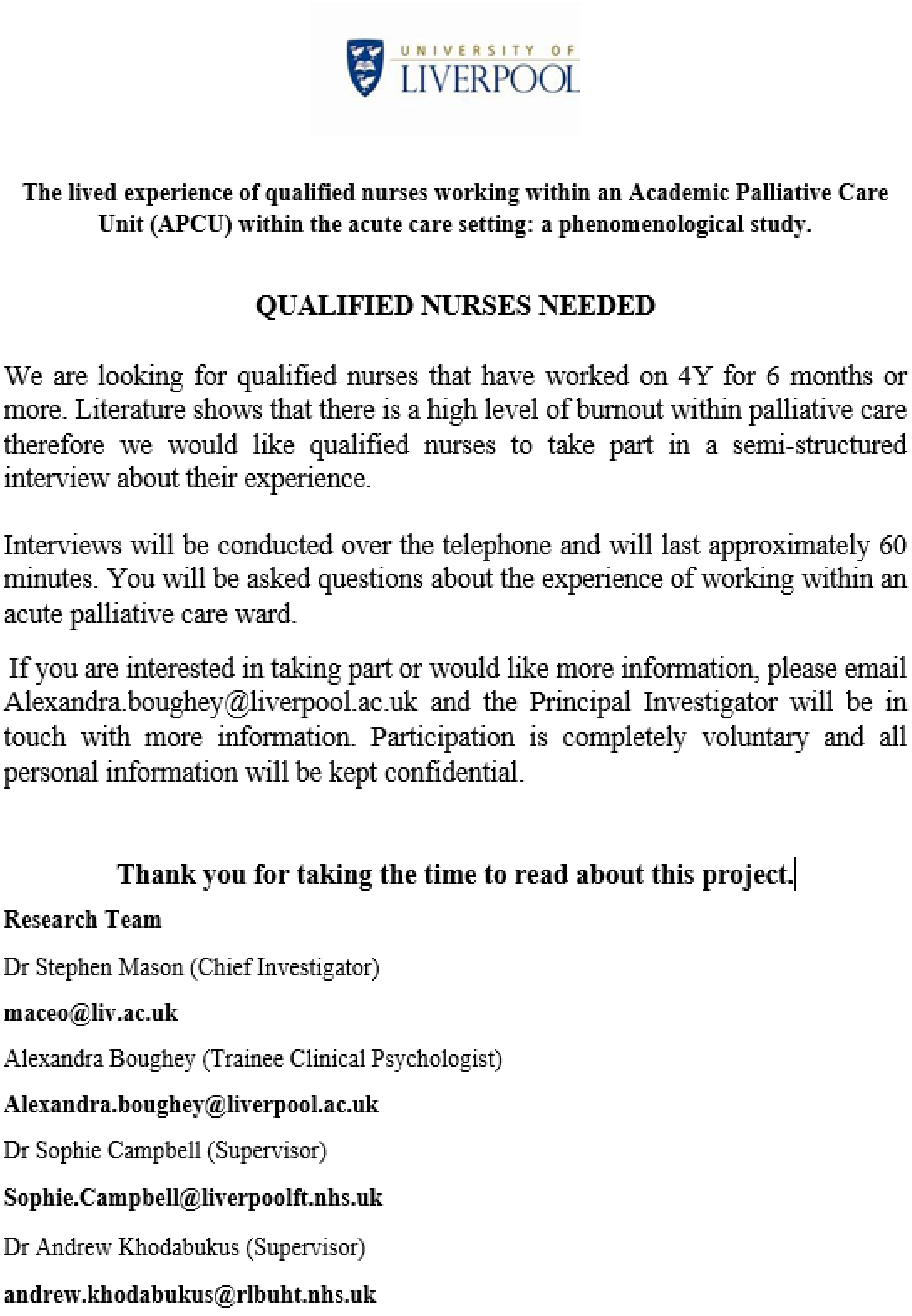
Your IRAS project ID is **271190**. Please quote this on all correspondence.

Yours sincerely,
Helen Penistone
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Mr Alex Astor*

Appendix R - Participant Study Advertisement



The lived experience of qualified nurses working within an Academic Palliative Care Unit (APCU) within the acute care setting: a phenomenological study.

QUALIFIED NURSES NEEDED

We are looking for qualified nurses that have worked on 4Y for 6 months or more. Literature shows that there is a high level of burnout within palliative care therefore we would like qualified nurses to take part in a semi-structured interview about their experience.

Interviews will be conducted over the telephone and will last approximately 60 minutes. You will be asked questions about the experience of working within an acute palliative care ward.

If you are interested in taking part or would like more information, please email Alexandra.boughey@liverpool.ac.uk and the Principal Investigator will be in touch with more information. Participation is completely voluntary and all personal information will be kept confidential.

Thank you for taking the time to read about this project.

Research Team

Dr Stephen Mason (Chief Investigator)

maceo@liv.ac.uk

Alexandra Boughey (Trainee Clinical Psychologist)

Alexandra.boughey@liverpool.ac.uk

Dr Sophie Campbell (Supervisor)

Sophie.Campbell@liverpoolft.nhs.uk

Dr Andrew Khodabukus (Supervisor)

andrew.khodabukus@rlbuht.nhs.uk

Appendix S - Participant Study Information Sheet

The lived experience of qualified nurses working within an Academic Palliative Care Unit (APCU) within the acute care setting: a phenomenological study.

STUDY SPECIFIC INFORMATION SHEET AND CONSENT FORM

Introduction

We have provided you with this information, as we would like to invite you to consider taking part in a research study that we are currently undertaking. In order for you to decide whether you wish to take part, this information sheet has been created to explain why the research is being done and what it would involve for you, if you decide to take part.

Please feel free to talk to anyone you feel comfortable with about the research before making your decision, however if you have any further questions about the study and wish to contact the researcher again, please feel free to do so using the contact details at the bottom of this information sheet.

What is the purpose of the study?

Research evidence clearly shows that individuals approaching the end of their life benefit from support by Palliative Care (PC) services. However, population and mortality statistics from England and Wales (2006-2014) indicate that if mortality rates increase at the current level, then 160,000 more people will need PC by 2040. The quoted figures indicate that there will be additional demands on the National Health Service (NHS) and pressure on the delivery of PC.

Working in an environment such as PC presents both clinical and personal challenges, requiring professionals to make difficult clinical and ethical decisions, alongside supporting patients, families and other staff. In addition to existing challenges of working in the NHS, the increasing demand for PC provision may produce additional stressors for staff, for example, limited time with patients and families, more complex health conditions and differing disease profiles. The aim of this research is to provide an in-depth understanding of the lived experience of nurses working in an acute academic palliative care unit, how they apply meaning to their role and examine how meanings may impact upon psychological well-being. This research study will involve participants partaking in an in-depth Interview regarding your lived experience of working on this particular unit.

This study will contribute towards a thesis project. The main researcher is currently undertaking her Clinical Psychology Doctorate Training and this study will be conducted as a requirement for that course which is supported through members of staff that work for The Royal Liverpool Hospital and University of Liverpool.

Why have I been approached?

You have been approached as you are a qualified nurse working on the Academic Palliative Care Unit at The Royal Liverpool University Hospital. You have also expressed an interest in taking part in the research. As a qualified nurse you have first-hand experience of working on the PC unit and this insight will be invaluable as part of this research project.

Do I have to take Part?

No. It is up to you to decide whether or not you wish to take part. We would like to reassure you also, that even if you have signed the consent form, you can withdraw from the study at any point, without needing to provide a reason or an explanation. If you decide not to take part in this study, or to withdraw at any point, we would like to reassure you that this will not have any impact on your work or career.

What will happen if I take part?

We will contact you to clarify that you are eligible to take part in the study, then invite you to take part in an in-depth telephone interview, this interview will last for approximately an hour. The interviews will be audio recorded and transcribed by the researcher to develop themes across the transcripts.

With your permission, the researcher will contact you to ask if you would be happy to talk to them about your experience of working on the palliative care unit. If you wish to take part in this interview, it will take place at a time and place most convenient to you (with current COVID19 restrictions, we will conduct the interview by telephone – if restrictions are lifted, this could be done face to face). We expect that this will last no longer than an hour, however this will be determined by you. During this interview, the discussion will be open, and the researcher will ask you to explain in your own words, your experience of working within this particular unit. Your input will help to provide an-depth understanding of the "lived-experience" of nurses, and the meanings that they attribute to the care they provide. We hope the data from this study will contribute to establishing parameters for safeguarding staff and potentially identifying approaches to assist staff in coping with the challenges of this particular setting.

How will my data be used?

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 protective legislation, the *University acts as the Data Controller for personal data collected as part of the University's research. The [Principal Investigator / Supervisor] acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Stephen Mason (maceo@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?	Interview
How will my data be stored?	Electronically on a password protected computer in a password protected file
How long will my data be stored for?	10 years
What measures are in place to protect the security and confidentiality of my data?	The computer is password protected and so if the file containing your information. All information does not contain any personal or identifiable information. Pseudo names will be used.
Will my data be anonymised?	Through the use of pseudo names
How will my data be used?	To be transcribed and analysed to pull out themes
Who will have access to my data?	Researcher (AB and SM)

Will my data be archived for use in other research projects in the future?	It will be archived through the University of Liverpool archiving process
How will my data be destroyed?	Any files will be deleted

What will happen if I don't want the study to carry on? If you change your mind about taking part, even after you have signed the consent form and participated in the interview, you are free to withdraw from the study at any time without giving a reason or explanation. We will withdraw your data from the study analysis if notified of this wish within one month of the interview.

Expenses and Payments

Due to current restrictions due to COVID19 and central guidance from the University of Liverpool, we will be conducting the interviews by telephone. However, should restrictions be lifted, we can conduct the interview face to face if you would prefer. COVID If you participate in the research, the researcher will visit you at your place of work. Any travel expenses you incur will be covered by the research team.

What are the possible disadvantages and risks of taking part?

We do not think that there are any major risks involved in being part of this research. However, it is possible that talking about your experience may prompt some challenging and potentially upsetting memories. Please remember, you do not have to answer questions within the in-depth interview that you do not wish to, and you are free to withdraw from the study at any point if you so wish. If you have any concerns during any stage of the research study, or you experience any distress or upset as a result, you can contact the Chief Investigator for the study (contact details below), who will discuss potential sources of support.

What are the possible benefits of taking part?

It is not intended that this study will confer direct benefits to you, but some participants find taking part in these studies enlightening. It is hoped that the study will provide an understanding the meanings that nurses attribute to their work, and may contribute to establishing parameters for safeguarding staff and potentially identifying approaches to assist staff in coping with challenges found in this particular setting.

Will my taking part in the research be kept confidential?

Yes. We will follow current ethical and legal practice and all information collected will be handled in confidence. However, we may need to breach confidentiality for any issues that may arise where we have a statutory duty to disclose. For example, if during the in-depth interview an issue of malpractice, poor care or abuse is highlighted, the researcher has a professional duty to share such information. The researcher will report the 'incident' in line with current governance and risk arrangements within The Royal Liverpool University Hospital.

With your permission, we would like to collect and store the information you provide as part of the study, for analysis. Data from the interview will be stored in a password protected secure computer, all words spoken during the in-depth interview will be audio recorded and transcribed. You will not be identified by name at any stage – only a number will be used, and only members of the research team (including the transcriber) will have access to the information you provide. The recording will be destroyed and an electronic transcript will be stored. The interview electronic transcript will be stored on a secure network drive in the Palliative Care Institute Liverpool, University of Liverpool, for a period of 10 years after which it will be securely destroyed. With your permission we may also like to use some direct quotes from your interview to illustrate the findings of the study in presentations and research articles published in professional peer reviewed journals; these will be presented anonymously. You will not be named in any reports or published articles. Any interview transcript and analysed materials will be kept in a locked filing cabinet in the Palliative Care Institute Liverpool, University of Liverpool for 10 years after which they will be securely destroyed.

What will happen to the results of this study?

All of the information that we collect will be brought together and analysed to help us to develop a better understanding of the experience of being a qualified nurse working within a specialist academic palliative care unit. The results will be written up as a thesis project for the University of Liverpool as part of the researchers Clinical Psychology Doctorate Training. We also intend to publish the findings in professional journals and make presentations to national and international research conferences to make sure that the messages from this study are shared widely and appropriately.

Who is organising and funding the research?

This research is sponsored by the University of Liverpool.

Who has reviewed the study?

This proposal has been reviewed and approved by Liverpool University Ethics Committee, which is a committee whose task it is to make sure that research participants are protected from harm. Details of the chair of that committee can be provided when requested.

Please note

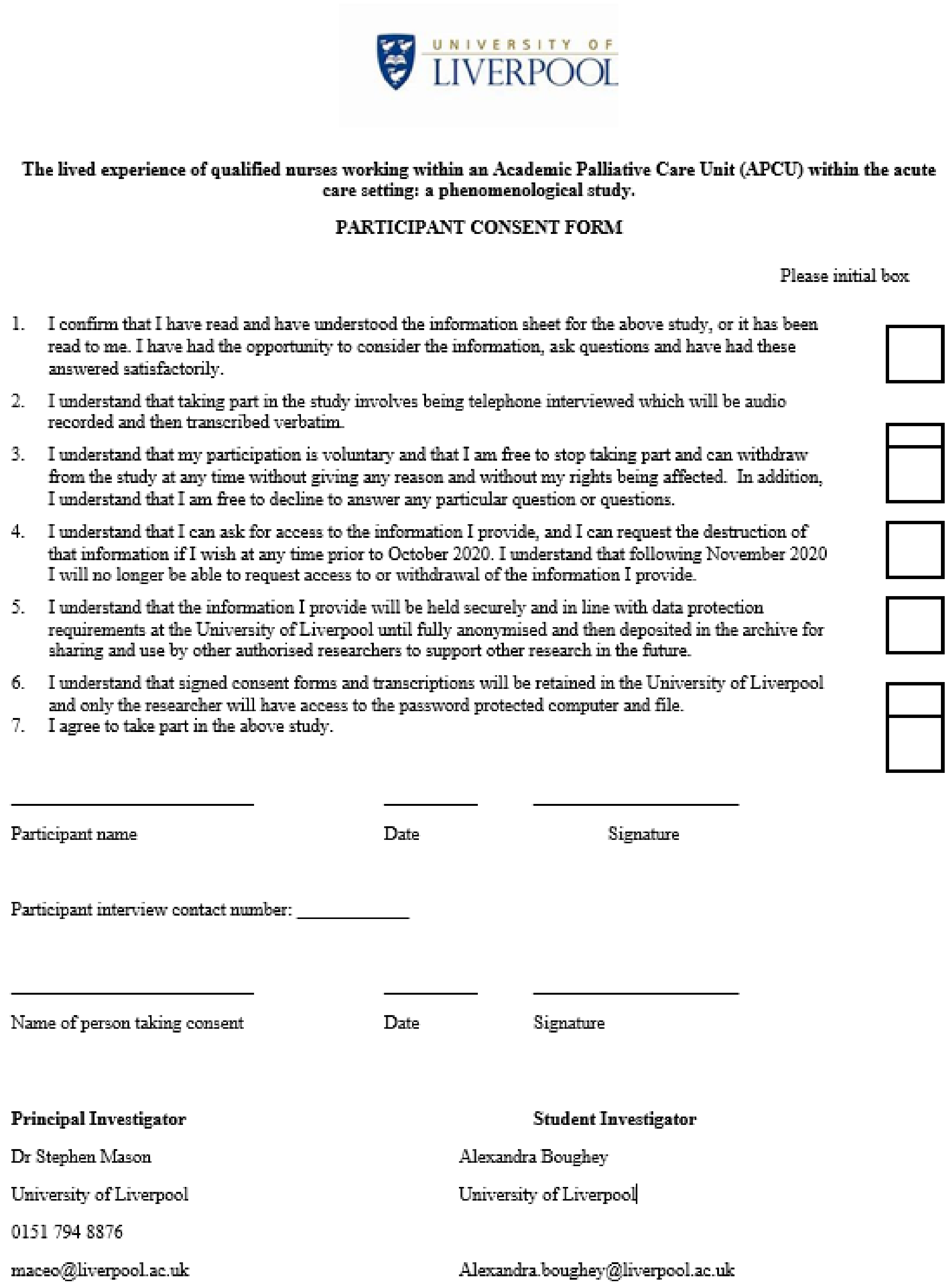
If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (see contact information below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from The Royal Liverpool University Hospital.

Further Information

If you would like any further information about this study please contact:

Principal Investigator	**Student Investigator**
Dr Stephen Mason	Alexandra Boughey
University of Liverpool	University of Liverpool
0151 794 8876	
maceo@liverpool.ac.uk	Alexandra.boughey@liverpool.ac.uk

Appendix T - Participant Consent Form



UNIVERSITY OF LIVERPOOL

The lived experience of qualified nurses working within an Academic Palliative Care Unit (APCU) within the acute care setting: a phenomenological study.

PARTICIPANT CONSENT FORM

Please initial box

1. I confirm that I have read and have understood the information sheet 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 that taking part in the study involves being telephone interviewed which will be audio recorded and then transcribed verbatim. ☐
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 October 2020. I understand that following November 2020 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 fully anonymised and then deposited in the archive for sharing and use by other authorised researchers to support other research in the future. ☐
6. I understand that signed consent forms and transcriptions will be retained in the University of Liverpool and only the researcher will have access to the password protected computer and file. ☐
7. I agree to take part in the above study. ☐

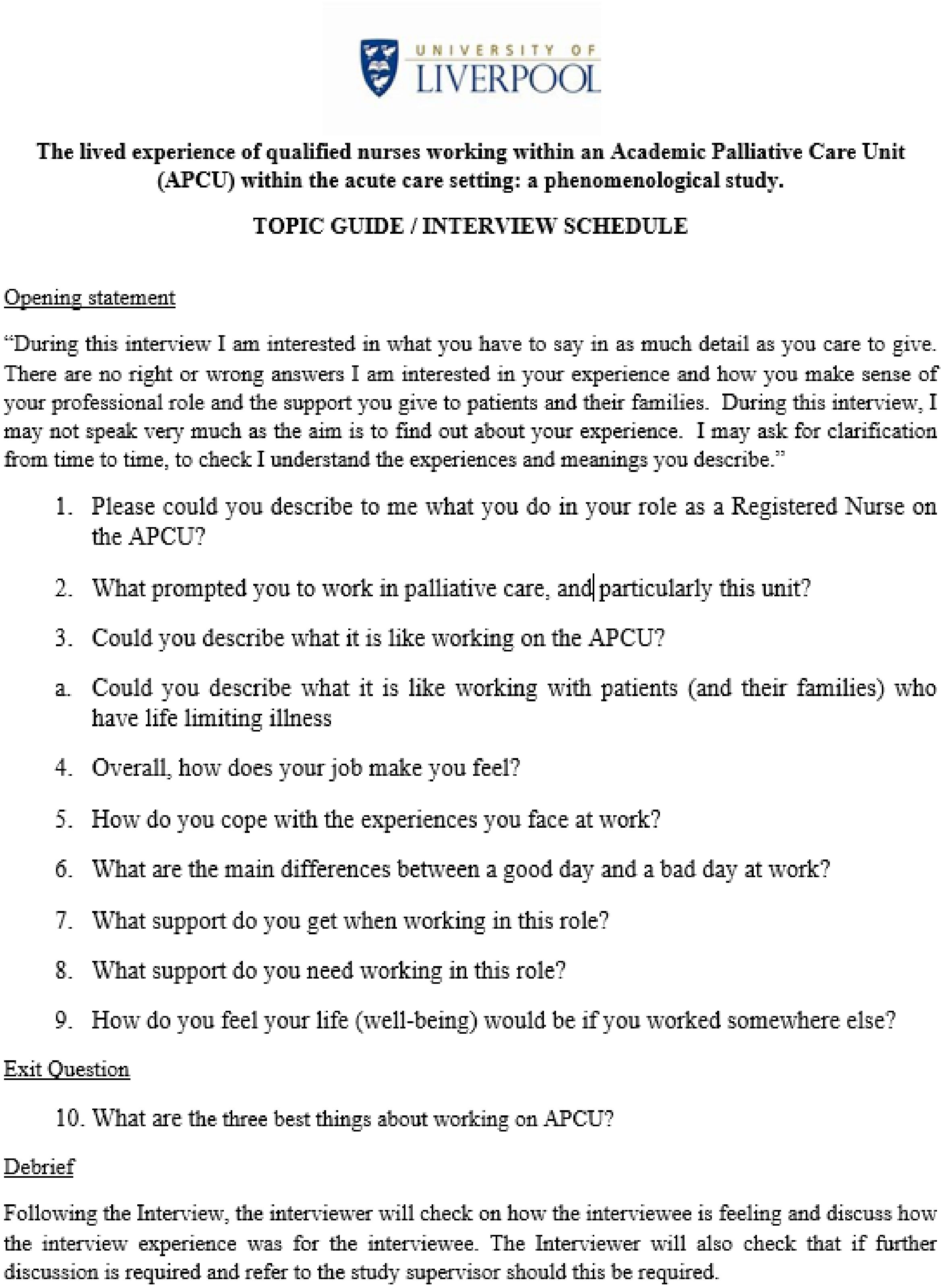
______________________	________	__________________
Participant name	Date	Signature

Participant interview contact number: ____________

______________________	________	__________________
Name of person taking consent	Date	Signature

Principal Investigator	**Student Investigator**
Dr Stephen Mason	Alexandra Boughey
University of Liverpool	University of Liverpool
0151 794 8876	
maceo@liverpool.ac.uk	Alexandra.boughey@liverpool.ac.uk

Appendix U - Topic Guide



The lived experience of qualified nurses working within an Academic Palliative Care Unit (APCU) within the acute care setting: a phenomenological study.

TOPIC GUIDE / INTERVIEW SCHEDULE

Opening statement

"During this interview I am interested in what you have to say in as much detail as you care to give. There are no right or wrong answers I am interested in your experience and how you make sense of your professional role and the support you give to patients and their families. During this interview, I may not speak very much as the aim is to find out about your experience. I may ask for clarification from time to time, to check I understand the experiences and meanings you describe."

1. Please could you describe to me what you do in your role as a Registered Nurse on the APCU?
2. What prompted you to work in palliative care, and particularly this unit?
3. Could you describe what it is like working on the APCU?

a. Could you describe what it is like working with patients (and their families) who have life limiting illness

4. Overall, how does your job make you feel?
5. How do you cope with the experiences you face at work?
6. What are the main differences between a good day and a bad day at work?
7. What support do you get when working in this role?
8. What support do you need working in this role?
9. How do you feel your life (well-being) would be if you worked somewhere else?

Exit Question

10. What are the three best things about working on APCU?

Debrief

Following the Interview, the interviewer will check on how the interviewee is feeling and discuss how the interview experience was for the interviewee. The Interviewer will also check that if further discussion is required and refer to the study supervisor should this be required.

Appendix V – Position Statement

Appendix __ - Position Statement

I am a 26-year-old white, female, trainee clinical psychologist, with lived experience of family members having contact with Palliative Care (PC) services. My interest in the lived experience of professionals working in PC stemmed from this personal experience but also developed through my professional experience working within physical health psychology services.

When working within physical health services it became apparent how much support patients and their relatives received, when on a PC pathway. It caused me to reflect on how much support staff were getting when working in such a highly emotive environment. During my time within a PC pathway as relative I struggled to see how staff had time for their own support and reflected on how staff maintain a high level of patient care when having to manage the emotions of others alongside their own.

When working as an Assistant Psychologist in an acute hospital I came across a patient that wanted to withdraw from his dialysis treatment. Staff were extremely angry about the fact that this patient wanted to refuse treatment which would subsequently end his life. Staff struggled with being able to support this patient to have conversations around dying and his wishes which caused the patient to disengage from services. Again, this sparked an interest into how nurses cope with having difficult conversations with patients around death and how as a nation death and dying is often a topic left unspoken.

My hope is that, together, this research and systematic review will start to build a picture of the lived experience of qualified nurses working within PC settings and allow staff space to talk about death and dying in a way that is helpful. From this, I hope I can develop new ideas and recommendations that will increase understanding and enable safer and supportive environments for staff.

Expectations of Findings

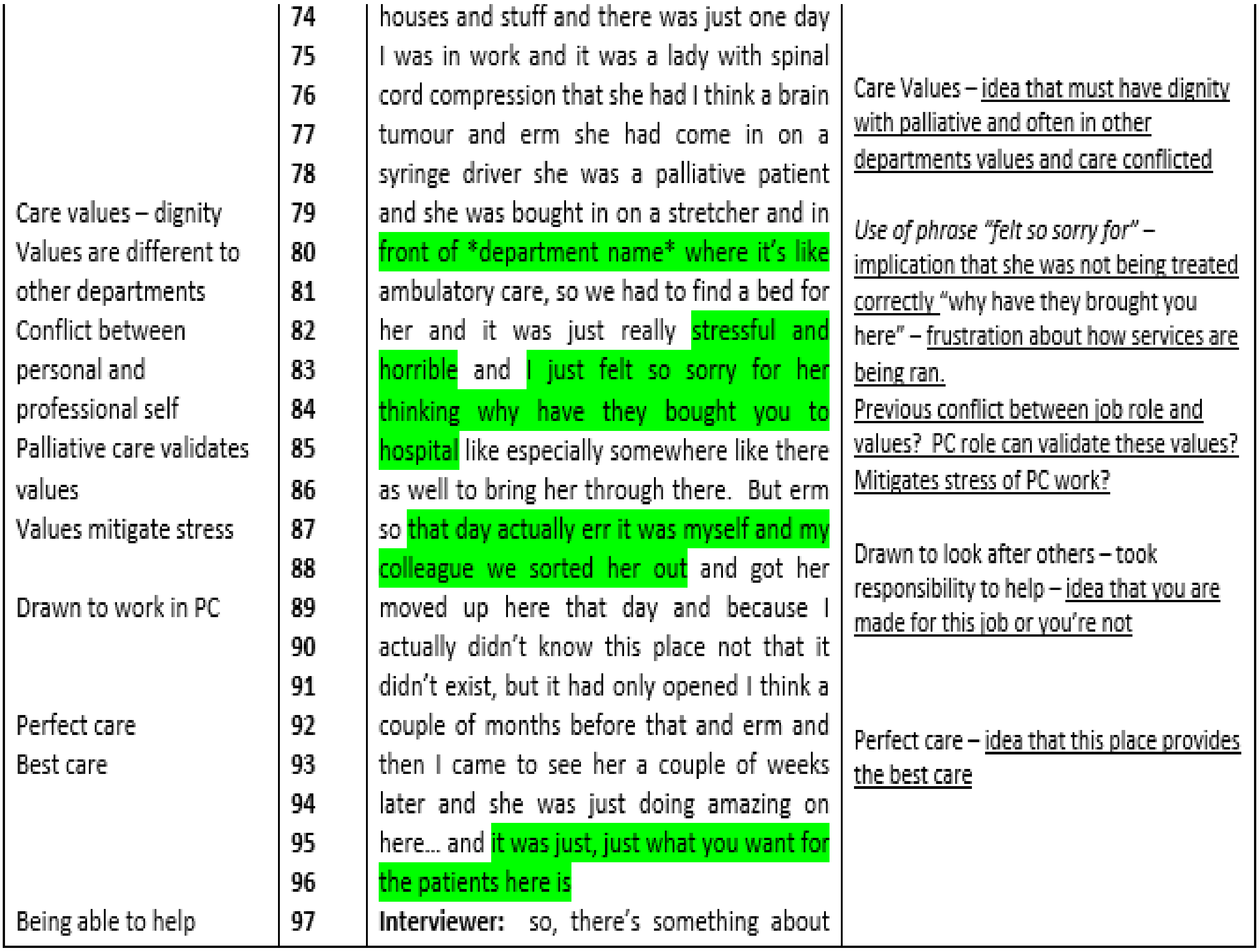
I expect to find different experiences across qualified nurses however, consistent themes highlighting the lack of support and the inability to communicate their own psychological well-being. I suspect that their role will play a part in their experience hence the reason for picking a particular profession to focus on. For instance, as nurses have a high level of bedside contact this may also have an impact on the experiences they have and their psychological well-being.

Overall, I feel that I will find that there is a culture within qualified nurses that it is negative to talk about your own mental health and that focus must be on the patient and families they are supporting. The needs of the professional coming second to the needs of the patients and their families.

Appendix W – Analysis Procedure and Audit Trail

1. Following interview an entry was made within my reflective diary based on experience, feelings and dynamics present during interview.
2. After completing all the interviews, they were then transcribed onto a word document or listen to audio then send to transcriber for transcription.
3. Read and re-read transcripts making line by line coding in right hand column of any descriptive, conceptional or linguistic themes.
4. During line-by-line coding, highlighted any areas of rich data or stand out words of phrases.
5. Repeated steps 1-4 for each of the 8 interviews.
6. Emergent Themes – used the left-hand margin to jot down any emergent themes from the initial notes, areas of rich data, and standout phrases. This was completed for each transcript separately.
7. Once completing this for each transcription the emergent themes were transferred to an excel database under new tab for each participant. Then coloured coded the emergent themes into similar clusters for each participant individually (See appendix U).
8. Once clusters for each participant were developed, we then used individual clusters to generate across participant clusters (See appendix V).
9. Developed clusters into sub themes and explored overarching subordinate themes (See appendix V).

Appendix X – Example of Transcription Coding



	74	houses and stuff and there was just one day	
	75	I was in work and it was a lady with spinal	
	76	cord compression that she had I think a brain	Care Values – idea that must have dignity with palliative and often in other departments values and care conflicted
	77	tumour and erm she had come in on a	
	78	syringe driver she was a palliative patient	
Care values – dignity	79	and she was bought in on a stretcher and in	*Use of phrase "felt so sorry for"* – implication that she was not being treated correctly "why have they brought you here" – frustration about how services are being ran.
Values are different to	80	front of *department name* where it's like	
other departments	81	ambulatory care, so we had to find a bed for	
Conflict between	82	her and it was just really stressful and	
personal and	83	horrible and I just felt so sorry for her	
professional self	84	thinking why have they bought you to	Previous conflict between job role and values? PC role can validate these values?
Palliative care validates	85	hospital like especially somewhere like there	
values	86	as well to bring her through there. But erm	Mitigates stress of PC work?
Values mitigate stress	87	so that day actually err it was myself and my	
	88	colleague we sorted her out and got her	Drawn to look after others – took responsibility to help – idea that you are made for this job or you're not
Drawn to work in PC	89	moved up here that day and because I	
	90	actually didn't know this place not that it	
	91	didn't exist, but it had only opened I think a	
Perfect care	92	couple of months before that and erm and	Perfect care – idea that this place provides the best care
Best care	93	then I came to see her a couple of weeks	
	94	later and she was just doing amazing on	
	95	here... and it was just, just what you want for	
	96	the patients here is	
Being able to help	97	**Interviewer:** so, there's something about	

Appendix Y- Context to the Sample

Staffing Ratio/ Issues

At the time the empirical analysis was conducted the Academic Palliative Care Unit had a staffing ratio of one qualified nurse to six patients alongside a nurse coordinator that would support either side of the unit. The unit is usually divided in half with a one qualified nurse running each side. Each qualified nurse is responsible for two side rooms and a bay of four patients. Three healthcare assistants support both sides of the unit. When the ward is at maximum capacity it can hold 12 patients. Student nurses and Trainee Nursing Associates would be facilitated on placement, but where not included within the establishment as active carers.

When recruiting for the study there had been several staff changes. Firstly, the ward manager had been seconded out to another department, and a band 6 nurse back filled this role as interim ward manager. Having a band 6 step up into this role left a spare band 5 vacancy which was not yet filled. Two new band 5 nurses were due to start during the time of recruitment, one of which was back filling the band 5 role that was currently vacant. Finally, two nurses were due to leave the unit to take up jobs in other departments within a different trust. Overall, the different staffing changes may have impacted on the findings, highlighting a lack of support and organisational challenges within this setting.

The unit is staffed for highly complex patients, however with it being an acute setting the duty manager could redeploy nursing and care assistant staff to other areas. Nursing staff do not have any control over whether they can have empty beds as this is governed by the organisation. Hospice settings can be more protected in that they have more control over the admissions they receive, whereas this palliative care unit does not have the facility to control admissions onto the unit. This may show a lack of understanding from an organisational level about what palliative care entails.

Due to the COVID-19 pandemic while conducting recruitment two healthcare workers were shielding at the time and this may have contributed to the extra responsibility that staff where experiencing.

Shift Patterns

Most staff have a shift pattern of three long days a week which last for 12 hours each equating to 37.5 hours a week as per agenda for change. The shifts often run from 7am until 7pm for the day and 7pm to 7am for the night shift. All staff rotate across day and night shifts however depending upon personal circumstances some nurses may work more nights or weekends than others.

Delayed Transfer of Care

During the time conducting the study delayed transfer of care was not a problem due to the NHS COVID discharge support, as the NHS agreed to pay for everything to free up the movement within the hospital. However, this may not be the case if we were to review this at the present day.

Length of Stay

Patients with the highest average length of stay were those that were discharged to a new care home (30 days). Patients who were discharged back to a hospital ward had an average length of stay of 19.2 days. Patients who were discharged home had a similar average of 15.3 and 12.3 days respectively. Patients discharged to a hospice had a mean length of stay of 9.9 days and the lowest average length of stay was from patients who die after being admitted to the unit (6.8 days). Those who were admitted at the unit from an emergency assessment unit had a shorter average length of stay 7.8 days compared to those admitted from a general hospital ward (10.6 days).