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Improving End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness - An Exploratory Study of the Experience and Perceptions of Mental Health and End of Life Care Clinicians

Jerwood, Jed S

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Jerwood, J. S.

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Master of Science by Research in Clinical Practice:

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By

Jed Samuel Jerwood

June 2016

Master of Science by Research in Clinical Practice

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Improving End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness - An Exploratory Study of the Experience and Perceptions of Mental Health and End of Life Care Clinicians

By

Jed Samuel Jerwood

June 2016

A thesis submitted in partial fulfilment of the University's requirements for the Degree of Master of Science by Research in Clinical Practice

Coventry University

Abstract

Background

People with mental illness experience higher rates of many life-limiting conditions and die on average twenty years earlier than the general population. The researcher observed that people with mental illness appeared to be under-represented in hospice care. A literature review was carried out which revealed limiting research concerning the end of life needs of people with long term mental health conditions. The role of clinical staff was highlighted as a key factor, yet their views were not reflected in the published research. There were very limited studies originating in the UK.

Aim

The aim of this research was to conduct an exploratory study to develop further understanding of how to improve end of life care for people with long term mental health conditions through exploring the views, experiences, attitudes and insights of clinical staff working in both mental health and end of life services.

Method

Four focus groups with clinicians were conducted, using the CUbe method (Magee et al 2015), across a large Mental Health Trust and a hospice. 23 participants from a range of professional backgrounds attended and shared their experiences and perceptions of the barriers to delivering good end of life care to people with mental illnesses. The data was analysed using the Framework Method and themes and explanatory concepts were drawn.

Findings

The findings of the study were clustered into five themes: Structural and Systemic Factors, Patient Factors, Clinician and Service Factors, Partnership Factors and Solutions and Improvement Factors. Explanatory concepts were developed from the themes which can be used to inform innovations and improvements to practice.

Conclusion

The barriers to providing good end of life care were described within the literature, which largely originated outside the UK. The findings of the data analysis found many similarities and some new findings. Recommendations were made which include improvements to partnership working, involvement of patients, carers and clinical staff in improving care and the need to develop the confidence, knowledge and skills of clinical staff from both mental health and end of life services.

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Contents

Appendices

List of Illustrations and Figures

1.0 Introduction

The aim of this research study is to explore the experiences and perceptions of clinical staff, in both mental health and end of life care services, in contemporary, UK-based clinical settings, on providing end of life care for people with long term mental health conditions and terminal illnesses. It aims to identify barriers to provision of services and identify potential improvements to clinical practice, from a clinician perspective.

The initial research question arose from clinical observations by the researcher in mental health and end of life care clinical practice. Patients in mental health services appeared to have higher rates of many life-limiting illnesses, but were under-represented in hospice care. An initial review of the published literature revealed a lack of research within the United Kingdom (UK) regarding the end of life care needs of patients with long term mental health conditions and co-existing life-limiting or terminal illnesses. The limited pool of research led the researcher to undertake an exploratory study, using qualitative methodology. Although some studies exist, carried out internationally, which explore some of the difficulties of providing good end of life care to people with long term mental illnesses when they become terminally ill, there are limited research studies concerning the ways care can be improved.

The researcher’s professional and personal beliefs and values shaped the decisions behind the choice of approach, methodology and methods. The research topic was approached from an equalities perspective and a value base which includes challenging discrimination and prejudice and improving care for the most marginalised individuals and groups (Scullion 2009: 699). Direct experience of working with patients with mental illness, as they struggled to access the services of the hospice where the researcher is employed, led him to question the quality and provision of end of life care.

The researcher's professional background is in art psychotherapy. Art psychotherapy places the making of images and objects at the centre of the therapeutic relationship between therapist and patient. The selection of data collection method was informed by the researcher's professional practice and the belief that providing additional methods, alongside verbal discussion, for participants to share their views and experiences would add a richness and depth to the data collected, and therefore an added dimension to the understanding of the research topic.

The research study was also informed by a belief that clinical staff often hold answers to clinical problems, but do not often have a voice or power to influence change. The initial review of literature, and the researcher's clinical observations, highlighted limited and lower quality care to this particular group of patients. However, the researcher was motivated to investigate whether pockets of good practice exist, and to capture and include these alongside clinicians' views of where improvements could be made and barriers to good care delivery overcome.

The researcher's belief that learning can be shared from other areas of clinical practice and that care can be improved by understanding the experiences and perspectives of those providing it (as well as those receiving it, although not within this stage of the research) underpinned the development of the research question, choice of methodology and data collection and analysis methods.

1.1 Research Question, Aim and Objectives

From the perspectives of mental health and palliative care clinicians, what are the barriers to providing end of life care for people with long term mental health conditions, and how can care be improved?

Aim

- To conduct an exploratory study, based in contemporary, UK-based clinical practice, to develop further understanding of how to improve end of life care for people with long term mental health conditions

Objectives

- To explore the views of mental health and end of life care staff on current clinical practice in providing end of life care to people with long term mental health conditions
- To gather the views, experiences, attitudes and insights of clinical staff working in both mental health and end of life services
- To gain understanding of the barriers to providing end of life care
- To identify possible improvements to current practice and care pathways

1.2 Background and Rationale

Adults with long term mental illness die on average 20 years earlier than the general population (Brown, Mitchell and Inskip 2010:116). These patients are more likely to live in poverty, find it harder to find and stay in employment, are more likely to live in poor housing or be homeless and are more likely to have poor physical health – due in part to higher rates of smoking, alcohol and substance use and poor diet (Department of Health 2013: 2).

The Parity of Esteem agenda (R C Psych 2013) is a key priority for NHS England and focuses on improving the disparities between physical and mental healthcare services, and also improving the opportunities for people with mental illness to access good physical health care services, including end of life and palliative care, where appropriate. Indeed, the All-Parliamentary Group on Mental Health (Department of Health 2013) identified that people with long term mental health problems typically have less choice of services and less control over the kind of support they need – and this is also the case in relation to accessing end of life care. The Mental Health Foundation (MHF 2008) carried out a literature review which identified a significant gap in published research regarding this client group at the end of life, noting an urgent need for further research to understand the needs of people with long term mental ill health and terminal illness in end of life care (MHF 2008: 12).

People with long term mental illness are often diagnosed with terminal illnesses much later than the general population, often because of difficulties accessing GP services, communicating symptoms, lack of trust and not being taken seriously by healthcare staff (Department of Health 2013). Therefore, it would be expected that a higher rate of people with mental health diagnoses would need end of life and palliative services (Woods et al 2008: 726).

The national End of Life Care Strategy (Department of Health 2008) seeks to improve the provision of care to people at the end of life. It identifies that not all groups or individuals have equal access to end of life services, and that many people do not die in their preferred place and many more people die in hospital. The National Institute for Health and Care Excellence (NICE) quality standard for end of life care for adults states that ‘people with advanced life threating illnesses and their families should expect good end of life care, whatever the cause of their condition’ (NICE 2014).

Since the publication of the strategy, there have been initiatives to raise awareness of end of life issues, promote discussions about death and dying and encourage planning for the end of life. Initiatives such as Dying Matters (http://www.dyingmatters.org) and organisations such as the National Council for Palliative Care (http://www.ncpc.org.uk/) have campaigns and resources available to support this, but have not focused on the specific needs of the long term mental health population in their attempts to target potentially marginalised or excluded groups such as black and minority ethnic communities, people with learning disabilities or lesbian, gay, bisexual and transgender people.

The Palliative and End of Life Priority Setting Partnership (PeolcPSP), supported by the James Lind Alliance, published the top ten priorities for research in palliative and end of life care in 2015. Whilst understanding the needs of people with long term mental health problems are not cited within the top ten priorities, adequate staff training to deliver palliative and end of life care, no matter where it is being delivered, is one of the top ten priorities. Other relevant priorities include improving access to end of life care for everyone, improving advanced care planning, out of hours care, improving continuity of care at the end of life and improving end of life care for non-cancer diseases (PeolcPSP 2015: 24). In addition, improving care co-ordination, training and staff support, managing distress and improving access to hospice care are also pertinent to this study and apply to people with long term mental illness and palliative care needs as well as the general population. It is perhaps also relevant that the needs of people with long term or pre-existing mental illness were not highlighted within the listed priorities when other marginalised groups, for example were included.

In 2015, a report ‘Equity in the Provision of Palliative Care in the UK: A review of Evidence’ was published (Dixon et al 2015) which examined inequities in access to and provision of palliative and end of life care. Several factors such as diagnosis, age, ethnicity, marital status (or having a partner) and sexual orientation were considered in relation to end of life care quality. The needs of people with long term mental health conditions were not addressed in this report, despite clear findings in the MHF review (2008) which called for further research to be carried out.

1.3 Structure

This thesis is presented as a series of chapters. Following the introductory chapter, which outlines the background to the research question and the study aims and objectives, chapter two is a review of the published literature. The search strategy and appraisal methods are outlined and a summary of the themes within the literature is presented.

Chapter three outlines the methodology and research methods used for data collection and analysis. Focus groups were conducted, using multiple methods of data collection, including the CUbe method (Magee et al 2015) and a Framework Analysis of the findings was carried out. The process for analysis of the data and the development of the analytic framework are outlined and illustrated with extracts from the raw data to illustrate the analysis process. Transcripts of the focus groups, the data collected on the CUbe and the post-it notes which participants could complete anonymously, were all analysed using the same method and an analytic framework developed and applied to each group of data.

Chapter four presents the findings from the data analysis. Findings are presented as a series of themes which were developed from the coding and application of the analytic framework. Each theme is supported by relevant quotes taken directly from the transcripts and source data to ensure the analysis remains true to the original participant account. Explanatory concepts were developed from the themes and provide a structure from which improvements to the delivery of care can be developed.

Chapter five presents a discussion of the findings and links the themes and concepts synthesized from the data analysis to the findings within the literature review. Recommendations, implications for practice and the limitations of the study are presented and the conclusions of the dissertation are stated.

2.0 Literature Review

2.1 Rationale for literature review

This chapter presents the results of a literature review, intended to help give a greater understanding of what the published literature says about the factors which affect the provision of end of life care for patients with long term mental illnesses who develop a life-limiting or terminal illness, and how care can be improved.

As explained in Chapter 1.0 Introduction, the research question arose from observations within the researcher's clinical practice in adult mental health services and hospice care. Whilst long term mental health service users appeared to experience higher rates of many different life-limiting conditions there appeared to be very few people with mental illness within the services the hospice provided. Those who were referred often arrived into the services late in their illness, provoked anxiety within the staff team and found it difficult to engage in the breadth of services on offer at the hospice. These observations were followed by a review of the End of Life Strategy for the city where both organisations were based, and a review of the National End of Life Care Strategy (2008) published by Department of Health. Neither document appeared to include actions or objectives in relation to people with long term mental health problems, despite mentioning other potentially excluded groups - Black and Minority Ethnic communities (BME), the lesbian, gay, bisexual and trans (LGBT) community and people with learning disabilities.

An initial search was undertaken which focused on understanding what factors affect the provision of end of life care for patients with long term mental illnesses who develop a life-limiting or terminal illness; and how care can be improved. This revealed limited robust evidence. Therefore, it was decided, for the study, a more comprehensive search was required.

2.2 Methodology

2.2.1 The Search Strategy

A review, using a robust, systematic approach to searching the published literature, was conducted from November to December 2015, using consistent search terms and subject headings. The SPIDER tool (Cooke et al 2014) was used to refine the research question and guide the search for published literature. Search tools such as PICO (Cooke et al 2014: 1436), have been used to enhance rigour in searching for literature, but have been developed for searching for quantitative studies. The SPIDER tool, shown in Table 1, was developed to enhance rigour in searching for qualitative and mixed methods studies, which the topic for this literature review was likely to include.

Sample	Mental Health, Palliative Care, Staff, Patients
Phenomena of Interest	Access to end of life care for patients with long term mental health conditions, barriers to accessing end of life care for people with long term mental health conditions
Design	Research studies – observational, questionnaire, interviews, case studies
Evaluation	Experiences, barriers, factors, outcomes, views impacting on access to end of life care, provision of palliative care
Research	Qualitative, mixed-methods

Table 1 SPIDER tool

2.2.2 Inclusion and Exclusion Criteria

Due to the variety of terminology used to describe similar issues and conditions, the search terms were expanded to cover the most common clinical language used across mental health and palliative care, as illustrated in Table 2.

Published papers (there was a limited pool of empirical studies, so case studies, practice papers and discussion papers were also included) were excluded, if they focused on depression and anxiety which had developed following a life-limiting diagnosis. Dementia studies were also excluded, as dementia is a specific condition, which is life-limiting in itself – this is not to say people with long term mental ill health do not also develop dementia, however this search aimed to find papers concerned with long term mental health service users, who develop terminal illnesses, accessing end of life care. Studies were included when they concerned patients with diagnosed mental illnesses – (defined in the International Classification of Diseases ICD-10 published by the World Health Organisation (WHO 2010) and used as diagnostic criteria in UK mental health services) such as schizophrenia, schizoaffective disorder, psychosis, bi-polar disorder, anxiety disorders and chronic depression. Personality disorder diagnosis was also included. People who are long term mental health service users have usually been diagnosed with at least one of these conditions. Studies in languages other than English were excluded. The research study was concerned with contemporary practice and current issues impacting on the access to and experience of palliative care, rather than a historical perspective, so papers published before 2000 were also excluded. The year 2000 was chosen as the limit of the search as the end of life care strategy in England was released in 2008 and the researcher was concerned to capture papers which were published in the period leading to the publication of the strategy. In addition, much of the available literature originated overseas, and several papers were published in 2002/03 which the researcher felt it was important to include, given the limited pool of research published within the UK.

Search Terms	Terms and Combinations
Mental Health	“Mental Health” or “mental illness” or “enduring mental ill health” or “secondary mental health” or “psychiatric patient”
Palliative Care	“Palliative” or “end of life” or “terminal” or “hospice” or “life-limiting”

Table 2 Search terms used

The initial search of the databases highlighted that it was impossible to distinguish, through the search criteria, studies which concerned mental health conditions (such as depression and anxiety) which some terminally ill patients developed as a result of their diagnosis, and studies concerning people with pre-existing mental illness who developed terminal illness and therefore required end of life care. Therefore a manual review of the search results was undertaken to exclude those articles which fell outside the review remit.

2.3 Quality Assessment and Data Synthesis

A manual review of results by title and abstract was carried out which greatly reduced the number of relevant studies from over 1000 to 26. Papers which met the inclusion criteria were critically appraised to assess the quality of the research undertaken.

Fig. 1 adapted PRISMA diagram (Moher et al 2009)

Studies were appraised using Garside's (2014) Critical Appraisal Tool (see Appendix 1a) which offers a structured approach to the appraisal of qualitative studies and therefore enhances the rigour of the process of identifying studies for inclusion in the review. Critical appraisal of literature is important in ascertaining the quality of the research, the relevance to the study and in becoming familiar with the content (Aveyard 2014: 99)

Only ten of the papers appraised were empirical studies (including two case studies) but due to the limited database, it was important to include all available and relevant studies. In addition to the ten empirical studies, the body of literature included practice papers, two reviews of literature and discussion papers. Although of variable quality, all papers contributed useful data to the review.

A thematic analysis of the papers was undertaken (see Appendix 1b). As there was such a limited pool of research available, all potentially relevant themes were noted. Themes were listed, then clustered into overarching themes as illustrated in Table 3. Themes were identified as major or minor, relating to how often they arose across the literature, and presented in the findings section below.

2.4 Results

Four overarching themes arose from the thematic analysis of the literature.

- Patient Factors
- Clinician factors
- System/Structural Factors
- Improvements and Solutions

Within each overarching theme are sub-themes, illustrated in Table 3. Major sub-themes, those which arose in multiple papers, multiple times, are highlighted in blue. Other themes which did not arise so often, but which appear to have significance to the review have been included because the pool of literature is small, so an inclusive approach to identifying themes was adopted. The researcher did not apply a list of pre-identified themes to the analysis of the studies because the topic was not widely researched.

THEME	**SUB-THEME**
Patient Factors	Prevalence rates Poor health outcomes Social and Family Issues Behavioural Issues Issues in EOL settings Patient desires/beliefs Capacity and Consent
Clinician Factors	Expertise and Confidence Fear of escalating risk – leading to avoidance of EOL discussions and planning Fear of legal action/lack of understanding of legal issues Assumptions about capacity and consent Poor understanding of advanced care planning and resuscitation practice
System/Structural Factors	System design Training of healthcare staff
Improvements and Solutions	Training Issues • Mental health awareness for palliative care staff • End of life/palliative care awareness for mental health staff • Assessing capacity and risk assessment • Techniques for working with challenging behaviours/personalities • Prescribing advice/medication management • Legal Issues • Communication Skills Multi-disciplinary/Partnership Working including with family • Specialist MH role within EOL teams • Integrated approach between MH and EOL services, incorporating social work, family and other services as

	appropriate • Individualised care planning across agencies Qualities/Skills of staff • The ability to work within boundaries, whilst bringing flexibility to meet patient needs • High levels of self-care • High levels of resilience Policy and Practice • Development of policies, procedures and strategy – standardisation of process

Table 3 Summary of Thematic Analysis with significant themes highlighted in blue

2.4.1 Patient Factors

Five studies (Bloomer et al 2013; Chochinov et al 2004; Durkin et al 2003; Terpstra and Terpstra 2014 and Woods et al 2008) make attempts at estimating the prevalence rate of both mental illness and of rates of life limiting illness in patients with long term mental illness. However, the accuracy of these prevalence attempts were questionable, partly due to the different definitions of mental illness. For example, Bloomer et al (2013) estimate that one in five Australians suffer from chronic mental illness, which is defined as mental illness that lasts for more than 12 months. Whereas Terpstra and Terpstra (2012) state that an estimated 6% of the adult population has a chronic mental illness. Different terms are used – schizophrenia and personality disorder are mentioned in several studies specifically, other studies use ‘Severe and Persistent Mental Illness (SPMI)’ or ‘serious mental illness’ ‘psychiatric patient’ or ‘enduring mental illness’. For the purposes of this review, all papers concerning what would be described in the UK as long term mental illness have been included. Use of different definitions and the breadth of life-limiting and terminal diagnosis which may be experienced make it difficult for prevalence to be accurately determined.

The link between poor physical health and poor mental health is clearly made across the body of literature. Bloomer et al (2013), Ganzini et al (2010), and MHF (2008) helpfully outline the reasons behind this – which link to some of the behavioural and social factors identified – people with long term mental illness are less likely to make use of preventative measures and screening available and present for treatment and diagnosis much later than the general population, which leads to poor prognosis and advanced progression of disease. Terpstra et al (2014) use a case study of a patient with schizophrenia to illustrate this. Social factors identified include poor diet, less physical exercise, greater rates of smoking and use of substances, including alcohol. Poor housing and limited family and social relationships are also highlighted as more common within people with long term mental illness.

The challenges the patient group can present within an end of life care setting are described across the literature. Although challenging behaviour of mentally ill patients as a barrier was a minor theme rather than a major one, it is significant when considering how staff work with patients and underpins some of the issues explored in Clinician Factors. Feely et al (2013) and Hill (2005) explore the challenges of working with patients with borderline personality disorder in a palliative care setting. Terpstra and Terpstra (2012 and 2014) explore the challenges of working with patients with long term schizophrenia diagnosis. These four papers are useful for the clinician working in palliative care as they explore helpful techniques for managing difficult behaviours outside a mental health setting.

The literature reviewed supported the assumption that delivering end of life care to people with long term mental illnesses can be challenging due to the circumstances and behaviours of the patient. In addition to the circumstances and behaviours of the patient, the assumption that patients lacked capacity and did not want to think about or talk about end of life care was prevalent amongst the clinician population (Candilis et al 2004; Geppert et al 2011; Terpstra and Terpstra 2012; Woods et al 2008). However, studies by Foti (2005) and Sweers et al (2013) explored the end of life preferences and views, beliefs and desires of mental health patients. Foti's study asked 150 patients with serious mental illness to consider two scenarios – management of pain and delivery of life support interventions. Patients were asked to state treatment preferences first for the patient, and second for themselves, if they were in the same situation. Foti's study demonstrated that patients were both able and willing to participate in these conversations. Sweers' study consisted of twenty interviews with patients with schizophrenia. Grounded theory was used to build understanding of the views and beliefs and priorities of the patient group. Despite symptoms associated with schizophrenia, such as emotional flattening and cognitive deficits, patients were able and willing to explore treatment preferences, feelings about death and dying, what they needed from clinical staff ('skilled companionship'), maintaining quality of life and autonomy, the desire not to die alone and the importance of social support. The notion of home was also explored and the importance of the institution as home, for some patients, was noted in both studies.

Contrary to the beliefs and fears of clinical staff, outlined under 2.4.2 Clinician Factors, patients were able and expressed desire when asked, to discuss end of life issues and had capacity and ability to consent to treatment. That is not to say capacity does not fluctuate and negate the need for regular assessment, but the assumption of lack of capacity should be challenged.

2.4.2 Clinician Factors

Many of the themes identified within the analysis related to the role of the clinician – both in end of life care services and mental health services, in delivering effective end of life care. Many of the barriers to delivering good care to this patient group related to the confidence and expertise of clinical staff.

Some of the reasons for this are dealt with in the sections relating to structural and systemic issues, such as staff training in specialisms and the design of services leading to 'silo' working. 'Silo' working is a common term for working in professional groups or within individual services, and is usually used to indicate working in isolation (Taylor-Robinson et al 2012: 8).

However, all the studies reviewed made reference to specific issues regarding the fears and anxieties of staff – both in palliative care and in mental health services, about addressing issues of death and dying – which impact on care quality. Durkin et al (2003) highlighted the lack of expertise of palliative care staff in identifying and working with mental health difficulties. Durkin’s study assessed prevalence of mental illness in a cohort of 224 patients admitted to a palliative care unit. In assessing patients to establish those with previous mental illness, Durkin et al highlight the role of palliative care staff in noticing and assessing mental ill health – especially where referral information is incomplete.

More than half the studies, but particularly Foti et al (2005), Geppert et al (2011) and Hill (2005) explored the fear in clinical staff in mental health services and in palliative care, of initiating end of life care discussions in mental health patients. Clinical staff expressed fear of creating emotional instability and escalating risk, particularly in patients with depression, schizophrenia and history of suicidal ideation. This fear can lead to the avoidance of conversations around end of life care planning.

McGrath and Forrester (2006) undertook a thematic analysis of interviews with eight mental health professionals, exploring their experiences of delivering end of life care within a mental health institutional study. This study explored, in some depth, issues referred to throughout the body of literature, relating to another fear in clinical staff which has (or had) an impact on provision of care – fear of the legislative framework surrounding the end of life. The professionals interviewed highlighted confusion around their obligation to resuscitate, concern about inquests following deaths within the institution, including police investigations and lack of expertise in working with advanced care planning and ‘do not resuscitate’ orders. These fears were echoed across other studies, particularly Sweers et al (2013), Terpstra and Terpstra (2012 and 2014) and in literature reviews by Woods (2008) and the Mental Health Foundation (MHF). The table in Appendix 1b shows how often these issues were referred to in the literature reviewed.

The third major theme which arose in relation to clinicians was assumptions made about the patients' ability to consent and confidence in assessing capacity (Foti et al 2005; Ganzini et al 2010; Geppert et al 2011; McGrath et al 2006; MHF 2008; Sweers et al 2013; Terpstra and Terpstra 2012, and 2014; Woods et al 2008). Candilis et al (2004) developed a model for end of life discussions using risk assessment and healthcare preference assessment tools. This arose following observations about the tendency of clinical staff to avoid end of life discussions for fear of creating instability in the patient and the assumption of lack of capacity and ability to consent in mentally ill patients.

2.4.3 System/Structural Factors

The negative impact of the design of healthcare systems is highlighted by Bloomer et al (2013). Mental health and physical health have traditionally been commissioned and managed as separate systems – in Australia, USA and Canada, as well as the UK. Clinical staff are trained in mental health or physical health (nurse education for example), and palliative care and end of life care is a specialism within physical healthcare. Whilst this leads to clinical staff developing specialist skills, which is desirable, it can cause 'silo' working. Within clinician factors above, the need to work in partnership was highlighted multiple times. However, this may need to be supported by systemic change.

A pertinent example would be the training of healthcare staff. All clinical staff should have core skills in working with patients with mental illness, and an understanding of some of the challenges different mental illnesses present. The same is true of end of life and palliative care. All clinical staff should have an understanding of the differences in providing palliative care rather than curative care. The literature highlighted that this is not often the case (MHF 2008; Durkin et al 2003; Feely et al 2013). In addition, the need for specialist staff working across both systems was highlighted. Staff with mental health training were particularly needed in palliative care settings.

2.4.4 Improvements and Solutions

In the variety of research studies and discussion papers, solutions to the barriers identified by patients, clinical staff and researchers are suggested. These can be clustered into categories:

- *Partnership Working*

Many of the barriers identified relate to ‘silo’ working – in system design, in staff clinical training and in day to day clinical practice. The main improvement which is suggested relates to improved partnership working. Woods et al (2008) acknowledge that this is a small but significant patient cohort, and that it would be unrealistic to expect all mental health practitioners and services, and all end of life practitioners and services to have dedicated clinical teams to work with patients with mental and terminal illness. However, the need for mental health services and palliative services to work more closely together is clearly stated across the reviewed literature.

The need for specialist mental health input to hospice care is highlighted (Foti et al 2005; Durkin et al 2003; Feeley et al 2013; Geppert et al 2011), particularly in relation to medication, risk and behaviour management. Mental health clinicians expressed limited knowledge of end of life and palliative care and the need for training was highlighted (McGrath 2006). The need to include family and carers, where appropriate, in the partnership, was also identified (Ganzini et al 2010; Geppert et al 2011) as an issue, although the lack of family and social support in the patient group is acknowledged, where family relationships are positive, the need for inclusion is suggested (Bloomer 2013 and Hill 2005).

- *Training Issues*

The need for effective training of clinical staff is a major theme within the analysis. Cross-training between mental health and palliative care clinicians is suggested. Other training interventions are identified, focusing particularly on the following themes:

  - Mental health awareness for palliative care staff
  - End of life/palliative care training for mental health staff
  - Assessing capacity and risk for palliative care staff
  - Techniques for managing challenging behaviour/working with difficult personality issues in palliative care
  - Prescribing and medication management
  - Legal issues and duty of care for mental health staff
  - Communication skills

- *Qualities/Skills in Clinicians*

The ability of staff to work within boundaries is important, especially when working with patients with challenging behaviours (Hill 2005). Mental health patients have not always experienced good care and the ability of palliative care staff to engage and support patients at the end of life is critical. Patients may be more reticent, suspicious and rejecting of care (Feely et al 2013) which may be challenging for care staff. The need for clinical staff to have high levels of resilience and self-care is important in working with the patient group. There was an absence of literature concerning reflective practice, use of supervision and action learning interventions, all of which can enhance resilience and self-care in staff.

- *Policy and Practice*

The absence of specific guidelines for working with mental health patients at the end of life was described by Woods et al (2008) in a review of published literature which included a review of policy and strategy. This was echoed in the MHF review (2008). Subsequently published papers make no reference to improvements and the End of Life Care Strategy (2008) and (2011) do not make specific reference to patients with mental illness.

2.5 Summary of Review

The aim of the literature review was to explore what the published literature says about the factors which affect the provision of end of life care for patients with long term mental illnesses who develop a life-limiting or terminal illness, and how care can be improved.

There is a relatively small body of literature concerning the specific needs of the patient with long term mental illness at the end of life. The paucity of literature was highlighted throughout the studies reviewed (twenty-five separate references). The need for methodologically sound, empirical studies is clear.

Much of what is published (over 1000 studies) concerning mental health and end of life care explored the mental health problems patients developed *as a result* of terminal diagnosis. There were comparatively few (less than twenty) studies concerning the end of life care needs of people with pre-existing mental illnesses. The body of literature reviewed included some research studies and some discussion papers, as well as two previous reviews of literature. These were included as they provide a good summary of the literature up to 2008, but also to see whether the subsequently published literature has developed the understanding further. Many of the recommendations of the two reviews are echoed in subsequent studies and there is still a lack of research published which addresses improvements to practice. Most of what has been published further describes the problem and identifies potential solutions, but little has been published which pilots these interventions.

All but one of the studies reviewed originated outside the UK. The literature review results highlighted the need to understand the issues facing patients and clinicians within clinical services in the UK. Indeed, the initial observations and curiosity of the researcher originated in clinical services within the UK. The review of the literature provided understanding of barriers to providing good end of life care in other healthcare systems, and in the previous twenty years of practice, but did not provide a clear picture of current clinical practice in the UK, the views of clinical staff, views of the patient or carers, or the results of pilot interventions to improve care.

Therefore, the need for further research which addresses these issues, as well as involving patients directly, is highlighted. The review in 2008 by the Mental Health Foundation identified that further research must include the views and experiences of patients themselves, must attempt an estimation of prevalence in the UK, challenge stigma in the general public but also in professionals, through joined up training initiatives, improving understanding of the mental health and palliative care systems and improving multi-disciplinary and partnership working. Since the publication of this review in 2008, there have been no published studies in the UK concerning the pilot or trial of these interventions.

A key theme within the literature related to the training needs of clinical staff, in both mental health service and end of life services. Research studies are required which develop and pilot the most effective ways of training staff so that clinical practice is improved.

Following the completion of this more rigorous literature review, the research question defined in the Introduction was developed. The research question builds on the results within the literature review, and aims to address some of the gaps within the literature. The views of clinical staff in both mental health and end of life care services will be sought, barriers to delivering good end of life care to people with long term mental illnesses in current clinical practice will be identified, and clinicians' views or the clinician's view of potential solutions will be identified. Data collection methods will be developed which build on the researcher’s professional background and clinical strengths. The methodology, data collection and data analysis methods will be discussed in the next chapter.

3.0 Methodology

This chapter describes the methodology used within the research study, including the rationale for the choice of data collection and analysis methods. Ethical issues, sampling and recruitment issues will also be discussed. The choices of methodology and methods will also be critically reflected upon.

The literature review highlighted the need for empirical research to be carried out, as well as identifying barriers in providing effective end of life care to people with long term mental ill health which relate to the knowledge, understanding, confidence and competencies of clinical staff working across both disciplines. In order to understand the issues faced in clinical practice, and where improvements can be made, it was desirable to elicit clinicians' views in this stage of the research. The views of patients and families were also important, but will require full ethical approval through the NHS Regional Ethics Committee (REC) and Health Research Authority (HRA) and will form part of subsequent doctoral study.

The research question concerns understanding the experiences and perceptions of clinical staff. The study aims to develop understanding of an area of clinical practice which the literature review shows to be poorly understood and under researched. Exploratory studies seek to understand a subject in its entirety – and to describe a problem or issue rather than quantify it (Sim and Wright 2000: 46-47). The study used qualitative methods to explore clinicians' experiences and perceptions of the research question and to address the stated aims and objectives. A qualitative approach was selected because the aim of the research is to understand and draw upon individual's lived experience. Qualitative research aims to understand the experiences of individuals or group, of the phenomena or topic under question (Jolley 2013: 191). A qualitative approach is useful where little is known about a topic, or where views and experiences of participants are being sought, or where different perspectives may be held by participants (Bricki and Green 2015: 3).

3.1 Ethics and Governance

Discussions regarding the end of life, death and dying, mental ill health, as well as identifying barriers to delivering good care, may be emotive for participants (Kubler-Ross 2009: 19-21). Participants were provided with written information (see Appendix 2a) prior to taking part in the study and reminded, at the beginning of the focus groups, that they could withdraw at any time. Details of each organisation’s staff support service were made available to participants and the researcher is an HCPC qualified art psychotherapist, also experienced in running groups where emotive themes emerge and difficult materials are processed, so was able to be mindful of participants’ well-being throughout.

Ethical approval for the study was granted by Coventry University, who operate a sound ethics and governance framework and process (see Appendix 3a). As the study participants were members of clinical staff, rather than patients, full NHS Ethical Approval was not required. The Health Research Authority (HRA) decision tool was used to ascertain levels of approvals (Appendix 3b).

The research participants were recruited from the researcher’s employer organisations, so approval for the study was also obtained from Birmingham and Solihull Mental Health Foundation Trust (BSMHFT) Research and Innovation Department and John Taylor Hospice (JTH) Clinical Governance Committee (see Appendix 3c).

As the researcher is employed within the two organisations from which participants were recruited, it was important to consider the possibility of coercion and researcher bias, from both a recruitment and ethical perspective (Hewitt-Taylor 2002: 35). The impact of being an ‘insider researcher’ is discussed later in this chapter under 3.4 Reflectivity and Reflexivity.

Written consent was obtained from each participant prior to the focus group commencing, once the participant information sheet had been read (see Appendices 3a, 3b 3c). Participants were made aware that participation was voluntary and that they could withdraw at any time without explanation. Any data collected from such participants would not be used in the research project and destroyed (at the time of writing this had not occurred).

Documents were stored on the researcher's University password protected data drive. Focus group transcripts were password protected and also stored on secure drives. Recordings of interviews have been password protected and will also be stored on a secure drive. Due to the difficulties of accurately identifying each person's comments when transcribing a focus group, participants were identified by male or female voice only. A separate, anonymised list of the range of professions represented in the focus groups has been included (Table 6) to demonstrate the range of roles in attendance, whilst ensuring the anonymity of participants – i.e. if there is only one social worker within the end of life care organisation, then identifying their contributions by profession, would identify them to anyone reading the research from the organisation concerned.

No member of staff, patient or family member is identifiable in the transcripts of the focus groups or other written material generated in the sessions. Transcripts were fully anonymised and any names recorded were removed.

3.2 Sampling and Recruitment

The aim of the study was to gain clinical staff views and experiences of delivering end of life care to the defined patient group. Purposive sampling was used to identify participants from mental health and palliative care settings who would best be able to contribute to the study. Purposive sampling (Hicks 2009: 30) allows the researcher to identify a group of participants to take part in a study. It was important in this study that participants had some experience of working with the patient group and the issues of end of life care, so, rather than identify a random sample of healthcare staff, participants from a Mental Health Trust and a hospice were invited to participate. Participants were invited to take part from within the two organisations, and were able to self-select. The aim was to identify staff who had experiences to share, an interest in the issue and were either mental health or end of life care clinicians from any discipline. Inclusion and exclusion criteria are shown in Table 4.

Inclusion and Exclusion Criteria	
Included: Clinicians (multi-disciplinary) working in palliative/end of life care or mental health services.	Excluded: Clinicians unable to consent, unable to participate, or with no experience of the subject matter of the research.

Table 4 Inclusion and Exclusion Criteria

3.3 Methods

Four focus groups, two in each participating organisation, were developed and organised. Each group was run on a different day and at a different time, to try to maximise the number of staff who could participate. It was difficult, in both organisations, for clinical staff to come away from clinical settings, so focus groups were run as close to participants workplaces as possible. Across the four groups, 23 participants attended, from a range of clinical backgrounds (see Table 5). It can be difficult in a qualitative study to specify exact numbers of participants. The aim of a qualitative study is to continue to collect data until the point where no new data is being added – known as saturation (Jolley 2013: 192; Green and Thorogood 2009: 118-119).

The optimum number of participants in a single focus group is not defined but is suggested as being between six and eight (Green and Thorogood 2009: 127). However, groups can be facilitated with as little as three and up to fifteen participants, if required. Most importantly the group should not be too big to be facilitated effectively by the moderator (Sim and Wright 2000: 57). Time was allowed for additional groups to be run in each organisation, if attendance was too low. Within the confines of the dissertation, and the resource implications for a single researcher undertaking the data analysis, as much flexibility was built into the focus groups as possible, to maximise the range of participants able to take part.

Focus Group 1	Hospice	8 participants • Senior Management Representative • Pharmacy Technician • Nurse Consultant • Macmillan Clinical Nurse Specialist • Senior Team Assistant • Community and Corporate Development Manager • Community Development Manager • Palliative Care Assistant
Focus Group 2	Mental Health Trust	4 participants • Service User Engagement Worker • Matron (Older People's Services) • Senior Practitioner – Memory Assessment Service • Head of Spiritual Care
Focus Group 3	Mental Health Trust	4 participants • Care Home Facilitator • Consultant Clinical Psychologist • Occupational Therapist – Ward • Occupational Therapist - Community
Focus Group 4	Hospice	7 participants • Senior Nurse Trainer and Complementary Therapist • Speciality Doctor • Specialist Palliative Care Pharmacist • Dietician • Physiotherapist • Senior Patient and family Support Worker • Macmillan Clinical Nurse Specialist

Table 5 Focus Group Participants and Professional Role

Focus groups allow group discussion, and can allow participants to respond to other participants' contributions, developing the discussion and quality of data to a greater degree than in a one to one interview (Jolley 2013: 199). Focus groups can produce rich and plentiful information in a short space of time (Green and Thorogood 2009: 128) which is an advantage to this study because the desired participants had clinical commitments which made it difficult to recruit to studies which were more time consuming. Confidentiality and anonymity can be an issue in focus groups where participants know each other and also the researcher. The boundaries of confidentiality and anonymity were outlined to participants (as outlined in the research protocol Appendix 2d)) and participants were free to self-select to participate and subsequently, withdraw at any time, without negative consequence. A disadvantage of a focus group can be participants' ability and willingness to participate in a group discussion. This can be effected by who else takes part which remains unknown until the group begins.

To mitigate against this risk, additional methods were introduced to the focus group to create different opportunities for participants' views to be gathered. The CUbe ideas generation tool (Magee et al 2015) was used to facilitate the focus groups. The CUbe is a tool, developed by researchers within Coventry University (CU), for generating ideas and allows data to be collected in written and visual form to add to the verbal discussion within the focus groups. Figure 2 shows an image of the CUbe. It takes the form of a 30cm square cardboard box, which is covered with paper (the web). Participants can write or draw on the cube. There is no top or bottom, as the CUbe is literally a cardboard cube. This removes the hierarchy of contributions – all the sides of the cube are equal. The CUbe can be easily held, as illustrated in Figure 2, and is light so can be passed around participants easily. The researcher observed participants moving closer together during the focus groups, to enable the passing of the CUbe around the group. Participants are able to write and draw on the CUbe whilst the verbal discussion was taking place. Reflections of the impact of the method on the group discussion are included in Section 5.6.

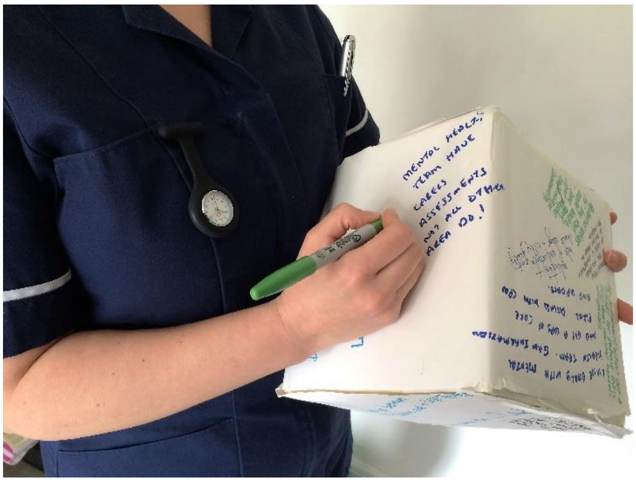


Fig. 2 CUbe

The process is dynamic and sessions are usually 30 minutes long. Focus groups were extended to 60 minutes to allow for introductions, consent to be obtained, and for the groups to be closed effectively. The CUbe method complements the focus group method by allowing different types of contributions to be included, not necessarily just those which flow from the verbal conversation in the group. Like other creative-based data collection methods, such as image-making or photography, it encourages people to contribute in a different way (Hays and Singh 2012: 278) and can incorporate visual images as well as text, and allow people who may find it hard to contribute verbally to share their thoughts and reflections, helping to break down traditional hierarchical relationships within groups.

In addition, paper and envelopes were also made available and time given at the end of the session to capture any contributions which had not been expressed within the group or which participants felt uncomfortable sharing in a group setting.

Focus groups were audio recorded to allow for transcribing. In addition, notes were taken by the researcher immediately after the focus groups, to capture additional materials shared outside the recording period, and other significant information. These notes helped the researcher with immersion in the data, and allowed space to record any important impressions, which helped the researcher reconnect with the transcripts during the data analysis process.

3.4 Reflectivity and Reflexivity

A reflective journal was used throughout the research study, detailing reflections on the process, including literature searching, ethics applications, discussions of research methods, sampling and data analysis, Public and Patient Involvement (PPI) opportunities and feedback, supervision meetings and discussions with other Stakeholders. Reflections on each focus group also formed part of the data analysis process. Use of a reflective journal forms part of the researcher's professional practice and aids reflexivity within the research process, by creating opportunities to reflect on the methodology and process of the research, record ideas and insights not captured in the focus group, to look at areas for additional exploration or which are unclear and the impact of the research process on the researcher. This is especially pertinent when the researcher is embedded in the clinical setting where the research is taking place (Sim and Wright 2000: 147).

3.4.1 Trustworthiness and Verification

There are several different strategies which contributed to the rigour of the study.

Audio recording the focus groups, rather than relying on written notes, use of the written information collected through the CUbe method and anonymous written additional comments from participants, allowed the data to be collected and analysed in multiple ways and differences compared. For example, the written data on the CUbe could be compared to the verbal discussion in the transcripts and then to the anonymous contributions. Each stage was photographed, to illustrate the data collection and analysis process.

The content of the reflective journal can also be used in the data collection and analysis process, to enhance rigour. A summary can tell how the researcher's understanding of the data developed and provide additional validity (Jolley 2013: 214).

Due to the limitations of the study, and the nature of ethical approvals, it was not possible to have multiple researchers involved in data collection. However, recording and transcribing in full, the data from the focus groups, and including the written artefacts in the analysis, helps mitigate against researcher bias in interpreting the data. The Framework Method also offers a structured approach to deducing themes from a large dataset and data can be checked to see if a theme is justified (Gale 2013: 6; Rabiee 2004: 657). Supervision was used throughout the study to discuss the process and the researcher's approach to data collection and analysis.

The decision was taken by the researcher to undertake all data analysis manually rather than using software packages. This was based on the researcher's desire to immerse himself in the data and in the process of using the Framework Method. As an art psychotherapist, the researcher is skilled in looking for patterns and meaning in visual imagery and text and analysing, not just transcripts, but other visual artefacts and so used these clinical skills in the research process. Photographing the process also allowed the supervisory team and the reviewer/examiner to see the process of analysis and get a feel for the data collected.

The researcher used supervision sessions and the reflective journal to reflect upon his role and explore the impact of his insider status on the research process.

3.4.2 Insider Research

The role of the researcher as an 'insider', someone employed by both sites within the research study, is important to acknowledge. There are contradictory beliefs about whether this is an advantage or disadvantage in the research process. It would be possible to build an argument for either perspective. More useful, is to acknowledge the potential impact of the research process, both positive and negative.

Brannick and Coghlan (2007) argue that there is always an inherent bias in any research and being an insider is not a barrier to undertaking research, rather the knowledge and understanding a researcher holds when an insider, enhances the collection and analysis of data, as long as the researcher remains reflexive and reflective during the process.

Hewitt-Taylor (2002) stated that when time is pressured, being an insider researcher can aid timely access to organisations and potential research participants. In developing the research protocol for this study, the researcher was mindful of the short timescales available to identify participants and set up focus groups and made the decision to gain approval from his two employing organisations (which were appropriate types of organisation to reach the target participants) to undertake primary research with employees. One of the organisations was a large mental health trust, and being an insider researcher allowed the researcher to make use of existing contacts to gain quick and free access to rooms and refreshments. Due to the size of the organisation (c. 5,000 employees) the researcher was not known to most of the participants who attended the focus groups. In contrast, the hospice was a small organisation where the researcher is well-known, as a colleague, to the participants who attended the focus groups. Attendance was greater in this organisation so it may be that the role of the researcher as ‘insider’ was a positive factor. Equally, it may be that the publicising of the focus groups was more effective in a smaller organisation or there was greater permission to attend.

Some of the potential negative impacts of being an insider researcher relate to the impact on the discussion within the focus groups, the perception of what the motivation behind the research might be amongst potential participants (relating to their perception of the researcher’s role within the organisation), fear of confidentiality and anonymity being compromised and the possibility of participants wanting to please the researcher. To mitigate against these impacts, the researcher provided clear written information about confidentiality and reiterated this at the start of each focus group. The researcher also attended team meetings within the second organisation to explain the purpose of the research and how it was being governed, as well as the intended dissemination plans. It was not possible to replicate this within the larger organisation, so a briefing was circulated, on the staff intranet, covering the same information.

Within the focus groups, the researcher took the role of moderator, prompting the discussion, but remaining detached from the discussion, paying particular attention not to participate in discussion about individual patients, staff members, teams or organisational dynamics.

3.4.3 Patient and Public Involvement

The study arose from discussions and observations in clinical practice and some patients were consulted about the research topic informally in the clinical setting.

The research has been presented to Coventry University RSVP Patient panel and feedback incorporated into the protocol and research design.

The data collection method was tested on a small group of staff prior to the focus groups being held. Informal consultation with a range of clinical staff across both organisations took place during the development of the research protocol and feedback from these was also incorporated into the research design.

3.5 Data Analysis

A Framework Analysis Method was used to analyse the data from the focus groups. Framework Analysis was developed by Ritchie and Spencer (1994) through the National Centre for Social Research (www.natcen.ac.uk) to orientate data analysis towards generating policy and practice-orientated findings (Green and Thorogood 2009: 208-209). The framework method is usefully described by Gale et al (2013) as a type of thematic content analysis which provides a seven stage approach to analysing large sets of qualitative data, such as that gathered from a focus group. In health research, the framework method is often described in five stages (an adapted framework analysis). The five stage model (Srivastava and Thomson 2009) based on Ritchie and Spencer's method is outlined in Table 6 and was used for this study.

Stage 1 – Familiarisation with the Data	Interviews/focus group data is transcribed verbatim. Transcripts are read and audio recordings listened to, checked for accuracy and the researcher becomes immersed in the data
Stage 2 - Identifying a Thematic Framework	A selection of transcripts is coded – open 'inductive' coding is often used to allow new data themes to emerge, codes are reviewed, grouped together in clusters to form categories or themes and a working framework (which is not finalised until all transcripts have been analysed)
Stage 3 - Indexing	The framework of themes or categories is applied to the remaining transcripts, additional codes are identified and the working framework is revised. The revised framework is applied to the original transcripts.
Stage 4 – Charting	Data is charted onto a matrix, using relevant quotes and summaries of the coded data to illustrate each category or theme (to reduce the volume of original data without losing the meaning)
Stage 5 – Mapping and Interpreting the data	Data is interpreted from the framework matrix, alongside field notes, reflective journal notes – concepts emerge and relationships between data are explored

Table 6 Summary of the stages of the adapted Framework Method

A framework analysis allows the researcher to become immersed in the data, and encourages continual reference back to the original transcripts as themes and concepts emerge. An analysis of the relationships between themes, as well as the identification of emerging themes, makes framework analysis a robust choice of methodology for investigating an under-researched area of clinical practice. The literature review identifies themes within the literature, but rather than apply these themes to the analysis of the transcripts, the researcher chose to use open coding to allow new themes to emerge. The differences and similarities between the themes in the literature review and the data analysis are discussed in Chapter 5.0 Discussion.

Parts of the data analysis process can be done electronically using software such as nVivo or manually, by an individual or team of researchers. A manual approach was taken for this study to allow for the inclusion of the different forms of data collected and to allow the researcher to become immersed in the data as fully as possible. The main challenge in this process was the amount of data to transcribe, code and chart as a lone researcher. The researcher used the supervisory team to sense check decisions as the analysis progressed, for example supervision meetings were used to discuss the emerging codes and the clustering of codes into themes and the researcher's analysis was challenged by the supervisory team.

3.5.1 Illustrated Procedure for Data Analysis

Stage 1 Familiarisation

Focus groups were transcribed verbatim, lines numbered and wide margins created for later coding. Web data (the outside covers) from the CUbe's were photographed, alongside the anonymous written contributions and assembled onto sheets of paper to be viewed together as a data set illustrated in Fig. 3.

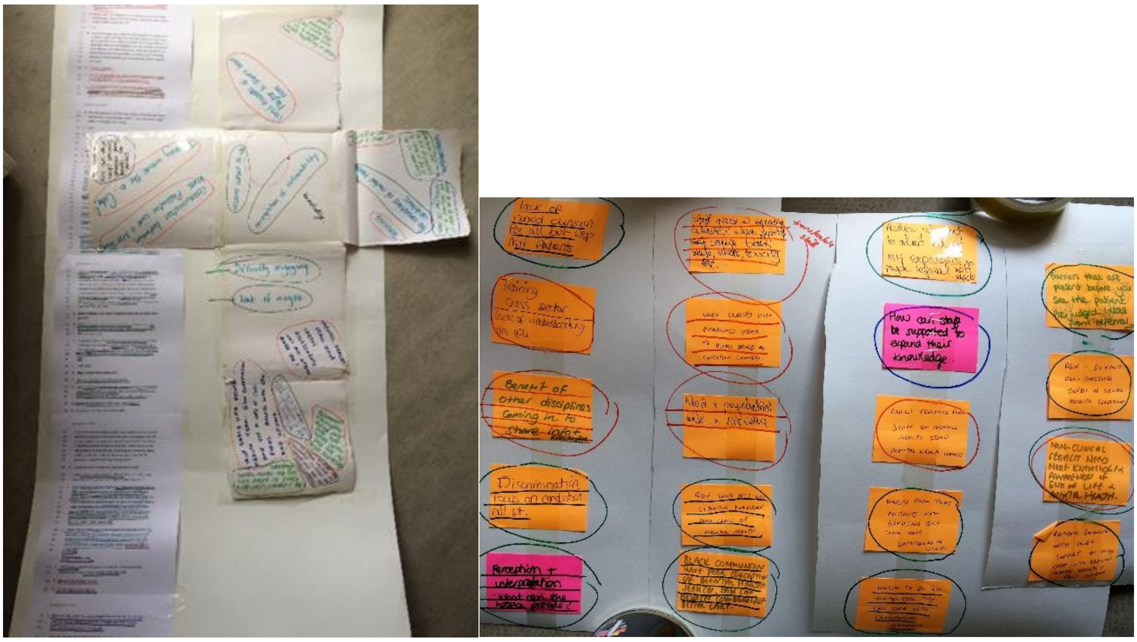


Fig. 3 Types of Data

Each transcript and recording were read and listened to simultaneously by the researcher, twice and checked for accuracy. Thoughts, impressions and reflections were noted. An extract of a transcript is included in Appendix 5a. Images of the CUbe covers and other written data collected are included in Appendix 5b and 5c.

Stage 2 Identifying a Thematic Framework

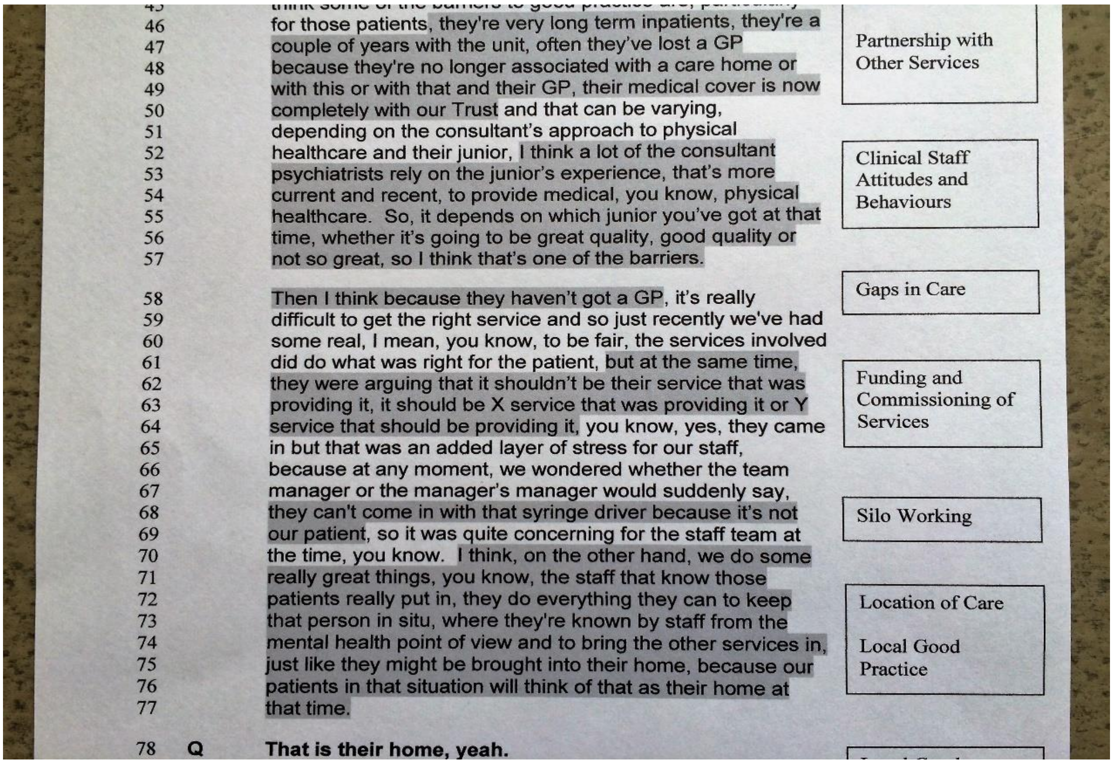
Transcripts were read in detail and codes applied to important content – themes, behaviours, values, emotions, observations. Gale (2013) states that coding can be open, coding anything which may appear relevant (useful in exploratory studies) or pre-defined, usually in studies where there is pre-existing theory or specific areas of investigation (Gale 2013: 4). As there is not a large existing body of theory, open coding was applied to the transcripts. An initial list of 82 codes was created from two of the four transcripts (see Appendix 4a). Codes were reviewed, duplications removed and the list refined to 34 codes, clustered into five categories. Descriptions were attached to each code for clarity and to allow review by the supervisory team (full list included in Appendix 4b). Table 7 is an extract of one theme and the codes within it.

Patient Factors	
Presentation for treatment	Delayed diagnosis, poor prognosis, use of preventative services
Fluctuating mental capacity and well-being	Variations in presentation, unstable mental health, fluctuating capacity and insight, ability to consent
Family and Social Support	Limited social support networks, poor or limited family support, social isolation, lack of consultation with family and carers,
Location of care	Use of care homes, institution as home, homelessness and unstable housing,
'Challenging' behaviour	Care seeking and care rejecting behaviours, unusual beliefs about death and dying/service provision, aggression, withheld, limited communication
Perception of services	Lack of trust, previous bad experiences, negative perceptions of end of life care, difficulties in making relationships with services
EOL Planning and Discussion	Ability and willingness to participate in discussions and planning about EOL care and preferences

Table 7 Example of Clustered Codes with descriptions

Stage 3 Indexing

The subsequent transcripts were analysed using the analytical thematic framework and code clusters. The data from the CUbe's and the written contributions were also analysed, using the same framework of codes and coded manually. Relevant passages of text from within the transcripts were highlighted and the appropriate code attached (Fig. 4).



for those patients, they're very long term inpatients, they're a couple of years with the unit, often they've lost a GP because they're no longer associated with a care home or with this or with that and their GP, their medical cover is now completely with our Trust and that can be varying, depending on the consultant's approach to physical healthcare and their junior, I think a lot of the consultant psychiatrists rely on the junior's experience, that's more current and recent, to provide medical, you know, physical healthcare. So, it depends on which junior you've got at that time, whether it's going to be great quality, good quality or not so great, so I think that's one of the barriers.

Then I think because they haven't got a GP, it's really difficult to get the right service and so just recently we've had some real, I mean, you know, to be fair, the services involved did do what was right for the patient, but at the same time, they were arguing that it shouldn't be their service that was providing it, it should be X service that was providing it or Y service that should be providing it, you know, yes, they came in but that was an added layer of stress for our staff, because at any moment, we wondered whether the team manager or the manager's manager would suddenly say, they can't come in with that syringe driver because it's not our patient, so it was quite concerning for the staff team at the time, you know. I think, on the other hand, we do some really great things, you know, the staff that know those patients really put in, they do everything they can to keep that person in situ, where they're known by staff from the mental health point of view and to bring the other services in, just like they might be brought into their home, because our patients in that situation will think of that as their home at that time.

Q **That is their home, yeah.**

Partnership with Other Services

Clinical Staff Attitudes and Behaviours

Gaps in Care

Funding and Commissioning of Services

Silo Working

Location of Care

Local Good Practice

Fig 4 Applying the analytic thematic framework to a transcript

The analytic framework was then updated to incorporate any additional codes. The revised analytic framework (See Appendix 4b) included 39 codes, clustered into five categories.

The framework was then applied to the first two transcripts in the same way to allow for the next stage of analysis. All four transcripts, CUbe covers and post-it notes were also analysed, using the final framework (Fig. 5).

Fig 5 Applying the analytic thematic framework to additional written contributions

Stage 4 Charting the Data

Data from each transcript was summarised and charted onto the matrix. This involved reducing the data without losing the original meaning. Quotations or references to the transcripts were included and referenced, enabling the data to be checked by a member of the supervisory team or a co-researcher. In this instance, the researcher worked alone, so the members of the supervisory team were used to review the process of applying the stages of the framework method. Table 8 below shows an extract from one category to illustrate the method.

Structural and Systemic Issues

	FG 1 EOL/PC	FG 2 MH	FG 3 MH	FG 4 EOL/PC
Funding and Commissioning Services		'we used to get a lot of support from the hospice. It has been a bit more difficult lately because before it was done on goodwill…you would ring them up and they would come in…you get a lot of we haven't got an SLA' (FG2	Commissioning of services in isolation 'things are commissioned in a piecemeal way, you know…they say about the patient being at the heart…it's about the commissioning services being joined up and they never have been and it's going to get a lot worse' (FG 3, 211-217)	Assumption amongst clinical staff that services are limited due to funding issues 'there appears to be limited services….to work collaboratively…. areas have been commissioned or de-commissioned' (FG 4,30-33)
Silo Working	Clinical staff trained in either mental health or physical health care; PC/EOL care a sub-speciality within physical health care – 'they deal with the mental health, we deal with the end of life' (FG1 42-43) 'One of the problems is specialisms, the fact that your trained to quite a high level in a particular area…mental health nurses have very little training in physical conditions and vice versa' (FG1 57-60)		Physical healthcare needs not able to be met in mental health inpatient services 'because our staff aren't trained to monitor this, it's a drip he would need…and they would have to have special training….and they wouldn't have enough opportunities to feel really familiar with that procedure' (FG3 153-156)	

Table 8 Example of Charting Process

Stage 5 Mapping and Interpreting the Data

The charted data was then reviewed, with constant reference back to the original transcripts, CUbe covers and notes, and synthesised into overarching concepts. The themes within the charts were also considered alongside the themes which had emerged from the literature review. Similarities and differences in the themes were noted and incorporated into the development of the concepts. This process was time consuming and involved multiple iterations. During the process of reduction and synthesis of the summarised data, it was important to return to the original data and quotes were used heavily to illustrate the link between the participant's voice and the developed themes. The development of concepts allowed the barriers and solutions, identified by participants and within the literature, to be synthesized into a conceptual explanatory framework. This process is illustrated, analysed and discussed in Chapter 4.0 Findings and an example can be seen in Table 9.

THEME	SUB-THEMES	CONCEPT
Clinician and Service Factors	• **Understanding of mental health system and conditions** • **Understanding of end of life and palliative care system and services** • Policy and Procedure • Legislative and Practice Concerns • Assessment of pain, mental capacity and risk	**Knowledge and Understanding**
	• **Clinical Staff Attitudes and Behaviours** • Clinical Staff confidence in practice • Resilience and Self Care	**Confidence and Resilience**

Table 9 Mapping and Interpreting Data into Themes and Explanatory Concepts

4.0 Findings

Findings were drawn using the iterative processes described in Chapter 3.0 Methodology. The emerging findings fell into five main themes, within which there are significant sub-themes. Significance was noted when a sub theme arose multiple times in the data analysis, or if it appeared to have a major impact on the provision of care. Therefore, whilst the number of times comments were made was relevant, as this was a qualitative study, depth was more important. If, for example, one or two practitioners raised an issue and others agreed, particularly when it may have been sensitive in nature and not easy to raise, this was also drawn out in the findings. The aim of this process was to capture the rich in-depth stories. Overarching concepts were then formed by linking themes, reflecting on original transcripts and considering the reasons behind and the links between the themes in the findings.

4.1 Theme 1 Systemic and Structural Factors

THEME	SUB-THEMES	CONCEPT
Systemic and Structural factors	• Funding and Commissioning of Services • **Silo Working**	**Designing the System**
	• Gaps in Services • Movement of patients	**Using the System**

Table 10 Systemic and Structural Factors Theme, Sub-themes and Concepts (significant sub-themes highlighted)

The first set of codes were clustered into the theme 'Systemic and Structural Factors' (Table 10). The sub-themes can be divided into two overarching concepts, 'Designing the System', which relates to those factors about how end of life care services are structured, designed and commissioned and 'Using the

System', those factors which relate to how participants are managed within the end of life care system.

Participants from both mental health services and end of life/palliative care services identified factors relating to the structure and design of services as a barrier to providing good end of life care to the patient group. The most significant sub-theme identified was described as 'silo' working. Furthermore, participants identified the separation of mental and physical healthcare as problematic.

> *'They deal with mental health; we deal with the end of life' (FG1 42-43)*

The separate commissioning and delivery (design) of mental health care, palliative and end of life care, acute hospital care and GP services was described as a barrier to effective joint working. Many participants felt the separation of services, and flexibility to work across agency had declined over recent years and attributed this to cuts in funding and competitive commissioning arrangements between agencies (re-tendering of services).

> *'We used to get a lot of support from the hospice. It has been a bit more difficult lately because before it was done on good will…you get a lot of 'we haven't got an SLA' (FG2 58-62)*

Further research would be required to ascertain whether this is actually the case, but the fact that staff perceived it to be still impacts negatively on the delivery of care, as some participants appeared to have no expectation that services exist for their patients, outside their own clinical area.

Two participants highlighted that clinical training also operates separate systems in many cases. For example, nurses who are mental health trained have limited experience, during training, of physical and end of life issues. Equally, palliative care staff, who are often physical health/adult trained nurses, physiotherapists or occupational therapists, for example, have often received very limited mental health training as part of their core professional development.

'One of the problems is specialisms, the fact that you are trained to quite a high level in a particular area…mental health nurses have very little training in physical conditions and vice versa' (FG1 57-60)

Some participants identified that operating in professional and service 'silos' led to some patients, particularly those from marginalised groups, such as people with long term mental illnesses, to fall between gaps in service provision, or receive less satisfactory care. For example, one mental health participant described the lack of physical healthcare available in mental health units as a barrier when trying to provide good end of life care.

'… because our staff aren't trained to monitor this, it's a drip he would need… and they would have to have special training… and they wouldn't have enough opportunities to feel really familiar with that procedure.' (FG3 153-156)

Gaps in service provision identified, included lack of a GP, where a patient has been placed in a mental health unit out of their home area for a number of years. This leads to difficulties accessing other services, such as hospice provision, close to the place where the patient is currently residing.

Several participants also found the movement of patients from service to service to be a barrier when providing end of life care. Problems accessing hospice care and an inability to meet some end of life medical needs in a mental health setting, were described as two contributory factors in patients being admitted to acute hospital settings at the end of life. Participants were clear that acute admissions via Accident and Emergency (A and E) were not desirable for patients at the end of life, particularly where complex mental health conditions also need to be managed.

> *'The woman was left day and night, you know, I think she didn't have any relatives who visited her at all and I think because they were an acute service they were overwhelmed and didn't know what to do with her' (FG3 89-92)*

4.2 Theme 2 Patient Factors

THEME	SUB-THEMES	CONCEPT
Patient Factors	• Presentation for Treatment • Fluctuating mental capacity and well-being • **'Challenging' Behaviour** • Perception of Services • EOL Planning and Discussion • Family and Social Support	**Presentation to Services**
	• **Location of Care** • Poor physical healthcare • Inadequate care observed	**Experience of Services**

Table 11 Patient Factors: Themes, Sub-themes and Concepts (significant sub-themes highlighted)

This theme has several sub-themes which can be grouped into two concepts: 'Presentation to Services' and 'Experience of Services' (Table 11) . Factors which participants described that relate to characteristics or behaviours of patients, led to the concept of presentation to services and factors which relate more to the circumstances patients find themselves in or how they experience care led to the development of the concept of experience of services. This theme has several sub-themes, the two most significant being 'Challenging Behaviour' and 'Location of Care'. Within this theme, all participants identified particular factors relating to behaviours, characteristics and circumstances, which people with long term mental illnesses experience or present and which make delivering end of life care problematic.

Challenging behaviour was not pre-defined, but all examples of behaviour which participants experienced as problematic, within the clinical setting, were included. Examples of behaviour, identified as challenging, varied between the different participant groups. For example, in the end of life care focus groups one participant said,

> *'I think it's also about interpretation of the behaviour… I saw her shuffling around in her slippers and her nightie, outside, fagging it … she was not the most co-operative person and very single-minded and if you said, "come on, it's raining, you know you could catch your death of cold"…"I'm alright, I've got my coat over my nightie…" She was incredibly difficult to engage and in the end went home… but she had no insight in how vulnerable she was…' (FG1, 243-262)*

In the mental health cohort of participants, behaviour identified as challenging, related more to the content of conversations between patient and staff, whereas end of life care staff identified behaviours which they found challenging. Different participants identified different behaviours as challenging, including care seeking and care rejecting behaviour. Interestingly, this was particularly noted in end of life care settings, where clinical staff were not used to working with such behaviour on a regular basis.

It was highlighted that this behaviour presentation left staff feeling uncomfortable and was not as easy to discuss, or acknowledge as angry or aggressive outbursts, for example. Many end of life care staff also described withheld and limited communication as a difficult behaviour for them to manage in an inpatient or community hospice setting.

> *‘every time I went to him, all he wanted to say was, “have you finished now, can I go?” and most of the time was spent with the actual carer and not the patient themselves ‘cause they just didn’t want to engage at all’ (FG 4, 19-22)*

Several mental health staff identified end of life discussions and unusual beliefs about death and dying as difficult for them to work with. For patients with past or current episodes of suicidal ideation, end of life discussions felt risky across all the focus groups.

> *‘I got called in because the team wanted to move towards coming to a decision about resuscitation, but this lady’s belief was that she was immortal. Well why would you need to have a conversation about resuscitation if you were immortal?’ (FG 2, 575-577)*

In addition, fluctuating mental capacity and well-being was noted as difficult to manage clinically – especially in relation to consent and capacity to participate in end of life care planning.

> *‘I really do think it’s tricky to assess people’s insight…I don’t think the mental capacity interview or assessment particularly helps’ (FG1, 141-146)*

Three participants described instances where staff had avoided end of life discussions, but the patient had instigated them.

‘We don’t have those conversations…I don’t think anyone would be equipped, maybe the nurses would be…we had one patient…but he was the one who started talking about dying’ (FG3 238-244)

Participants reported that when conversations do arise about end of life care planning patients appeared to be willing and able to have conversations with staff about their end of life care and treatment.

‘I get the feeling that people do really want to talk about it’ (FG2, 624-625)

‘She did in the end express her views very clearly, that no, she didn’t want to be resuscitated and so she was a very active partner in that’ (FG2, 585-587)

Several participants reported that people with long term mental health problems can sometime hold unusual beliefs about death and dying, and view services with mistrust.

‘In my experience, one of them I found very difficult to work with because they were suspicious and it was really difficult to get their trust’ (FG4, 17-18)

Patient mistrust of services was not described as a regular occurrence, however, when it did arise, it was quite profound and posed difficulties for clinical staff in both settings.

Additionally, it was noted, particularly in mental health participants that patients who have experienced long periods of mental illness often have poor physical health and are less likely to seek or receive preventative treatment. Most participants were aware that this meant patients may experience later diagnosis of illnesses, possibly poorer prognosis and described their patients as having high rates of many chronic illnesses which can become life-limiting/terminal.

‘It seems that often because of mental health needs, they don’t seem to get the same sort of support you’d hope they would get’ (FG2 533-535)

Both mental health and end of life care participants felt that issues relating to family and other social support (friends, care staff or other agencies) were a factor which could be a barrier to providing good end of life care. Furthermore, several participants raised the issues of lack of family support, both in terms of family to support the patient and family for staff to liaise with and the general social isolation people with mental illness of ten experience as barriers to delivering care. Other participants raised the issue of problematic and challenging family relationships, which some patients experience and the challenges of managing these relationships in a clinical setting. The importance of including family and other support where appropriate, and being mindful of problematic family relationships and lack of family and social support, were raised consistently by most participants from both mental and end of life care services.

‘Some people… will have close family who’ll want to engage, others won’t want their family to know anything’ (FG1, 367-369)

Several participants described the location of end of life care as a barrier to effective care delivery. Mental health establishments, such as residential units and in-patient units, were described as unsuitable for end of life care due to the lack of physical healthcare needs which could be met on site. Two participants from mental health services also highlighted the poor living conditions of many of their clients, which made receiving ‘hospice at home’ services challenging (hostels, shared houses, poor quality housing, living alone). Additionally, they felt that people with long term mental illnesses found it harder to access hospice services at home, or as inpatients and did not have equal access to care of this kind.

‘I think it’s sad when people go home to die and something happens and they end up in hospital when they shouldn’t have done and could have been managed at home…there’s a lot of nervousness I think’ (FG3, 68-69)

Some patients viewed the institution in which they reside, as home, and chose it as their preferred place of dying. Participants from inpatient units in mental health care were particularly aware of this and the importance of delivering end of life care in these settings, but highlighted the difficulties in doing so in the current system.

Interestingly, other factors which arose were the poor general physical health of patients with mental illnesses and the lack of physical healthcare they received and observations of poor care given to mental health patients’ in general healthcare settings. Acute care was particularly cited, but participants were not critical of acute healthcare staff, rather, they raised the challenges on behalf of acute healthcare staff, of delivering end of life care in a non-specialist, highly pressured service.

‘but that woman was left day and night, I think she didn’t have any relatives visit her at all and I think because they were an acute service they were overwhelmed and didn’t know what to do with her’ (FG3, 90-93)

4.3 Theme 3 Clinician and Service Factors

THEME	SUB-THEMES	CONCEPT
Clinician and Service Factors	• **Understanding of mental health system and conditions** • **Understanding of end of life and palliative care system and services** • Policy and Procedure • Legislative and Practice Concerns • Assessment of pain, mental capacity and risk	**Knowledge and Understanding**
	• **Clinical Staff Attitudes and Behaviours** • Clinical Staff confidence in practice • Resilience and Self Care	**Confidence and Resilience**

Table 12 Clinician and Service Factors Theme, Sub-themes and Concepts (significant sub-themes highlighted)

Many factors affecting the delivery of good care related to knowledge, skills and attitudes of clinical staff. This theme was synthesised into two concepts 'Knowledge and Understanding' and 'Confidence and Resilience' (Table 12).

The concept of 'Knowledge and Understanding' relates to the information and specific skills participants identified as central to the ability to delivery good end of life care to the patient group. For example, understanding the structure and range of services available for patients and having specific skills in risk assessment and mental capacity assessment. The concept of ‘Confidence and Resilience’ includes the attitudes, behaviours and qualities that participants identified as required in delivering good end of life care, such as, attitudes to mental illness, the ability to reflect upon practice and use of professional autonomy in decision-making.

Overall, end of life care participants identified understanding the mental health system and mental health conditions as the most significant factor. Nearly all participants in the end of life cohort stated that they had limited understanding of the structure of the mental health system locally, were unclear how to contact relevant teams for additional information following referral, and of different mental health diagnoses and how they may affect patients. Most participants identified limits in their own knowledge and confidence in working with complex mental illness. In contrast they identified competence and confidence in working with high levels of anxiety.

> *‘There has been gaps in my knowledge in connection with mental health and I admit that, same as any other nurse’ (FG1 69-70)*
>
> *‘So many medics have no mental health experience at all… as individuals we should try and find out more about conditions we know nothing about …’ (FG1 61-65)*

All but one mental health participant identified a lack of understanding of what constitutes end of life and palliative care, how and when to refer to services, what services are available for their patients and how services are funded. In addition, participants were not aware of the breadth of services available through hospices, either in the community or inpatient services. Most participants’ understanding of these services was that they were available in the last weeks of life only.

‘We don’t know about lots of those [hospice] services to refer people on to’ (FG2 561)

‘And things change all the time, like new projects start up and we wouldn’t be informed, so we can’t access it for our patients’ (FG3 189-191)

Most mental health participants had limited levels of understanding about whether end of life care was delivered in mental health services. Just one participant (from older people’s services) had a greater understanding and experience of delivering and discussing end of life care issues with patients.

‘I suppose I have had fairly frequent contact with people really close to the end of their lives through working in complex care units but also downstairs on acute wards’ (FG3 37-40)

In addition to understanding the range and structure of services, many participants, across both cohorts, identified assessment as an issue. Specifically, assessment of risk, pain and mental capacity when working with patients with long term mental illness. Risk assessment was identified in relation to fluctuating mental well-being. Many palliative care participants felt a lack of confidence in assessing risk sometimes led to conservative risk management, especially regarding medication issues. This is illustrated by one participant below.

'I really do think it's tricky to assess people's insight, because I've certainly nursed people who knew what they had was serious, but nobody was going to have the conversation with them about it… I don't think the mental capacity interview or assessment particularly helps assess the insight of somebody with a long term mental illness either, so they may agree to things on a superficial level' (FG1 141-149)

This was highlighted particularly in patients with history of suicidal ideation. Some participants identified the assessment and management of pain as an area which is sometimes more difficult when working with patients with long term mental illness. Clinical staff felt the lack of a partnership approach between mental health and end of life care sometimes impacted negatively on the patient, with regard to pain management and also in relation to assessment of capacity.

'A lot of pain relief isn't being sorted as it should, because people can't verbalise it' (FG2 305-306)

'We've just recently had somebody who has tried to commit suicide by taking an overdose just yesterday and then he spoke to me and I sort of thought, well, it was to do with symptom control, not to do with mental health, but then other people didn't agree' (FG4 68-71)

Both cohorts of staff identified a tendency to assume lack of capacity and insight in patients with long term mental illness, leading to an avoidance of engaging in end of life care planning discussions. Fear of upsetting patients, and creating emotional instability or distress also contributed to an avoidance of discussions about end of life care and preferences.

'I've found with my particular patients, I didn't go down the normal route… in connection with end of life discussions because of behavioural elements… I just didn't go down the route I normally would have' (FG1 93-105)

A small number of participants identified concerns about legislative responsibility and duty of care, linking this to a lack of standard policy and procedure for supporting patients with long term mental illness, at the end of life, both within the mental health services and hospice provision. Participants noted a lack of national and local strategy, regarding end of life care and mental illness. One mental health participant noted a lack of standard guidance available, regarding resuscitation practice and guidance on appropriate end of life care, within the mental health setting (inpatient).

'I think it varies [in relation to guidance]' (FG3 245)

The significant sub-theme under the concept of confidence and resilience was clinical staff attitudes and behaviours. Several participants described barriers to effective end of life care delivery which related to how clinical staff approached care of patients with long term mental illness. This related to GP's and primary care staff as well as mental health and end of life care staff. Some end of life care participants identified the prejudice against mental illness as an underpinning factor, affecting how patients were referred to, quality of referral information, assumptions about care, management of risk and involvement in care planning.

‘From my personal experience as well, not having a background in mental health, I’d have to address my own biases too, if I get a referral of someone I see has a history of mental health, I’m not sure, you know, without even seeing them, how much I’m going to be able to do…I guess I sort of go in sometimes prepared not to be able to do very much and I think that affects the care they get from me’ (FG 4 133-142)

Assumptions about end of life care were also described and highlighted as a barrier to good care delivery.

‘Thinking about end of life and mental health drugs and when do the mental health team stop those drugs, I’ve got a gentleman who’s on our books at the moment and he hasn’t had his depot injection for six weeks and he’s still up and about…And that palliative period can be really long, can’t it and I don’t necessarily think everyone always appreciates that that might be six months or a year’ (FG4 147-156)

Some mental health participants felt a lack of common understanding about care at the end of life, within the mental health workforce, was a barrier and that the perception that end of life care falls outside the remit of a mental health service was prevalent within mental health services. All participants had chosen to attend, so tended to have an interest in the end of life care agenda, but referred to barriers within their own services in trying to improve or develop the quality of end of life care to patients.

Two end of life care participants also described concerns that lack of experience led to caution when accepting referrals for people with mental illness. A lack of confidence in working with unusual of challenging behaviours was also identified as a barrier to good care delivery.

‘Sometimes when you see a certain diagnosis, you wonder what that person’s going to be like when you enter the room. A lot of them put barriers up very quickly to forming relationships…’ (FG4 374-377)

‘and sometimes you can have that as part of their mental ill health isn’t it, that kind of very complex attachments and relationships that we probably aren’t trained in terribly well in how to manage that’ (FG4 384-386)

4.4 Theme 4 Partnership Factors

THEME	SUB-THEMES	CONCEPT
Partnership Factors	**Information Sharing** Flexible Working	**Breaking down Barriers**
	Partnership with EOL Services Partnership with MH Services Partnership with family/carers Partnership with Primary Care and Other providers	**Breaking down Boundaries**

Table 13 Partnership Factors Theme, Sub-themes and Concepts (significant sub-themes highlighted)

Clinicians described a lack of partnership working as a significant barrier to good end of life care delivery. This theme has been clustered into two concepts (Table 13), ‘Breaking down Barriers’ which are the factors which impact upon clinical staff being able to share information and work flexibly, and ‘Breaking down Boundaries’ which are the factors which contribute to the ‘silo-working’, discussed in Theme 1 ‘Structural and Systemic Factors’.

Poor sharing of information was noted multiple times across all focus groups, both in terms of quality of information and quantity of information. One end of life care participant highlighted the poor quality of referral information. There was no reference to a patient’s mental ill health, nor diagnostic label included, or explanation of the symptoms, issues for end of life care, risk information nor information about how best to work with the patient.

‘Sometimes we do get a patient referral and then in block writing it will say about their mental health condition… they need to describe the risks rather than assume it must be due to the mental health problem… they’re like pre-judged much easier to put “I’m referring this patient, could I request that we talk before we go to visit”. The prejudice is terrible’ (FG 4 443-459)

Mental health care staff described concerns about how much information to share, at what point, and how to involve the patient in this process. Both cohorts of participants described difficulties in sharing information across organisations and with primary care – and noted this as a barrier to good care delivery.

‘The roots might be in childhood trauma or abuse, neglect, things like that and it’s difficult to know always whether you can share that information with a care home, with a palliative care team’ (FG3 617-622)

Several participants shared their view that the ability to be able to work flexibly was important when working with patients with mental illness. This felt possible, to differing degrees, amongst the participants – but was highlighted as an important factor in overcoming barriers to good care delivery. One end of life care participant talked about adapting her approach when working with a patient with schizophrenia and prostate cancer who began to feel suicidal.

‘because there were no beds… because with him, he was feeling so anxious about what he might do with his medication, and we don’t normally do this and I said right well we will take him in four days a week to the day hospice and that absolutely sorted it for him’ (FG1 330-225)

The need to work in partnership was described as desirable but problematic. Participants felt working together was essential, and this is discussed under Theme 5 ‘Solution and Improvement Factors’. Participants discussed multiple examples of where working together is challenging.

'So I think we’re often feeling in the dark a bit, because some of the long term mental health issues are beyond what we know how to deal with and we don’t have that expertise. So, it would be good for us either to learn some of that expertise or to be able at least to liaise with colleagues’ (FG4 178-182)

The need for mental health services and end of life services to work together was felt to be essential, but partnerships with other services, particularly GP’s and primary care staff (e.g. Community District Nurses) were also noted. A lack of opportunity to work together, or come together, to discuss patients, was noted. Participants felt that including other agencies, such as social services and housing was also challenging but desirable, if a more integrated approach to care planning was to be achieved. Individual staff felt it was difficult, at clinician level, to achieve this and felt changes to structures and design of services were required to overcome this barrier. One participant highlighted the need to involve psychiatrists and other professionals in care planning and review.

> *'So actually come and see a patient or discuss a patient and bring the benefits of their wisdom into a scenario, you know and that would be really useful… could be housing people, it could be, you know, whoever, family' (FG4 510 – 518)*

Working with the patient, family and carers was also highlighted. This was felt to be more challenging with this patient group, as family relationships can be more challenging and problematic, or patients can be very isolated and lack people around them to provide support at the end of life.

4.5 Theme 5 Solutions and Improvement Factors

One of the aims of the research question was to identify improvements and solutions to the barriers to providing end of life care to people with long term mental illness and terminal illness, from a clinician's perspective. The participants of the focus groups were not academics or researchers, they were all clinically trained staff from different disciplines and professional backgrounds, responsible for the delivery of care to patients. Improvements were identified by participants at both the structural and service delivery level. Some improvements related to how clinical staff could work better together, and some related to how clinical staff could work more effectively with patients. The findings within the theme have been clustered into two concepts 'Working Together' and 'Using Existing Resources' (see Table 14).

THEME	SUB-THEMES	CONCEPT
Solutions and Improvement factors	• **Effective Partnership Working** • Improved Multi-disciplinary Working/Specialist Roles • Local Good Practice • **Staff training** • Care Planning	**Working Together**
	• Transferable Skills and Knowledge • Similarity of Culture • Change in Perceptions • 'Product' or Output	**Using Existing Resources**

Table 14 Solutions and Improvement Factors Theme, Sub-themes and Concepts (significant sub-themes highlighted)

The first major sub-theme identified was a need for effective partnership working, not just between mental health and palliative/end of life services, but with Primary Care, housing, social services and other agencies, where appropriate. Participants identified that the numbers of people with long term mental illnesses and end of life needs could be quite small in some services, and that it would be unrealistic to expect every service to have dual-trained clinical staff. However, participants were clear that additional expertise was required and that working in effective partnerships at a local level was an important factor in achieving this.

Some participants reflected that ad hoc local arrangements have been developed and that pockets of local good practice exist – often related to particular staff members' interest and knowledge of the local mental health or end of life care systems and services. This was true in both clinical specialisms. Participants felt that there was a lack of clarity and understanding of the mental health and end of life care systems in the locality and that a greater understanding of what services exist, links into local teams and a resource they could turn to for information, would lead to improvements in the delivery of care.

The second significant sub-theme identified by participants was the need for additional staff training – particularly co-operative, collaborative training between mental health and end of life care services. Participants identified the training of different professions in isolation as a barrier (discussed above). Participants identified the potential for collaboration in delivering training, with palliative care/end of life care clinical staff delivering training to mental health specialists and vice versa.

'It would be quite good if we could have some mental health training as well and then help train them on the palliative side' (FG1 229-230)

Nearly all participants from both specialisms identified a lack of training as significant. The principle of training each other arose several times in the focus group discussions. Palliative/end of life care clinicians felt they lacked understanding of mental illnesses, the symptoms and difficulties that patients diagnosed with different illnesses might experience or present, confidence in assessing mental capacity and risk, medication management issues and techniques for managing challenging behaviour, in hospice and hospice at home settings.

Most mental health participants felt they lacked understanding of what constitutes end of life care, the difference between care at the very end of life (the last weeks) and longer term palliative care, the breadth of services offered by hospices and other end of life care services and teams, how to access end of life care services for their patients, particularly in a residential or inpatient setting and what end of life care can be delivered by mental health staff in a mental health setting.

‘When somebody does have a diagnosis, a terminal diagnosis and enters the end of life phase… we discharge them, because, well, they’re not going to get better with their mental health concerns’ (FG2 362-366)

One participant highlighted the need for integration of the end of life care process and policies into mental health services.

> *‘I think the end of life care strategy within mental health is absent, I can’t believe we don’t have one, you know we have a policy for this and that … so how can we manage not to have a policy about how we will link with the local health and social care agencies…what our approach is, a positive, proactive approach, we don’t have it written into our health and social care assessment, it’s not in our care planning tools, it’s not in our outcomes framework, I mean a strategy would be able to identify everywhere this needs to touch what we do’ (FG3 382-391)*

The other ideas which arose under the concept of working together included identifying and sharing examples of local good practice, developing individual care planning and case management processes for patients diagnosed with life-limiting illness. Several participants suggested that a multi-disciplinary and multi-organisational approach to developing an end of life care plan would be beneficial and one which family and carers would be included in where appropriate.

> *‘CPN or GP or whatever, communicating together so you’re holistically doing it, I think the patient will have a lot better journey..’ (FG3 561-563)*
>
> *‘I think it’s joined up work, like, joined up working really or communication between different teams (FG1 35-36)*

Participants identified some similarities in the culture of end of life services and mental health services in that both systems deal with patients who may not recover in the same way that other health specialities experience. Participants identified examples of transferable skills i.e. working with people with dementia or learning disabilities, where they had adapted practices and care, to meet patient need; which could be transferable to working with some patients with mental illnesses.

Interestingly, two end of life care participants discussed situations where direct contact with a patient with a mental illness had led to a change in their perception and attitudes.

'I mean the gentleman X was on about, with the issues when he was really ill and we had to take his medication off him… he's obviously a very sort of sick man with sort of his mental and physical health, but he's so easy to engage with' (FG1 308-213)

'He's an open book … he's got lots of insight as well… it's very easy to work with him… ' (FG1 308-320)

Similarly, one mental health participant reflected on feeling more confident after working closely with people at the end of their lives.

'I suppose I have had fairly frequent contact with people really close to the end of their lives, through working in complex care' (FG3 37-40)

5.0 Discussion

People with long term mental illness experience higher rates of many chronic and life-limiting illnesses, and whilst there is a focus within public health on improving the health and well-being of the general population, and targeting marginalised groups within this, it is reasonable to expect that end of life care services and mental health services will continue to need to provide effective end of life care to this patient group (Rethink 2013; 14).

The aim of this research was to conduct an exploratory study to develop further understanding of how to improve end of life care for people with long term mental health conditions. This was achieved by gathering the views, experiences, attitudes and insights of clinical staff, working in both mental health and end of life care, in contemporary, UK-based clinical settings. It aimed to discover barriers to provision of services and identify potential improvements to clinical practice, from a clinicians' perspective.

As described in Chapter 3.0 Methodology, the study was carried out in one area of the UK, in two individual organisations, but its findings reflect the themes which emerged from a review of published literature from other parts of the world. Although the sample size was relatively small (23 participants), many of the findings converged with those in the literature review, however, some new findings also emerged. Rather than apply the themes from the literature review findings to the analysis of the focus group data, the researcher chose to use open coding, as suggested within the Framework Analysis method (Gale 2013: 4) to ensure that if different themes and concepts emerged in the focus groups, that they would be captured in the data analysis, findings and recommendations. This felt important to the research study as the body of literature was spread across different countries and covered different healthcare systems. The aim of the study was to understand contemporary UK clinical practice so ensuring all themes were captured was important to achieve this aim. As the findings show, there were overlapping themes, but clinical staff referred to issues of partnership working extensively, so this became an additional theme in the findings of the study.

The study adds to the body of research in two main ways. First, it explores the views and experiences of clinical staff working in contemporary end of life and mental health care settings in the UK, and concerns current clinical services and practice. The published literature mainly focuses on studies published in other countries, such as USA, Australia and Canada and only explores the views of clinical staff to a very limited degree (McGrath and Forrester, 2006). Second, the methodology, particularly the data collection methods, are novel and contribute to the expansion of qualitative research methods. Reflections on the impact of the methods are included later in the Chapter.

Each theme will now be discussed in this chapter, highlighting similarities with the literature and examples of new or novel findings, followed by a discussion about methodology. Recommendations and implications for practice will be made, using the concepts which emerged in the data analysis for structure. Finally, conclusions will be drawn. A visual diagram of the themes and concepts is provided in Fig. 6.

Fig. 6 Themes and Explanatory Concepts

5.1 Theme 1 Systemic and Structural Factors

Participants made multiple references to factors which impact on care, which are beyond the scope of their own, individual clinical practice and related to the wider system, within which care is commissioned and structured. Much of the content which was clustered within this theme related to what clinicians called ‘silo-working’, highlighting the separation between mental health services, primary care, acute services and end of life care. The separation of services appeared to go beyond the way in which they are delivered. For example, as mental health and physical health care services are commissioned separately, clinical staff are trained to work either in mental health or in physical health, and within physical health, end of life and palliative care are sub-specialisms. Health services are provided not only within the NHS, but also by charities, social enterprises and private healthcare organisations. Whilst expertise and specialism are desirable, many of the findings within the data, as well as the literature, point to a need for greater partnership working, multi-disciplinary working and for the need for clinical staff to have greater knowledge and skills of both mental health and physical health (Durkin et al, 2003; Hill 2005; Sweers 2013; Woods 2008).

Consequently, there is a need for greater integration, at all levels from frontline service delivery through to the funding and commissioning of services and the training of clinical staff. Ganzini et al (2010) carried out a study of veterans with schizophrenia and cancer in the USA. This study compared the quality of end of life care between veterans with and without schizophrenia who had died of cancer. It was the only published study where the outcomes for a group of patients with a mental illness and a terminal illness were comparable or better than those without mental illness. The researchers attributed this to the structure of the healthcare system for veterans in the USA, which is and integrated health care system, locating mental health, physical health and social care services under one umbrella and where end of life care is valued. In all other studies reviewed, references were made to the need for greater partnership working, to break down barriers and boundaries between services and to work better together with patients and carers, in planning and delivering good end of life care for this patient group. On the whole, findings and the literature were consistent. The findings confirmed that the issues regarding the systemic and structural barriers raised within the literature are still to be addressed within services in the UK. There was one exception, where the data captured a new dimension. This related to the funding and commissioning of services. Several participants, from both mental health and end of life services, had raised the issue of the reductions in funding of healthcare services and having to operate in an environment of austerity. This was raised in relation to referring patients to other services in that participants appeared to feel that there was little point referring on, as there were no services available, no funding available, or very long waits. Further research would be required to ascertain whether this is actually the case, but the fact that staff perceived it to be, still impacts negatively on the delivery of care, as some participants appeared to have no expectation of services existing for their patients, outside their own clinical area, or that there would be funding problems, or long waits, if they knew they did exist. The factor which became a barrier was *perception* of funding and commissioning, and was related to working in 'silos'; rather than the realities, or otherwise, of the current funding and commissioning arrangements in the UK.

In this exploratory study, which aimed to capture the views and experiences of clinical staff, about the barriers they experienced and about possible solutions, the researcher was not expecting to consider the systemic and structural factors which contribute to the delivery of care. However, although many of the findings, in the data and in the literature, concerned changes to individual clinical practice and the provision of information and training, it is important to consider the wider environment within which care is delivered. Changes could be made at a service level, but unless the structural and funding issues are also addressed, improvements will continue to be made only in isolation and without consistency.

5.2 Theme 2 Patient Factors

Barriers relating to the characteristics and behaviours, which people with long term mental illnesses present, were highlighted in many of the studies reviewed (Bloomer et al 2013; Durkin et al 2003; Feely et al 2013; Terpstra and Terpstra 2012 and 2014; Hill 2005). Behaviours described as challenging, varied, depending on the setting, but included care-seeking and care-rejecting behaviour, anger and aggression, withdrawn or flat presentation, suspicion of services and unusual beliefs about death and dying. However, participants in the focus groups placed less emphasis on the presentation of the patient as a barrier. End of life care staff referred to behaviour they experienced as challenging, more than did mental health staff, which was expected. Interestingly, although it was described as a factor, the barrier they identified was their own lack of expertise in dealing with the behaviour. So, although the presentation of the patient was identified as a barrier in both the literature review and the data analysis, the emphasis on how to overcome the barrier was different. The findings from the focus groups put an emphasis on developing the skills of clinical staff, rather than the locating the problem with the patient, as a means to improving care.

The themes in the findings of the study began to interrelate once improvements or solutions were considered. Several end of life participants commented that once they had experienced working with a patient with mental illness, their fears and prejudices had been alleviated. Although they initially talked about behaviour displayed by the patient as challenging and that there was a need for more training, as the discussion developed, participants began to share experiences of clinical work, which had changed their preconceptions and helped them to feel more confident in their practice. In this way, factors which were patient-related, also linked to clinician factors and improvement factors.

Other patient-related factors in the findings concern the social, economic and environmental circumstances, which patients with long term mental illness often experience and how they impact on their presentation to and use of healthcare. Poor physical health, low income, fractured family relationships, inadequate housing and poor experiences of services are all factors which people with long term mental illness are more likely to experience (Department of Health, 2013). Whilst it is important to understand these factors, addressing them requires consideration of a broad range of public health and equalities initiatives. The Parity of Esteem agenda (RCPsych, 2013) is a key priority for NHS England and aims to improve the disparities between mental and physical healthcare. Within mental health services, a focus on recovery and rehabilitation, and initiatives such as Time to Change (www.timetochange.org.uk) aim to challenge the stigma associated with mental illness and address some of the disadvantages which patients experience.

5.3 Theme 3 Clinician and Service Factors

A number of interesting findings emerged out of the data, from clinical staff in both mental health and end of life services. Most significantly was the lack of understanding of the mental health system by end of life clinical staff and the end of life system by mental health staff. References to a lack of mental health expertise in end of life care are made in studies by Durkin et al (2003) and Foti et al (2005) but on the whole the published literature does not highlight awareness of the structure of the systems as an issue. It was impressive to see the level of expertise participants had within their own specialism. However, only one participant talked about feeling a level of confidence or expertise in working across the specialisms. A mental health care participant, who had experience of working in older people's services, talked about the initiatives they had developed within the service, around working with patients at the end of life. It was surprising how this was not known about in other parts of the organisation.

The participants in the end of life focus groups talked at length about their lack of understanding of mental illness, the mental health system and how to work more closely with mental health services. The hospice, where the focus groups were carried out, has some mental health expertise within the wider staff group, so there is some internal resource, but participants found working closely with mental health professionals, who were involved in their patients' care, very difficult.

The need for working more closely together is explored under the theme of partnership working. However, there was also a clear need for access to information about local mental health services, how to contact teams and how to access services for patients. In addition, participants expressed a need to access expertise in how best to support the patient within the end of life care service, with issues such as advice about medication, how to manage anxiety and distressing behaviour, and retaining the support, often in place for many years, which the patient has had from the mental health team right until the end of life.

Within mental health services, the lack of an End of Life Strategy, or a position statement, appeared to lead to a lack of understanding of the role of mental health services in end of life care. Reviews of literature by the MHF (2008) and Woods et al (2008) call for specific guidelines for working with mental health patients at the end of life. However, there appears to be little or no strategic position of guidelines available. Participants referred to the common perception that end of life care is not the responsibility of mental health services. Although the participants in the groups did not seem to hold this belief, it was referred to as common amongst colleagues. The fact that participants' self–selected to attend, probably meant that there was a degree of interest or acceptance that end of life care was relevant to mental health services, amongst the cohort. This potential bias is discussed in Chapter 3.0 Methodology and Section 5.3 Limitations. Mental health participants also expressed a lack of awareness of the end of life system, of local services available and like much of the general population, a lack of understanding of the breadth of end of life and palliative care, and of when services can become involved with a patient.

The attitudes and behaviours of clinical staff appeared also to impact on the delivery of care. Studies by Sweers et al (2013) Terpstra and Terpstra (2012 and 2014) and Foti et al (2005) refer to the anxiety in staff when working with people with mental illness, of causing emotional upset, or de-stabilising mental well-being or provoking distress. The findings in the literature review highlighted that this anxiety can lead to an avoidance of talking about end of life care with patients. Combined with a tendency to presume lack of capacity (Foti et al 2005 and Sweers et al 2013), the quality of end of life care planning and delivery is negatively impacted upon. The findings in the focus groups concur with this picture. Participants, in both cohorts of staff, referred to times when they had avoided conversations with patients for fear of upsetting them or because they believed them to lack capacity. Studies by Ganzini et al (2010) and Geppert et al (2011) challenge this perception, stating that when asked, patients with mental illness most often can and wish to talk about their end of life care. Challenging these attitudes and behaviours in staff, and supporting them to feel more confident in having end of life conversations, in both clinical settings, form part of the recommendations in this study.

The findings within this theme were reflected in the literature, and no new findings emerged, however, the possible solutions, identified by participants, to the issues highlighted, do contain novel findings and will be discussed below.

5.4 Theme 4 Partnership Factors

The findings of this study confirm that it is very difficult to provide good end of life care to people with long term mental illness without sound partnership working. There was an understanding amongst participants that the numbers of people with mental illness and end of life care needs are unknown, but that they might be described as a significant minority, compared to the general population needing end of life care. However, their specific needs require attention and consideration in particular ways. It would not be realistic to expect every service to have specialists in both mental health and end of life care needs. There may be a need for additional mental health expertise in end of life services, and additional end of life care knowledge and understanding in mental health services, but this will never replace the need for effective partnership working. The need to work well together, as different healthcare providers, but also with other agencies, patients and families, is well documented throughout the literature and the findings from the focus groups (Terpstra and Terpstra 2012; MHF 2008; Woods 2008 and Geppert et al 2011).

Information sharing is problematic across the healthcare system and links back to the earlier discussions about the structure and funding of healthcare services and training and working in professional silos. Participants cited poor sharing of information, especially referral information between services, as a key barrier in providing good care. Clinical staff appeared cautious about the degree of information that could be shared. What is shared is often fleeting reference to a mental health issue, without relevant information about how best to work with the patient. Protecting patient confidentiality is important. However, when the attempt to protect confidentiality impacts negatively on care, clinical staff would benefit from guidance and structure, to enable appropriate and relevant information to be shared. Closer collaboration between services would improve the quality of information sharing and consequently the care delivered to the patient.

Mental health services should remain involved with the patient even when they enter the last few weeks of life. Individual practitioners or teams may have known the patient for a long time and so continuity of support may be important. In addition, advice and guidance may be required regarding medication, management of behaviour and providing support to end of life care clinical staff, to ensure the patient remains fully supported until the end of life.

5.5 Theme 5 Solutions and Improvement Factors

Most of the published literature focuses on describing the characteristics of the cohort of patients that this study concerns and the barriers to delivering good end of life care. Most papers make some form of recommendations for improvements but none report on the results of improvement interventions. Literature reviews by the MHF (2008) and Woods (2008) make clear recommendations about improvements to care. None of the studies, published subsequently, report the success, or otherwise, of any improvement interventions. Improvements suggested come from the researcher’s observations, rather than directly from patients or clinicians. What was new in the findings of this study were the clinician-led suggestions for improvements. Clinical staff often hold important intelligence about the problems in healthcare delivery, but lack the influence or autonomy to implement improvements (Parker et al 2009: 2).

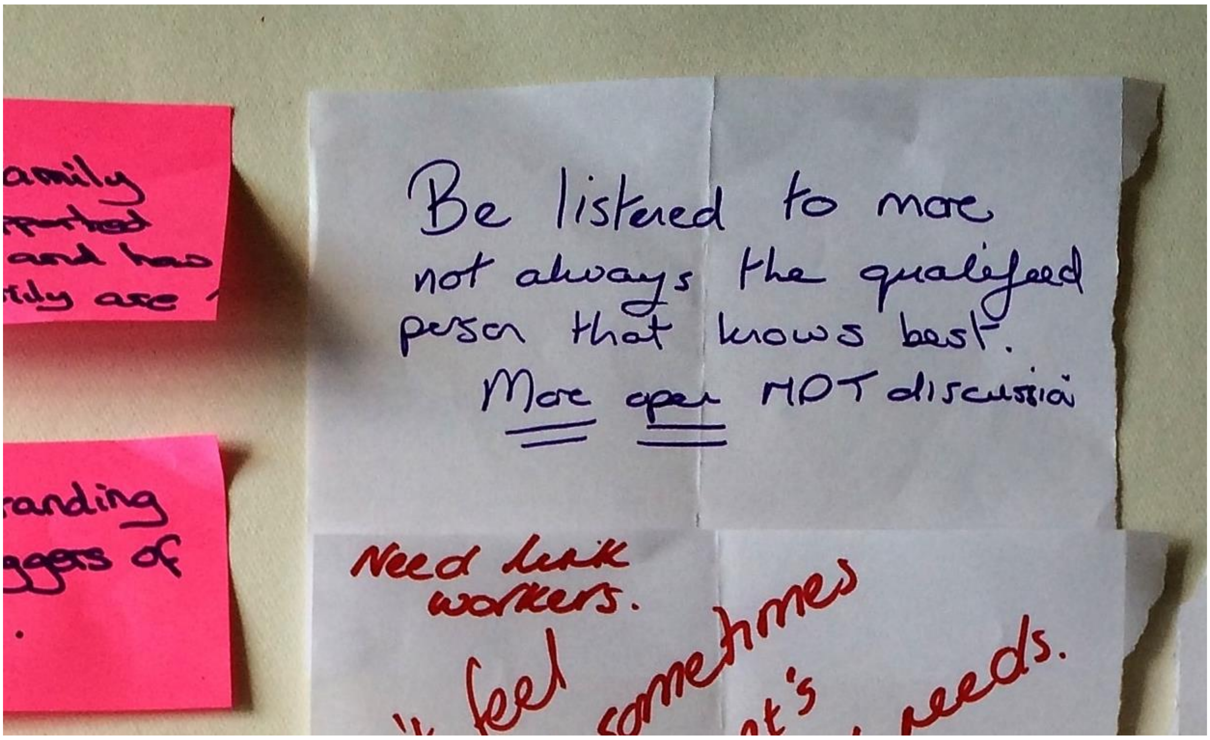
The researcher noted the willingness of participants to improve care. Despite being very aware, and feeling the limitation of, the barriers to delivering good care, the participants who attended the focus groups, shared many ideas of how barriers could be overcome. Immersion in the data led the researcher to understand the importance of including clinical staff in the development of improvements to care, in the same way that there is importance placed upon the involvement of patients and carers in healthcare developments (Mockford et al 2012: 28).

The potential to develop improvements and innovations which combine themes and concepts appears novel within this field of clinical practice. Improvements include enhancing partnership working, flexibility of working, involving staff and patients, sharing good practice, providing effective staff training and increasing the confidence and resilience of staff. By bringing groups of staff and patients together from mental health services and end of life care services and potentially, including primary care staff as well, to develop training and information resources, it would be possible to address several of the key barriers identified in the literature and the study findings. This is explored further in the recommendations below.

5.6 Reflections on Methodology

As described in Chapter 3.0 Methodology, the data collection method combined focus groups with the CUbe (Magee et al 2015) method, and offers an innovative approach to qualitative research methods, by extending the opportunities for participants to share their views beyond a traditional focus group discussion.

Providing additional means for participants to share views in the groups, using the CUbe method and making resources available for participants to record anonymous contributions, added a layer of richness to the data collected. Whilst much of the content of the CUbe and written data echoed the themes raised within the verbal discussion, there were a number of contributions made which were not raised verbally. Fig. 7 illustrates an example of something that was not raised in the discussion.



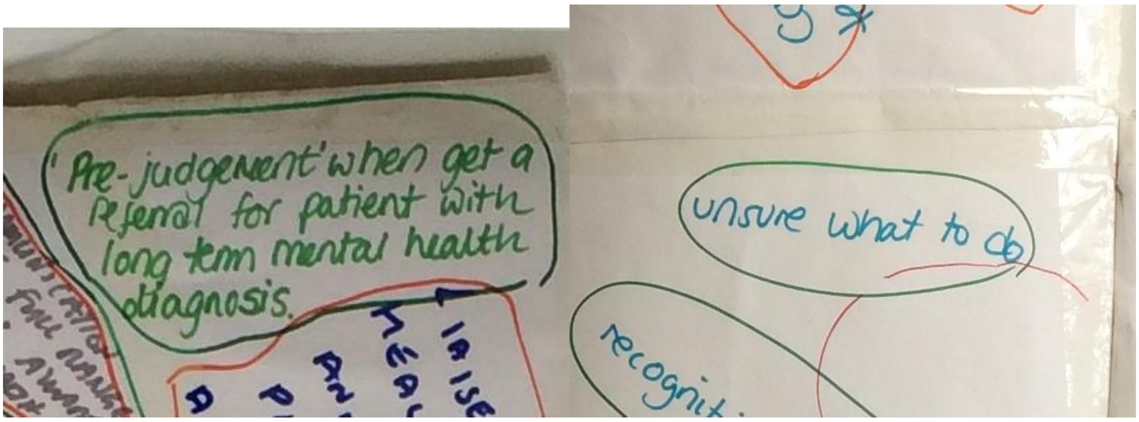
Be listened to more
not always the qualified
person that knows best.
More open MDT discussion

Need link
workers.

Fig. 7 Example of contribution made in written form but not shared in verbal discussion

The reference to qualification implies this contribution was made by a more junior member of staff – it may be difficult for more junior members of staff to share their feelings and experiences in a focus group which is open to all levels of staff within an organisation. Providing pens and paper allowed information like this to be shared and included in the data analysis.

The CUbe method captured instances of participants expressing lack of knowledge or uncertainty. Fig 8 shows two examples.



'Pre-judgement' when get a Referral for patient with long term mental health diagnosis.

unsure what to do

Fig. 8 Examples of participants sharing uncertainty in written form but not in verbal discussion

It may have been difficult for the participants to talk openly within in a group of colleagues and possibly line managers, about feeling unsure, or pre-judging; but it is these fears and attitudes which need to be addressed and supported if care is to improve. So having the CUbe integrated into the focus group allowed this data to be captured, where it may not otherwise have been. The other observation made by the researcher about the use of the CUbe, was the impact on the energy and level of debate in the room. The researcher observed that the CUbe offered a starting point to the discussion and something of a distraction, which appeared to improve the quality of the discussion in the two groups where the CUbe was used extensively. The discussion felt more dynamic and flowed more freely. The physical presence of the CUbe and the way it prompted participants to interact, passing it between them, writing on it, using different coloured pens and standing closely together, all appeared to impact positively and increase the richness of contributions.

5.7 Recommendations and Implications for Practice

A series of recommendations and implications for clinical practice emerge from the findings in the data and the literature review. The framework method provided a structure, which enabled large amounts of primary data to be analysed, clustered into themes and then synthesized, with the themes in the literature review, into explanatory concepts (Gale et al 2015). Each recommendation or implication for practice has impact or links to a number of the concepts which are highlighted in Table 15 below.

Recommendation/ Implication for Practice	**Concepts**
Further Research There is a clear case for further research to be carried out within the UK. High quality research studies which include patients and families and the design and delivery, that pilot potential improvements and solutions to care are required. The difficulties of providing good quality end of life care to people with long term mental illnesses are well described and understood. The findings of this study largely reflect those within the published literature. Research studies and practice interventions exploring improvements to practice are needed – the findings of which must be published and disseminated to ensure research impacts clinical practice.	Experience of Services Knowledge and Understanding Confidence and Resilience Breaking Down Barriers Breaking Down Boundaries Working Together
Improved Partnership Working Innovations which bring together clinical staff from end of life care and mental health services are recommended. Partnerships with other services, particularly primary care, are also recommended. Formal joint working arrangements aimed at making expertise available to clinical staff are also suggested.	Breaking Down Barriers Breaking Down Boundaries Working

	Together
Improved Patient and Carer Involvement The involvement of patients and carers in care planning and the development of innovations to practice is recommended.	Breaking Down Boundaries
Confidence and Resilience of Clinical Staff The development of reflective practice and action learning opportunities for groups of staff from across disciplines to come together to think about clinical practice are recommended.	Knowledge and Understanding Confidence and Resilience Working Together Breaking Down Boundaries
Training of Clinical Staff Continuing professional development (CPD) training must be embedded within clinical practice. The development of co-designed training, which involves patients and carers, as well as clinical staff from mental health services and palliative care services is recommended. Involving clinical staff in the design and delivery of training, allowing them to share their expertise and learn from each other, as well as from patients and families may create greater investment in the learning process.	Knowledge and Understanding Confidence and Resilience Breaking Down Barriers Breaking Down Boundaries Working Together Using Existing Resources
Access to Information and Guidance Clinical staff need information, skills and knowledge to support the delivery of good end of life care to this patient group. Information must be accurate, locally specific and easily accessible to clinical staff. There is a place for strategy documents to inform the design and commissioning of services, but clinical staff need easily accessible,	Knowledge and Understanding

clear information about local service availability (mental health services and palliative care services).	
Development of Strategy As well as interventions at a clinical level, there is a need to ensure the inclusion of the needs of people with long term mental illness at the end of life within national and local strategy and policy development. Change in clinical practice must come from both practice and policy developments. The dissemination of good quality clinical research, focused on improving care, could influence the development of policy, strategy which in turn informs the commissioning and design of clinical services. Mental health services would benefit from development of end of life care strategy, which outlines how and why end of life care is relevant and in reality, actually often provided within mental health services. There are different needs within residential, particularly long-stay units, and units where patients are detained. A strategy would outline the roles and responsibilities of the mental health service when working at the end of life, and outline partnership approaches and where other agencies should be brought in. A strategy would set the tone within mental health services that supporting patients to the end of their lives is an important part of clinical practice.	Designing the System Using the System Knowledge and Understanding Breaking Down Boundaries Working Together Using Existing Resources
Sharing Good Practice and Myth busting There are examples of good local practice which should be identified, shared and incorporated into working policies and practices. There are widely held myths and misconceptions about both end of life care and mental illness which could be challenged in the wider clinical community through an information campaign.	Knowledge and Understanding Working Together Breaking Down Boundaries
Integrated Care Planning Care planning needs to be co-ordinated and multi-agency. Following diagnosis of a chronic, life-limiting condition, or diagnosis of terminal illness, a referral to palliative care can be made by the GP or specialist, which should be supported by the patient's care co-ordinator (this may	Presentation to Services Experience of Services

be a psychiatrist, community psychiatric nurse or other CHMT member). Patients with long term mental illnesses will usually be supported by secondary mental health services, rather than in primary care. Services required will depend on the stage and nature of diagnosis, but hospice care involves much more than inpatient services. For instance, there may be services available to the patient to enable them to stay living independently for longer. There may be a pain clinic or breathlessness support clinic. Many hospices have psychological well-being support services, family support and day hospice provision, all of which may be considered for patients will mental illnesses. All agencies involved with the patient should be included in care planning, including the patient and their family/carers.	Breaking Down Barriers Working Together Using Existing Resources
Development of Guidelines on End of Life Care for Mental Health Staff Clinical staff in mental health services need access to guidelines for delivering and managing end of life care in mental health settings, especially where patients choose an inpatient or residential setting as their preferred place to die. Guidelines would sit underneath a strategy and form a resource for clinical staff to refer to when necessary.	Knowledge and Understanding Confidence and Resilience
Improving Mental Health Expertise in End of life Care End of life and palliative care services – both inpatient and community, would benefit from embedding mental health expertise within the workforce. It may not be realistic to have mental health specialists employed full time within teams, but good local partnerships with mental health services and developing the capacity of some staff to have more in depth mental health knowledge, and of all staff to have some level of mental health awareness is recommended.	Knowledge and Understanding Working Together Designing the System

Table 15 Recommendations and Implications for Practice linked to explanatory concepts

5.8 Limitations

The research study had several limitations. It was carried out in two services in a diverse urban area of the UK. It would be valuable to extend the reach of subsequent research to include rural areas and areas of varying socio-economic need. It was small in scale, in line with the parameters of a Masters study, and would have benefitted from inclusion of the views of a greater number of mental health practitioners, including those more hostile to the idea of providing end of life care within mental health services. As participants could self-select, there was an inevitable bias towards clinicians who hold an interest in end of life care for people with mental illness.

The researcher was a staff member in both organisations. Whilst in the mental health trust, he was not known to participants, he was known to participants in the hospice. The issues surrounding insider research are explored within Chapter 3.0 Methodology. However, it is important to note the potential limitations of insider research in this section. It may be that participants were not as open as they may have been with an unknown, external researcher. It may be that the researcher responded differently to facilitating focus groups with people he knew from those he did not.

The data collection method has limitations, in that the date, time and location of focus groups precluded some participants from taking part. The nature of data collection within a group will have discouraged some members of staff from taking part. It is difficult for some staff to come away from the clinical setting to take part in a focus group, particularly more junior staff. The researcher mitigated against this as much as possible by undertaking preparation work with managers in advance. This was easier within the hospice, due to the smaller size of the organisation. It was not possible to communicate as widely with managers or clinical staff within the mental health trust, due to the size and complexity of the organisation.

5.9 Conclusions

People with long term mental illness have higher rates of life-limiting illness, yet many barriers to accessing effective end of life care exist. This study draws together the themes, within the published literature, with findings from an exploratory study of the experiences and perceptions of clinicians working in both mental health and end of life care of the barriers to providing end of life care to people with long term mental illnesses and the possible solutions to overcoming these barriers.

The study makes links between the similarities in the themes within the literature and the findings from the research study. New and novel findings are highlighted and recommendations and implications for clinical practice are made. The study highlights that many barriers still exist, but that the factors which contribute to the barriers in delivering end of life care to this patient group are well understood. It draws out the recommendations from the published literature and the proposed improvements and solutions from clinical staff and makes recommendations to improve clinical practice.

Building the confidence and resilience of clinical staff, in both end of life care and in mental health services and involving them in the development of innovations to practice, with patients and carers, are key to improving end of life care.

People with long term mental illnesses have often led extremely challenging lives, characterised by experience of prejudice and inequality. Improving the quality and availability of good end of life care to this often marginalised and excluded group is an important healthcare issue.

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www.timetochange.org.uk

www.ncpc.org.uk

www.dyingmatters.org.uk

Appendix 1a

Critical Appraisal of Literature

Criteria	1. Bloomer et al (2013)	2.Candalis et al (2004)	3.Chochinov et al (2012)	4.Durkin et al (2003)	5.Feely et al (2013)
1.Trustworthiness					
Are the design and execution appropriate to the research question?	Discussion paper based on review of literature and research	Exploration of particular model of community psychiatry	Yes, quantitative, comparative study looking at access to services	Yes – review of patient notes and information gained on admission, through assessment used	Yes, case study exploring clinical practice
What evidence of reflexivity is there?	None explicitly	None	None	Limited – researcher is MH trained, which is apparent	Limited
Do the voices of the participants come through?	N/A	No, not the purpose of the paper	No – quantitative study of health records	No – N/A	Observations of patient through case study – no use of direct quotes
Are alternative interpretations, theories, etc. explored?	N/A	No	N/A	No	No – it's a case discussion
How well supported by the data are any conclusions?	Literature supports the recommendations of the paper	Limited	Supported	Well supported within scope of the study	Supported by literature regarding working with people with PD diagnoses
Are ethical consideration given appropriate thought?	n/a – no patients involved	No ethics process outlined	Yes, anonymised data was used	Yes – explicit reference made in paper	Anonymised case study
2.Theoretical considerations					
Does the report connect to a wider body of knowledge or existing theoretical framework?	Yes – considers practice issues in the context of the evidence base (which is limited)	Yes – links to what is already known about views of people in the mental health system and stigma/assumptions	Yes, acknowledges the lack of quantitative studies, but links to wider evidence base which is largely qualitative	In a limited way	Yes – links to limited research available
If so, is this appropriate (e.g., not uncritical verification)?	Yes	Yes	Yes – locates in body of research	Yes, but limited	Yes
Does the paper develop explanatory concepts for the findings?	Yes, considers findings in literature with regard to clinical practice and future research	To some extent, uses theory of assessing risk and heath care assessment to build case for pilot study	Yes, hypothesis and discussion	Yes, to some extent, makes practice recommendations	Limited, not findings does develop (with evidence) way of working with BPD in EOL
3. Practical considerations					
Does this study usefully contribute to the clinical setting?	Yes, clinical practice recommendations	Yes – could influence treatment of people in the mental health system and end of life discussions	Limited – contributes to understanding rather than specifically to practice	Yes, call for staff training	Yes, advice for clinical staff
Does this study provide evidence relevant to the policy setting?	Yes, limits of 'system' identified, recommendations for structural change	No – practice orientated	Yes, structural issues identified	Yes, shows how MH patients excluded	Not really, implications for joint working mentioned
Does this study usefully contribute to the review?	Yes, conclusions/recommendations echoed in UK clinical practice	Yes – in terms of locating debate in risk and avoidance of EOL discussions	Yes	Yes – but concerns all MH issues in EOL not just pre-existing	Yes, specific but translatable example

Criteria	6.Foti et al (2005)	7. Ganzini et al (2010)	8.Geppert et al (2011)	9.Hill (2005)	10.McGrath et al (2006)
1.Trustworthiness					
Are the design and execution appropriate to the research question?	Yes, questionnaires given to participants and responses collated	Yes, Cross-sectional study, comparing individual veterans with and without schizophrenia diagnoses	Yes, although limited to one case example, but clearly states this	Yes, case study exploring clinical practice	Yes, descriptive phenomenology used as little is known about the group the study is concerned
What evidence of reflexivity is there?	Some – although somewhat limited	Limited, some comments about authors professional role in relation to study	Very little	Some – limited in the write-up	Little
Do the voices of the participants come through?	Responses collated and presented in the paper, patients preference presented	No – observations and conclusions made by researchers but direct quotes not used	Yes, the ethics panel members present their views within the paper, representing patients' interests	Observations of patient though case study – no use of direct quotes	Yes, participants are quoted directly as well as their views summarised
Are alternative interpretations, theories, etc. explored?	No	In a limited way – the paper seeks to understand a specific group and doesn't make links to other, similar populations	Different authors present different issues/perspectives	Not really as it is a case study concerning working with BPD specifically	No, but there is limited literature on the subject matter
How well supported by the data are any conclusions?	Well supported within the scope of the study	Well supported and different from the hypothesis and other evidence within wider literature	The conclusions presented as an argument for a particular role	Supported by literature regarding working with people with PD diagnoses	Well supported
Are ethical consideration given appropriate thought?	Yes – limitations are clear and participant well-being was assessed after participation	Data used was post-death; doesn't refer to ethics approval, American study	Yes, the paper is a presentation of an ethical case study, ethical dilemmas in this scenario– anonymised appropriately	Yes, anonymised case study	Yes, the study is concerned with sensitive issues within the research setting and measures to mitigate risk are outlined
2.Theoretical considerations					
Does the report connect to a wider body of knowledge or existing theoretical framework?	Yes, references wider theory extensively	Yes, it is the only study with a positive outcome and makes some comment on why this may be which is helpful for wider practice and policy development	Limited, but not inappropriately given the nature of the paper	Yes – links to limited research available and PD theory	Yes, it links back to previous themes from reviews of literature and to relevant legal and ethical structures and legislation
If so, is this appropriate (e.g., not uncritical verification)?	Yes	Yes	Yes	Yes	Yes
Does the paper develop explanatory concepts for the findings?	Yes, conclusions and recommendations are drawn	Yes, challenges some preconceptions and speculates why results were unexpected	N/A	Limited	No
3. Practical considerations					
Does this study usefully contribute to the clinical setting?	Yes, encourages clinicians to engage in EOL discussions	Yes, holistic care recommended	Yes, the findings are useful, presents ethical dilemmas in clinical practice	Yes, good clinical example of how to adapt practice to work with BPD clients	Yes, the findings are useful given the small literature base
Does this study provide evidence relevant to the policy setting?	Yes	Yes	In a limited way	No	Yes implications can be taken
Does this study usefully contribute to the review?	Yes – limited due to hypothetical approach rather than palliative patients but useful when considering staff perceptions/fears about having EoL conversations	Yes, only positive outcome in research body	Yes, highlights dilemmas for clinical staff and behavioural and social issues MH patients can present	Yes, useful in considering adaptations to clinical practice	Yes

Criteria	11.MHF (2006)	12.Sweers et al (2013)	13.Terpstra et al (2012)	14.Terpstra et al (2014)	15.Woods et al (2008)
1.Trustworthiness					
Are the design and execution appropriate to the research question?	Yes – literature review of published literature	Yes – grounded theory approach; themes identified from interview transcripts	Review of existing literature and examples from clinical practice	Yes, case study used to illustrate and highlight clinical issues experienced in palliative care setting	Yes, systematic review of the literature
What evidence of reflexivity is there?	none	Some, examples of practice reflections included	none	Limited, some comments about authors professional role in relation to study	n/a
Do the voices of the participants come through?	n/a	Yes, through groupings of themes and direct quotes	No – summary of literature rather than direct contact with patients	No direct quotes included, researcher observations and descriptions used	n/a no patient based studies identified, few empirical studies identified
Are alternative interpretations, theories, etc. explored?	n/a	No but the study doesn't aim to do this	No	Practice is explored, but not alternatives interpretations of the barriers identified – this feels appropriate to the case study	n/a
How well supported by the data are any conclusions?	Well supported, review is comprehensive	Well supported	Supported by the published literature	Well supported	Well supported by the findings within the published literature
Are ethical consideration given appropriate thought?	n/a	Yes, patients in remission selected, none experiencing active suicidal thoughts included; results anonymised; ethical approvals given	n/a discussion paper	Anonymised case study used	Each study reviewed, commentary included about ethics and validity
2.Theoretical considerations					
Does the report connect to a wider body of knowledge or existing theoretical framework?	Yes	Yes, links to wider body of literature	Yes	Yes, consideration of case example set within wider evidence base – which is limited	Yes,
If so, is this appropriate (e.g., not uncritical verification)?	Yes	Yes	Yes	Yes	Yes
Does the paper develop explanatory concepts for the findings?	Not the purpose of the study	To some extent	Yes, makes recommendations from practice and literature	Yes – discusses implications for practice	Limited, used literature to make recommendations to clinical practice and policy/system
3. Practical considerations					
Does this study usefully contribute to the clinical setting?	Yes, calls for further research	Yes – includes recommendations for clinical practice	Yes, makes practice recommendations	Yes, recommendations for practice from real case example	Yes, implications for practice included
Does this study provide evidence relevant to the policy setting?	Yes, calls for further research	Yes – clarifies needs of the patient cohort which could inform policy development	Yes, covers some policy and structural issues	Yes	Yes, comment on structural and research gaps/needs
Does this study usefully contribute to the review?	Yes, summary of literature	Yes	Yes	Yes, case example	Yes, summary of literature

Appendix 1b

Thematic Analysis of Literature

Study Number	Author	Themes Identified
1.	Bloomer, et al (2013) Australia	Attempt at prevalence Clinician fear of escalating risk of emotional instability System design in Australia is a barrier – silo services, speciality driven Role of family as long term carers Need for a multi-disciplinary approach to care management Perception of risk, issues of security and detention, hospices not appropriate for this Lack of published literature/research studies Late diagnosis leading to poorer prognosis Reluctance to seek care Links poor mental health to poorer physical health outcomes Lack of confidence in palliative care staff in dealing with mental illness Recommends individualised treatment plans, incorporating mental health staff known to patient
2.	Candilis et al (2004) USA	Models of competency assessment and suicide risk assessment applied to assessing capacity and risk at EOL Clinician fear of causing emotional instability - Leading to avoidance of EOL discussions Clinician perceptions of lack of capacity/competency/understanding in MH patients – leading to avoidance of EOL discussions Recommends a case management model – pilot study, no findings, just hypothesis that this would improve treatment
3.	Chochinov et al (2012) Canada	People with MH see less specialists, even contact with psychiatrists lessened in last 6 months of life Attempts to identify prevalence Uses research available to identify barriers – listed in paper There is a lack of care for people with schizophrenia at the end of life People with schizophrenia are less likely to receive pain relief People with schizophrenia are less likely to access palliative care Identifies lack of published research on how to deliver better

		care Highlights people with MH more likely to be in care homes and poor PC delivered in care homes
4.	Durkin et al (2003) UK	Attempt at prevalence Identifies mental illness in the cohort admitted to palliative care unit Over half had pre-existing and pre-treated mental illnesses Lack of staff expertise in identifying all types of mental illness in palliative care setting (pre-existing and newly presenting) Poor handover information from referrer, MH absent or only alluded to Need for MH specialist in PC setting Recommends multi-disciplinary approach to case management Recommends additional staff training in MH for PC staff
5.	Feely et al (2013) USA	Case study Recommendations for managing challenging behaviour for palliative care staff Work with MH specialists to support staff to deliver improved care, manage behaviour Advice about appropriate prescribing Staff confidence and expertise Identifies limited research in effectively working with BPD at EOL Experience of pain different in patients with long term mental illness
6.	Foti et al (2005)	Fear of negative response leads to avoidance of EOL discussions Assumption of mental incapacity due to mental illness Lack of clinical knowledge of MH in EOL settings Lack of standard procedures and guidance Patients with long term mental illness were able to engage in EOL discussions and express preferences (not terminally ill, hypothetical scenarios)
7.	Ganzini et al (2010)	Patients less likely to accept preventative interventions Veterans received better than expected EOL care – linked to holistic care system for veterans in USA Impairments relating to mental illness do not impair good provision of EOL care Little is known about the specific EOL needs of the mentally ill population

		Impairments in capacity noted Less likely to have supportive family/social relationships Communication skills and motivation can be hindered by mental illness
8..	Geppert et al (2011)	Ethical issues Location of care Capacity limited Consent limited Lack of literature on treating MH patients at EOL MH patients are interested and able to have EOL discussions Limited social/family support Challenging behaviour No MH liaison re MH history upon referral Need for specialist MH staff in EOL care MH patients receive lower quality treatment in EOL care impaired therapeutic alliance Social issues – housing, substance misuse, Patients fear of treatment due to mental illness Poor quality EOL care planning Confusion about liaison with patient or NOK/surrogate care giver
9.	Hill (2005)	Need for self-care in staff High levels of resilience in staff needed Joined up approach with family and patient and care team Difficulty of care seeking and rejecting behaviours Social/family difficulties Patient presentation/challenging behaviour of PD patients for PC (non-MH) specialists Challenging behaviour when receiving care Behavioural approaches identified to overcome barriers MDT approach necessary Need for boundaried yet flexible approach
10.	McGrath et al (2006)	Confusion in staff about advanced care planning and use of DNR's Legal fears (police investigation following death within institution) Lack of end of life care understanding in MH staff – obligation to resuscitate

		Further research needed Higher mortality rates in MH population Ethical issues relating to detained patients at EOL Paucity of literature on EOL needs of MH patients Legal framework impacting negatively on provision of EOL care Limited family support of MH patients The institution as ‘home’ Dignity in death
11.	Mental Health Foundation (MHF) (2008)	Lack of research/literature of EOL needs of those with pre-existing mental illness Increased vulnerability to physical illnesses Decision making and capacity issues Multi-disciplinary working needed Lack of MH support/expertise in hospice care Lack of practice guidelines for EOL care for MH patients more research into: prevalence, service user views, challenging MH stigma
12.	Sweers et al (2013)	EOL expectations of MH patients similar to general population Lack of research into EOL needs of psychiatric population MH patients do want to discuss EOL wishes Shortened life expectancy of people with schizophrenia Poor physical health Assumed mental incapacity Fear of provoking emotional instability by staff leading to avoidance of EOL discussions Training needed on legal issues and communication skills (in MH and EOL staff) On the whole patients do have capacity MDT working needed Training packages needed Patients wanted quality of life, skilled companionship No fear of death Not to die alone Person-centred care Autonomy maintained More research needed
13.	Terpstra and Terpstra (2012)	Excess morbidity and mortality in MH patients Lifestyle factors

		Late presentation Poor treatment compliance Poor advanced care planning Fear of inciting negative response leading to avoiding EOL discussions Assumed lack of capacity Lack of EOL training in MH professionals Lack of literature Similarities in philosophies of PC and MH care Cross training of professionals in PC and MH MDT working needed
14.	Terpstra and Terpstra (2014)	Attempt at prevalence Negative impact of schizophrenia on capacity, communication with services, inability to verbalise pain Late presentation – poor prognosis Location of care impacts on quality of EOL care Lifestyle factors in MH patients: substance misuse, poor diet, low levels of physical exercise MDT working improved care Unusual perception of pain More research needed Issues in medication management
15.	Woods et al (2008)	System change needed Improved access to care Development of policies and practice guidelines More research needed Cross training recommended Common philosophies on MH and PC noted Attempt at prevalence High mortality rate and high risk of physical illness Few empirical studies exist Difficult behaviours and poor engagement of MH patients

		Need for partnership working Little literature about specific needs of people with SPMI in EOL care Non-abandonment, dignity, hope, respect desired Decision making and ACP poorly understood Integrated approach – patient, family, MH, PC, SW services Lack of co-ordinated approach Less access to care Delayed presentation Late diagnosis Limited family and social relationships

Appendix 2

a) Participant Information Sheet

b) Letter of Introduction

c) Consent Form

d) Research Protocol

2 a) Participant Information Sheet

End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness: An Exploratory Study of the Experience and Perceptions of Mental Health and Palliative Care Staff

Participant Information Sheet

Version 3 8/1/16

I would like to invite you to take part in a research study looking in to the factors which influence the provision of end of life care to people with long term mental health conditions. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully, and discuss with others if you wish.

Part 1 describes the purpose of the study and what will happen if you agree to take part.

Part 2 gives more detailed information about the conduct of the study.

Part 1:

What is the purpose of the study?

The purpose of the study is to gain an insight in to current practice in providing end of life care to people with long term mental health conditions who develop terminal illness, the barriers experienced and the views of those involved in both mental health and palliative care settings.

Why have I been invited?

As a clinician working with people in a mental health setting or a palliative/end of life service, you will have experiences and insights into current practice, barriers which exist and ways practice could be improved. These may or may not be similar to those in the published research and guidance. The longer term aim is to develop practice guidelines and interventions which will improve end of life care for this patient group.

Do I have to take part?

Participation in this research is entirely voluntary, and it is up to you whether you wish to take part. If you agree to participate, you are free to withdraw at any time without giving a reason.

What will happen if I do take part?

If you agree to take part, you will be invited to attend a focus group by the researcher. You will be asked to provide verbal and written consent to participate.

The focus group will take place near to your workplace in a non-clinical area. Patients and other staff will not be present. The focus group will be conducted in an open and informal fashion, and will consist mainly of open questions which will allow you to speak freely about your experiences. The focus group will run for approximately 60 minutes.

The discussions at the focus group will, with your consent, be recorded. This will allow the researcher to transcribe the content and analyse the data. Your identity, as well as the contents of the interview, will be kept completely confidential. Any personal information provided will be fully anonymised.

Refreshments will be provided and you will have the opportunity to write down any thoughts or experiences you don't feel comfortable sharing within the group discussion.

What are the possible benefits of taking part?

There are no financial rewards for taking part. However, your views and experiences will shape the findings of this research, which will inform future practice and also inform the design of the next stage of the research. The findings of the research may inform the development of good practice guidelines, policies and procedures within your organisation and more widely, be fed into the development of national policy and practice developments.

The findings will be submitted for publication in a peer-reviewed journal.

What support is available to me if I find participation upsetting?

Talking about death and dying, palliative and end of life care, and mental health issues, may be upsetting for some members of staff. No assumptions will be made about participants personal experiences. All participants will be provided with the contact details of their organisation's staff support service at the beginning of each focus group.

Will my taking part in the study be kept confidential?

Yes. The researcher will ensure that the contents of every interview remain confidential and that any personal information provided is kept fully anonymised. Ethical and legal practice will be followed.

This completes Part 1. If you are interested in participating in the study, please read the information in Part 2 carefully before you make a decision.

Part 2:

What will happen if I change my mind?

Participation in this study is entirely voluntary and you are free to withdraw from the study at any time without giving a reason.

You may withdraw consent at any point in the process. If you wish to withdraw consent following the focus group, all data relating to the group, including recordings and transcripts will be destroyed and not included in the study.

What if there is a problem?

If a problem arises and you wish to make a complaint about the conduct of this study or any people involved in it, you may do so by writing to or speaking to the researcher, Jed Jerwood (email: jed.jerwood@nhs.net tel: 07855 773982), who will do his best to answer your queries.

If you would prefer not to raise your concern with Jed Jerwood please contact Professor Jane Coad at Coventry University who is the Principal Investigator for this research project jane.coad@coventry.ac.uk

Will my data be kept confidential?

Yes. All data collected will be fully anonymised and confidential. Recordings of interviews will be destroyed following transcription. Anonymised transcripts will be kept securely and password protected on an NHS drive for 3 years.

Although not anticipated, should any examples of professional misconduct, negligence, adult or child safe-guarding concern be disclosed, the researcher is bound by the professional code of conduct to report this information to the Clinical Director of

……………………………………………*insert organisation name*

What will happen to the results of the study?

The results will be written up by Jed Jerwood as a thesis to be submitted for the award of Masters in Clinical Research from Coventry University. The thesis will be stored at Coventry University library. The results will also be submitted for publication in a peer-reviewed journal, will be presented locally and at professional conferences.

Who is organising and funding the research?

Jed Jerwood is organising the research, under the supervision of Professor Jane Coad as part of an NIHR funded studentship at Coventry University.

Contact details:

Jed Jerwood

Clinical Academic Research Student

Coventry University

Art Psychotherapist

Birmingham and Solihull Mental Health Trust and John Taylor Hospice

Jed.jerwood@nhs.net

Address for correspondence:

34 Lewis Road

Stirchley

Birmingham

B30 2SX

Tel: 07855 773982

2b) Letter of Introduction

Dear Colleague,

End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness: An Exploratory Study of the Experience and Perceptions of Mental Health and Palliative Care Staff

My name is Jed Jerwood and I am an HCPC registered Art Psychotherapist undertaking the Clinical Academic Research above, at Coventry University. I work for Birmingham and Solihull Mental Health Trust and John Taylor Hospice.

My interest in end of life care for people with long term mental health conditions originated in observations in clinical practice. Many patients in the mental health system have higher rates of life-limiting and terminal health conditions, yet are under-represented in hospice care.

Initial review of the published research showed this to be an under-researched area, despite a recent focus on improving end of life care provision for everyone, and a focus on improving access to physical health care services to people with mental ill health.

This study aims to gain understanding of the experiences of staff working within both mental health and end of life care services, to explore barriers to accessing and providing end of life care to this patient group, and clinician's views of ways care could be improved.

Participation in the study involves attending a focus group to be held near your place of work. The group will run for between 60-90 minutes and be informal in style. Refreshments will be provided.

My aim is to minimise inconvenience to you, however, participation will require some of your time. You may need your line manager to agree you can participate in the focus group.

I have enclosed copies of the participation information sheet which gives greater detail about the study and what will happen to the findings. Thanks you for taking time to read this letter and I hope you will consider participating in the research study.

Yours faithfully,

Jed Jerwood

jed.jerwood@nhs.net

Tel: 07855 773982

2c) Consent Form

End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness: An Exploratory Study of the Experience and Perceptions of Mental Health and Palliative Care Staff

Version 2 9/12/15

Researcher: Jed Jerwood

Chief Investigator: Professor Jane Coad

Please initial box

1. I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and I am free to withdraw consent at any time, including during the focus group, without giving a reason. ☐

3. I understand that all data I provide will be treated as confidential, will be fully anonymised and stored securely. ☐

4. I agree to audio recording of the focus group to allow for anonymised transcription. ☐

5. I agree that should any examples of professional misconduct, negligence, child or adult protection concern be disclosed during this study, that the researcher will report this information to the Clinical Director of …John Taylor Hospice…………*insert organisation name* ☐

6. I agree to take part in this study ☐

Signed: Date:

Name:

Role:

Contact details:

Email: Tel:

Signed: Date:

2d) Research Protocol

Protocol 8/2/16 v.4

Title:

End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness: An Exploratory Study of the Experience and Perceptions of Mental Health and Palliative Care Staff

Aims:

To investigate whether current clinical practice reflects the themes within the published literature, by seeking the views and experiences of clinicians in mental health and end of life care (hospice inpatient, day hospice and hospice at home) settings, and to gain understanding of the factors which influence access to, and provision of, good end of life care for people with long term mental illness, with a view to improving care.

Investigators:

Jed Jerwood

Diane Phimister – First Supervisor

Nikki Holliday – Second Supervisor

Professor Jane Coad – Director of Studies

Summary:

The published literature suggests one of the key factors in providing end of life care to people with long term mental health conditions is clinician confidence and competence across discipline.

This phase of the research study aims to explore the views and experiences of mental health and palliative care clinicians of the factors which influence delivering end of life care to this patient group, to see if current UK clinical practice is ahead of the published literature, or whether practice reflects the literature, with a view to understanding how care can be improved.

Background:

The researcher is an HCPC Registered Art Psychotherapist working in both adult mental health and end of life care. The study question arose from clinical observations and curiosity about the apparent under representation of people with long term mental health conditions in hospice care.

The parity of esteem agenda is a key priority for NHS England (RCPsych 2013). The parity of esteem programme identifies the importance of improving the opportunity for people with enduring mental health problems to access physical health care services.

Whilst there has been a focus on looking at the development of mental ill health, particularly anxiety, depression and suicidal feelings, in people who develop life limiting conditions, little attention has been paid to the end of life (EOL) and palliative needs of those with existing mental health diagnoses, despite evidence of higher rates of cancers and other life limiting conditions in these groups.

'While the relationship between mental health problems and poor physical health is well documented and extensively researched there was found to be relatively little literature on the challenges associated with treating people with co-morbidity. There was also found to be an overwhelming lack of literature on the palliative care needs of those with existing mental health problems….These gaps in the literature reveal a worrying lack in the provision of palliative care for those with existing mental health problems.' (MHF; 2008)

People with mental health problems are more likely to have delayed diagnosis due to the difficulty accessing primary care, communicating their symptoms, perceptions of physical symptoms in people with mental health problems by healthcare professionals and lack of trust in services. Therefore, it would be expected that a higher rate of people with mental health diagnoses would need end of life and palliative services.

'*people with severe mental illnesses die on average 20 years earlier than the general population, mostly due to preventable physical health problems. Having mental health problems increases mortality from heart disease, and increases the likelihood of heavy smoking, drug and alcohol misuse and poor diet. This maybe because mental health is treated on a separate track to physical health, meaning that a person's physical health needs are ignored.'* (All Parliamentary Group on Mental Health; 2013)

The wider research study concerns gaining understanding of the factors which influence provision of effective end of life care to this patient group, and developing interventions which may improve this care pathway and patient experience of end of life care.

Definitions:

End of life care is care that

'Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient

and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'

End of Life Care Strategy 2008

Long term mental health conditions

There are many different definitions of, and ways of categorising, mental illness. This research concerns people with long term mental health conditions, being treated within the mental health system. Diagnoses may include schizophrenia or psychosis, personality disorder, depression and anxiety and bi polar disorders.

The Research Question:

What are the factors which influence access to and provision of end of life care to people with long term mental health conditions and how might care be improved?

Objectives:

- To gain the views of mental health and end of life care staff on current clinical practice in providing end of life care to people with long term mental health conditions
- To identify barriers to providing care
- To identify possible improvements to current practice and care pathways

Method:

The study will use qualitative methods to explore staff experiences and perceptions of the research question and address the stated aims and objectives. An Appreciative Inquiry approach (Cooperrider and Srivastva; 1987) will be used to conduct focus groups and a framework analysis of the data will be conducted.

This phase of the research will explore the themes, via focus groups with clinicians with the intention of understanding contemporary practice and whether it mirrors the themes which arose in the literature.

Literature Search Strategy:

An initial search of the published literature revealed an overall lack of published research concerning the experiences of people with mental ill health in end of life care. The UK literature was particularly sparse and what articles were available internationally included predominantly practice papers, discussions papers and single case study based research papers.

A review of the published literature using a systematic approach will be carried out, papers will be critically appraised and a thematic analysis of the findings will be undertaken.

Why Use a Qualitative Approach?

A qualitative approach has been selected, because the aim of the research in this phase is to understand clinician's views and experiences of the factors which influence provision of end of life care for this patient group. A qualitative approach is useful where little is known about a topic, or where views and experiences of participants are being sought, or where different perspectives may be held by participants (Bricki and Green; 2015)

Study Design:

Data collection will take place in the form of a series of small focus groups will, close to participant's workplace to enable participation of frontline staff as well as those in management positions. It will be important to gain the views and experiences of staff working directly with patients, and these staff may have difficulty attending a focus group held off site or for a long duration. Focus groups will be offered over lunch time and at the start of the day in non-clinical areas. Refreshments will be provided.

Identifying a Study Site:

The researcher is employed in a large mental health trust and a hospice and has access to groups of clinicians via both sites. Approval to approach staff to invite them to participate in the research will be obtained from the Research and Innovation Manager at the MHT and the Clinical Governance Committee of the hospice. Both organisations have provided Executive Director level sponsorship of the research project.

Sample:

The aim of the study is to gain understanding of clinician's experience of delivering services to the patient group. Therefor purposive sampling will be used to identify participants who will be best able to illuminate the research question. Limitations of time and budget will restrict the sample size, as will the scope of a Masters level study.

Participants:

Staff from Birmingham and Solihull Mental Health Trust and John Taylor Hospice who have experience of working with people with long term mental illness and terminal illness will be invited to participate.

Recruitment:

Staff will be invited to participate by internal email invitation, from the researcher and Clinical/Executive Director. An introductory letter and copy of the participant information sheet will be sent and staff will be invited to email the researcher to indicate interest in participating.

If insufficient response received, a further email will be sent after two weeks. In addition, posters will be displayed in agreed locations and the internal intranet/staff newsletter will also be used.

Consent:

Written consent will be sought from participants before they commence involvement in the research. A written consent for has been prepared. Participants will be made aware that participation is voluntary and that they can withdraw at any time without explanation. Any data collected will not be used in the research project and will be destroyed.

Sample Size:

There is some flexibility in sample size due to a focus group being able to accommodate different numbers of people. Each group will aim to involve between 4-12 participants and 2 focus groups in each organisation will be offered at different times to engage as wider variety of participants as possible within the limitations of a Masters study.

Inclusion Criteria and Exclusion Criteria:

Included: Clinicians (multi-disciplinary) working in palliative/end of life care or mental health services.

Excluded: Clinicians unable to consent, unable to participate, or with no experience of the subject matter of the research.

Data Collection:

Setting

Focus groups will be held in non-clinical areas close to participant's workplace. Patients and other staff will not be present in the spaces used to run focus groups.

Procedure

Focus groups will run for 60 minutes to facilitate participation within clinical commitments. Participants will be asked to sign the consent form at the start of the session if they have not already done so in advance. Groups will be audio recorded and transcribed. Open questions and prompts will be used as appropriate. Discussion will be facilitated by the researcher who has experience running groups and an understanding of group dynamics. The CUbe (Magee et al, 2015) data collection method will be used to allow a different method of data collection to be included, participants will also be given pens and paper and envelopes to record any contributions they feel unable to make in a group discussion.

A reflective research journal will be used to collect reflections after each focus group. A log will be kept separately detailing dates, locations, numbers and roles of participants.

Materials:

Audio equipment will be loaned from Coventry University Centre for Technology Enabled Health Research (CTEHR). Recordings will be destroyed following transcription. Transcripts will be held on a University password protected secure drive.

Confidentiality:

Documents will be stored on the researcher's University password protected secure drive. Notes and interview/focus group transcripts will be password protected and also stored on the researcher's University secure drives. Recordings of interviews will be destroyed once transcribed. Participants will be identified using a simple code denoting their profession and workplace setting – for example MHN1 mental health nurse 1, PCP1 palliative care physiotherapist 1.

The Research Diary:

A dairy will be kept throughout the research detailing reflections on the process including literature searching, ethics applications, discussions of research methods, sampling and data analysis, PPI opportunities and feedback, supervision meetings and discussions with other stakeholders.

A separate log of interviews/focus groups/questionnaire rounds will also be kept. Both documents will be kept anonymised and no participant will be identifiable in the recording.

Data Analysis:

Data from the focus groups (transcripts and notes) and the reflective journal will be analyses using the framework method. Themes identified will be mapped against the themes arising in the literature and similarities and differences critically appraised. Identified to practice will be highlighted in the writing up of the research findings.

Ethical Considerations:

Discussions regarding the end of life, death and dying as well as identifying barriers to delivering good care may be emotive for participants. Participants will be reminded at the beginning of the group that discussions will remain confidential and that they can withdraw at any time. The researcher is a qualified Art Psychotherapist and has experience in running groups where emotive themes emerge. The groups will be run in an informal and discursive style. Pens and paper and envelopes will be made available for participants to record any comments they do not feel comfortable sharing in the wider group. Staff will be provided with the details of each organisation's Staff Support Service, should they feel the need to access it following the focus group.

Confidentiality and anonymity

No member of staff, patient or family member will be identifiable in the transcripts of interviews/focus groups/questionnaire responses. All transcripts will be anonymised. If a name is mentioned in an interview, this will not be recorded in the transcript or used within the research study.

Resources and Costs:

There is no specific budget associated with the conduct of this research. Anticipated costs are as follows:

- Travel – researcher funded
- Stationary – contributed in kind by BSMHFT (confirm with Sue Hartley – Director of Nursing)
- Digital recording equipment – loan from CTEHR – (confirm costs with Jane Coad
- Meeting rooms - where possible contributions in kind from organisation)
- Refreshments – £50 from CU funding or contributions in kind if possible

Coventry University have made a small amount of funding available (£250) and HEE have offered a small amount of funding which could be used to meet any additional costs.

Project management:

Supervision

The supervisory team consists of:

Director of Studies and Academic Supervisor

Professor Jane Coad

Associate Dean of Research

Professor of Children and Families Nursing

Director of the Centre for Children and Families Applied Research

Second Supervisor

Diane Phimister

Associate Head of Department – Nursing, Midwifery and Healthcare Practice

Third Supervisor

Nikki Holliday

Research Associate – Centre for Technology Enabled Health Research

Sponsorship

Coventry University acts as sponsor for MRes projects.

Ethics

Coventry University Ethics application will be submitted. This stage of the research does not require NREC/HRA approval. The HRA and IRAS Questionnaires have been submitted (see Appendix 4) and returned with no further approvals needed.

BSMHFT Research and Innovation Department approval and John Taylor Hospice Clinical Governance Committee/CEO approval will be obtained in writing.

Patient and Public Involvement:

The study arose from discussions and observations in clinical practice and some patients were consulted about the research topic informally in the clinical setting.

The research has been presented to Coventry University RSVP Patient panel and feedback incorporated into the protocol and research design.

BSMHFT's User Voice group will be approached and be invited to be involved in the form of an advisory group. The Palliative Care Lead's at the CRN and HEE will be approached with a view to presenting the research to patient involvement groups.

Rethink and MIND locally, will also be approached with a view to presenting the research to their patient involvement groups. The feedback and discussions from these groups will inform the design of questionnaires/ interview schedules and of the design of the next stage of the research proposal.

Dissemination:

The study will be submitted for the award of Masters in Clinical Research at Coventry University. A journal article will be submitted to at least one peer- reviewed journal for publication. The research will be presented at the West Midlands Palliative Care Research showcase, to the BSMHFT Clinical Senate and other clinical forms as appropriate. The research will also be presented to HEE and local LETC groups by invitation.

Benefits of the study and Future plans:

This study will add further understanding to the limited published research concerning provision of end of life care to people with long term mental health conditions. It will offer an insight into contemporary UK clinical practice. This will inform the third phase (doctoral research) of the study, which will involve gaining patient and carer views and experiences, the development of possible interventions to improve practice and the care pathway and consequently, improved end of life care to a marginalised and disadvantaged group.

Proposed Timeline:

September – December 2015

- Revise literature review
- Develop protocol with supervisory team
- Prepare and Submit Coventry University Ethics Application
- Complete IRAS and HRA Approvals Checklist
- Submit to BSMHFT R and I Department for Approval and JTH CGC for Approval
- Present to CU RSVP and (other patient groups if possible)

- Meet with Executive sponsor at BSMHFT and Clinical Director at JTH
- Meet with EoL Lead at HEE

January – March 2016

- Data collection

March – April 2016

- Data analysis
- Report and update RSVP Group

April – June 2016

- Write up and submit to Coventry University
- Write up and submit to journal for publication

Appendix 3

a) Coventry University Ethics Approval
b) HRA Decision Tool
c) BSMHFT and JTH Approval Letters

3a) Coventry University Ethics Approval

Coventry University

Certificate of Ethical Approval

Applicant:

Jed Jerwood

Project Title:

End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness: An Exploratory Study of the Experience and Perceptions of Mental Health and Palliative Care Staff

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

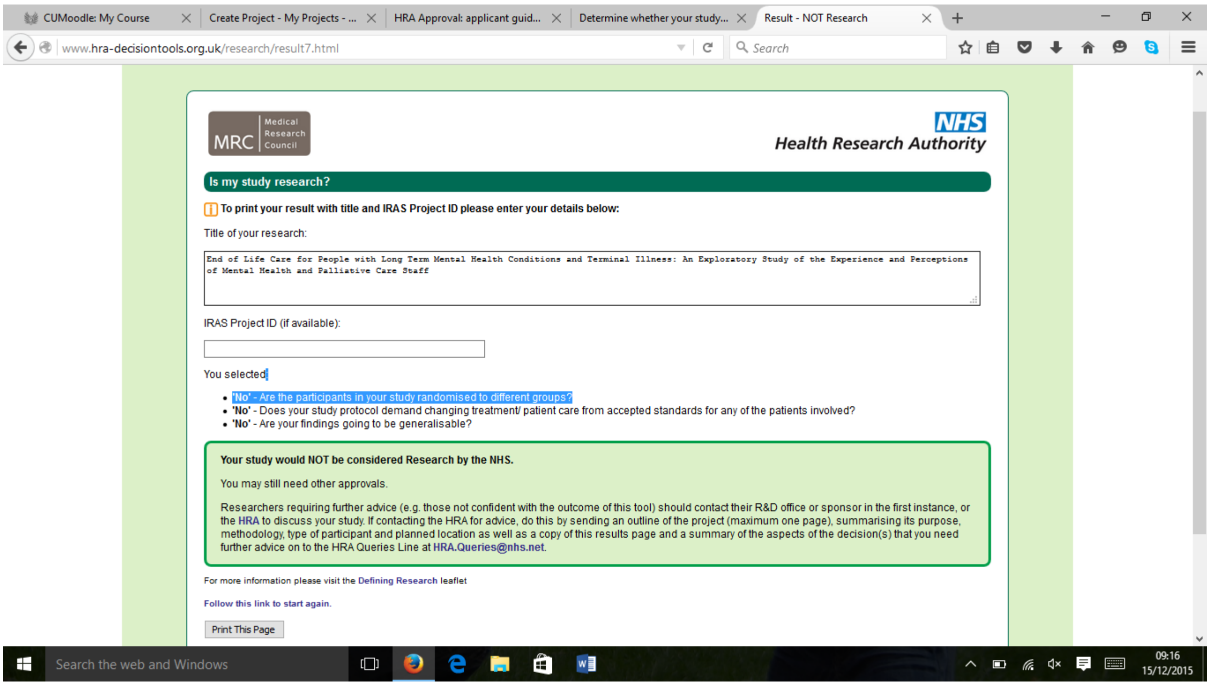
Date of approval:

14 January 2016

Project Reference Number:

P38881

3b) HRA Decision Tool



Is my study research?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness: An Exploratory Study of the Experience and Perceptions of Mental Health and Palliative Care Staff

IRAS Project ID (if available):

You selected:

- **'No'** - Are the participants in your study randomised to different groups?
- **'No'** - Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
- **'No'** - Are your findings going to be generalisable?

Your study would NOT be considered Research by the NHS.

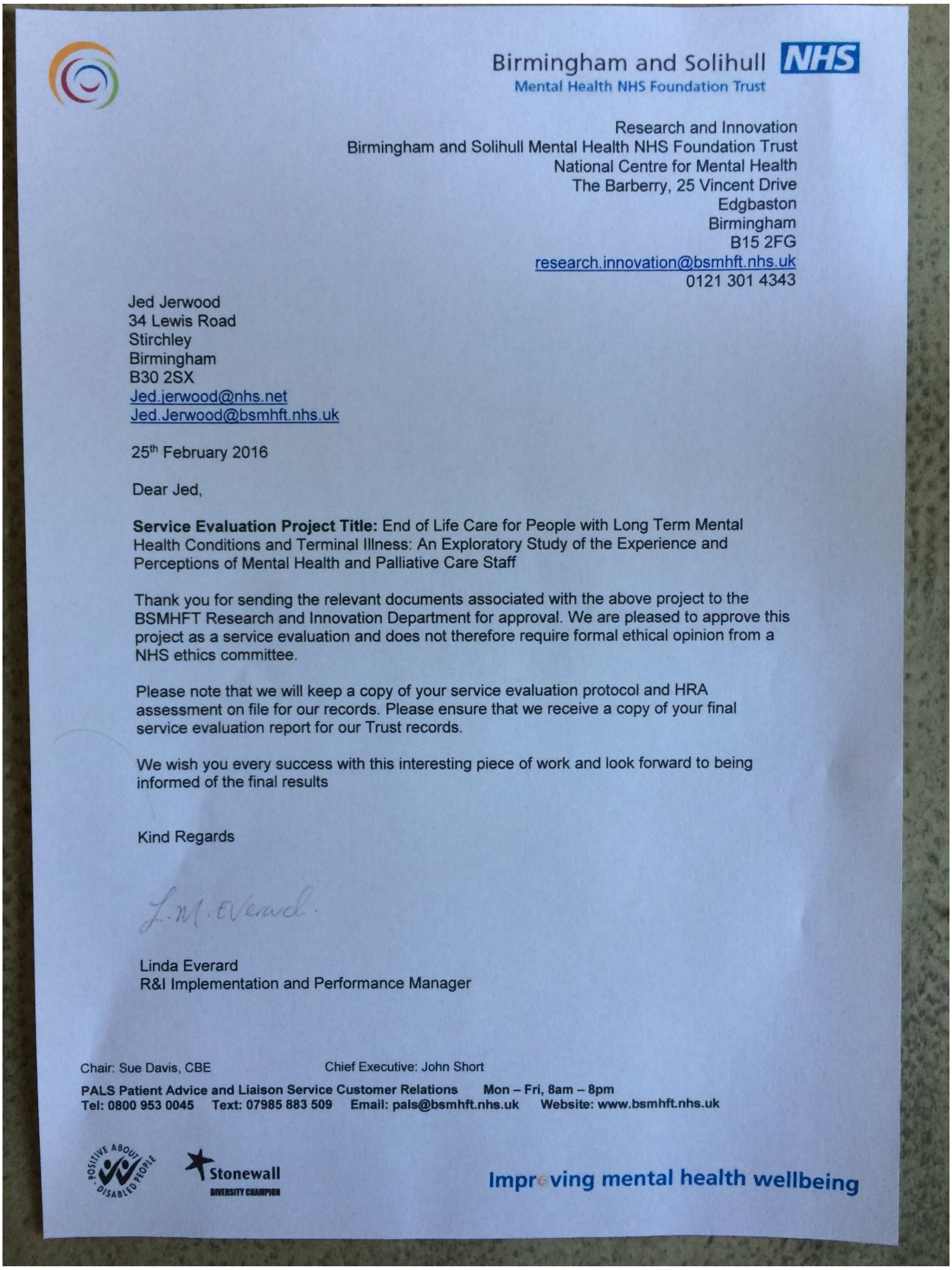
You may still need other approvals.

Researchers requiring further advice (e.g. those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the HRA to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of this results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at HRA.Queries@nhs.net.

For more information please visit the Defining Research leaflet

Follow this link to start again.

3c) BSMHFT and JTH Approval Letters



Birmingham and Solihull NHS
Mental Health NHS Foundation Trust

Research and Innovation
Birmingham and Solihull Mental Health NHS Foundation Trust
National Centre for Mental Health
The Barberry, 25 Vincent Drive
Edgbaston
Birmingham
B15 2FG
research.innovation@bsmhft.nhs.uk
0121 301 4343

Jed Jerwood
34 Lewis Road
Stirchley
Birmingham
B30 2SX
Jed.jerwood@nhs.net
Jed.Jerwood@bsmhft.nhs.uk

25th February 2016

Dear Jed,

Service Evaluation Project Title: End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness: An Exploratory Study of the Experience and Perceptions of Mental Health and Palliative Care Staff

Thank you for sending the relevant documents associated with the above project to the BSMHFT Research and Innovation Department for approval. We are pleased to approve this project as a service evaluation and does not therefore require formal ethical opinion from a NHS ethics committee.

Please note that we will keep a copy of your service evaluation protocol and HRA assessment on file for our records. Please ensure that we receive a copy of your final service evaluation report for our Trust records.

We wish you every success with this interesting piece of work and look forward to being informed of the final results

Kind Regards

L.M. Everard.

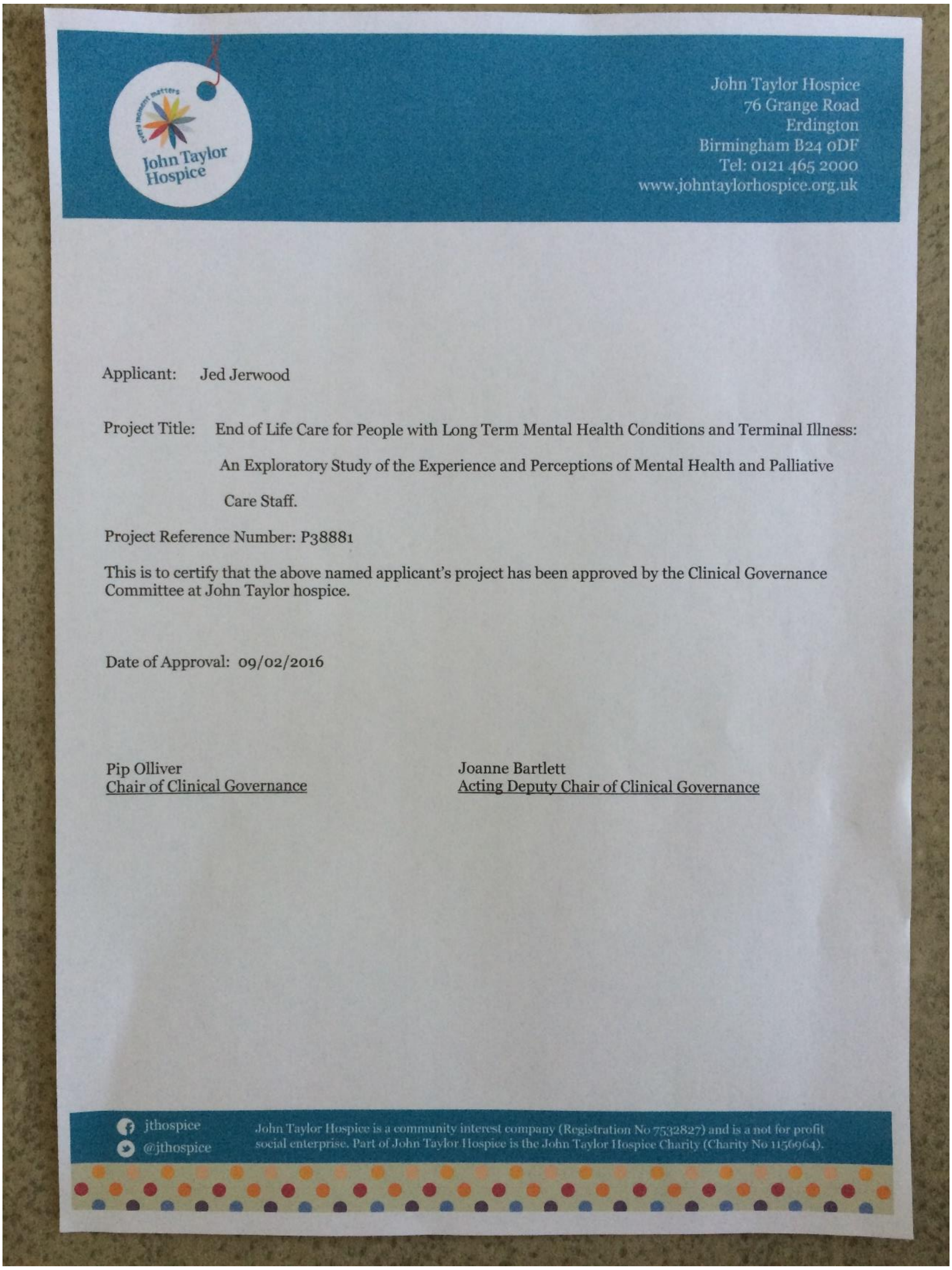
Linda Everard
R&I Implementation and Performance Manager

Chair: Sue Davis, CBE Chief Executive: John Short

PALS Patient Advice and Liaison Service Customer Relations Mon – Fri, 8am – 8pm
Tel: 0800 953 0045 Text: 07985 883 509 Email: pals@bsmhft.nhs.uk Website: www.bsmhft.nhs.uk

Stonewall DIVERSITY CHAMPION

Improving mental health wellbeing



John Taylor Hospice
76 Grange Road
Erdington
Birmingham B24 0DF
Tel: 0121 465 2000
www.johntaylorhospice.org.uk

Applicant: Jed Jerwood

Project Title: End of Life Care for People with Long Term Mental Health Conditions and Terminal Illness: An Exploratory Study of the Experience and Perceptions of Mental Health and Palliative Care Staff.

Project Reference Number: P38881

This is to certify that the above named applicant's project has been approved by the Clinical Governance Committee at John Taylor hospice.

Date of Approval: 09/02/2016

Pip Olliver	Joanne Bartlett
Chair of Clinical Governance	Acting Deputy Chair of Clinical Governance

jthospice
@jthospice

Appendix 4

a) Initial List of codes
b) Refined List of Codes and Analytic Framework

4a) Initial List of Codes

1. Poor information sharing	2. Effective partnership working
3. Poor partnership working	4. Difficult feeling or emotion in staff
5. MH staff expertise of EOL issues	6. EOL staff expertise in MH issues
7. Clarity of clinical roles	8. Staff Training
9. Lack of mental health expertise	10. Knowledge of medication
11. Medication management	12. Management of Risk
13. Fear of Escalating Risk	14. Avoidance of EOL discussions/planning
15. Mental Capacity Issues	16. Patient insight
17. Lack of Trust in Patient	18. Prejudice against mental illness
19. Lack of awareness of MH system	20. Lack of awareness of PC/EOL system
21. Confusion about appropriate course of action	22. Admission to acute hospital
23. Appropriate package of care (multi-disciplinary)	24. MH patient perceptions of PC/EOL care
25. MH Patient Characteristic – Isolation	26. MH Patient Characteristic – challenging behaviour
27. MH Patient Characteristic – family and social support limited	28. MH Patient Characteristic – family and social support
29. PC/EOL staff perception of challenging behaviour	30. Satisfactory Care Outcome
31. Unsatisfactory Care Outcome	32. Conflicting Cultures of MH and EOL/PC
33. Similarities in Cultures of MH and EOL/PC	34. Problematic engagement with MH services
35. Fluctuating mental illness	36. Fluctuating mental capacity
37. Change in staff perception (after MH contact)	38. Flexibility in care provision
39. Transferable skills	40. Role of family
41. Role of other professionals	42. Flexibility if providing care interventions
43. Lack of understanding of MH system	44. Lack of understanding of PC/EOL system
45. Pain management	46. Delayed/late diagnosis
47. Poor prognosis	48. Access to hospice
49. Partnership with family	50. Partnership working with hospice
51. Funding and commissioning of services is a barrier	52. System design is a barrier
53. Less long-term units – patients moving around services	54. ‘Institution as home’
55. EOL care is not core business for MH services	56. Use of care homes leading to poor EOL care for MH patients

57. Long term relationships with some patients aid good EOL care	58. Lack of GP involvement – some MH patients not registered locally
59. Goodwill/informal local relationships/partnerships	60. Lack of understanding of MH issues
61. Patients fall between gaps in service	62. Patient characteristic – lack of trust in services
63. Physical health needs not met in MH care	64. Silo working
65. Increase in presentation of life-limiting and chronic illness in MH patients	66. Ad hoc approach
67. Lack of partnership approach	68. Patients at EOL discharged from MH services
69. Not core MH business	70. Patient characteristic – unusual beliefs about death and dying
71. Patient characteristic – ability and willingness to participate in EOL care discussions	72. Patient characteristic – resistance to care
73. Staff ability to distinguish between normal fears about death and dying and decline in mental illness	74. Patient receiving unnecessary interventions at EOL (motivated by duty of care)
75. Staff fear of duty of care obligations not being met (resus)	76. Prescribing advice and guidelines
77. Local good practice example	78. Confusion about policy and procedure
79. Patient choice of place of death	80. Learning from dementia care
81. Staff transferable skills	82. MH patient transfers between MH service and acute care at EOL

Agreed abbreviations

MH – mental health

PC/EOL – palliative care/end of life care

4b) Refined List of Codes and Analytic Framework

Systemic/Structural Factors	
Funding and Commissioning Services	Separate commissioning of mental health and physical health care services, different service provision in different geographical areas
Silo Working	Mental Health, Primary Care, Acute and End of Life/Palliative Care operating as separate specialities, trained as separate specialities
Gaps in Services	Mental health patients identified as falling between gaps in service provision – may be geographical or lack of appropriate provision, lack of physical healthcare services in MH settings
Movement of patients	Patients moved between services, less availability of long term placements
Patient Factors	
Presentation for treatment	Delayed diagnosis, poor prognosis, use of preventative services
Fluctuating mental capacity and well-being	Variations in presentation, unstable mental health, fluctuating capacity and insight, ability to consent
Family and Social Support	Limited social support networks, poor or limited family support, social isolation, lack of consultation with family and carers,
Location of care	Use of care homes, institution as home, homelessness and unstable housing, end of life care in acute care setting
'Challenging' behaviour* *behaviour experienced as problematic by clinician	Care seeking and care rejecting behaviours, unusual beliefs about death and dying/service provision, aggression, withheld, limited communication
Perception of services	Lack of trust, previous bad experiences, negative perceptions of end of life care, difficulties in making relationships with services
EOL Planning and Discussion	Ability and willingness to participate in discussions and planning about EOL care and preferences, preferred place of death
Poor Physical Health	Mental health patients presenting with poor physical health
Inadequate Care Observed	Observations of inadequate or poor care by clinical staff, anecdotal accounts of poor quality care
Clinician/Service Factors	
Understanding of mental health system and conditions	Knowledge of mental health conditions, symptoms, structure of system, access to MH services, professional roles,
Understanding of end of life and palliative care system and services	Knowledge of palliative care and end of life care, scope and range of services, understanding of death and dying process, appropriate treatment interventions,

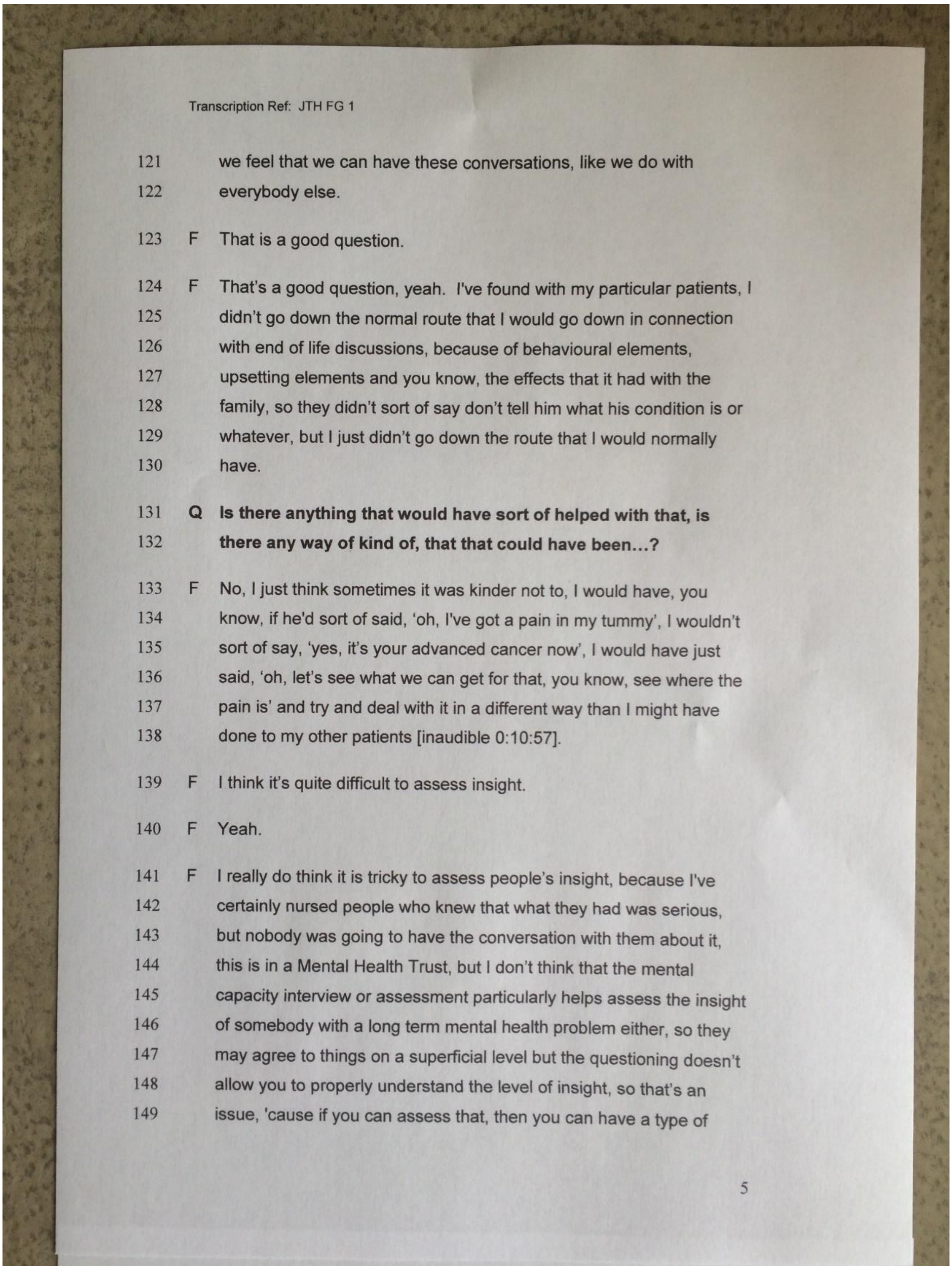
Policy and Procedure	Lack of standard operating procedures, strategy and policy; confusion about appropriate course of action, clarity of different clinical roles, ad hoc practice
Clinical Staff Attitudes and Beliefs	Lack of trust in patient ability, perception of challenging behaviours, mental health prejudice, discharge from MH services at EOL, conflict of cultures between MH and EOL services, EOL not MH remit, MH not EOL remit,
Legislative/Practice Concerns	Fears of not meeting duty of care, appropriate resuscitation practice, unnecessary interventions delivered at EOL, mental health legislation, restrictions on liberty
Pain	Assessment and management of pain, appropriate prescribing and access to pharmacy expertise
Risk	Assessment of risk, fear of escalating risk in patients following EOL discussions, risk management impacting of EOL care, avoidance of EOL discussions
Capacity	Assessment of capacity, consent issues, fluctuating mental well-being
Clinical staff confidence in practice	Lack of autonomy, low confidence in clinical practice, unsure of appropriate action
Resilience and Self Care in Clinical Staff	References to negative impact of work on staff, working with challenging patients or subject matter, references to need for self-care,
Partnership Factors	
Information sharing	Lack of referral information, poor information sharing, inappropriate sharing of information
Partnership with EOL services	Involvement of specialist palliative care staff, day hospice, hospice at home, specialist pharmacy, nurse specialists
Partnership with MH services	Involvement of care manager, psychiatrist, social worker, ward managers and key workers; specialist advice from MH professionals
Partnership with family/carers	Involvement of supportive family, carers, partner, friends
Partnership with primary care and other services	Joint working with services involved with patient, GP, housing, Social Services, residential care providers
Flexibility of approach	Individualised care planning, flexible approach to service delivery, admissions
Solutions/Improvement Factors	
Effective Partnership working	Working with partner agencies e.g. local hospices, local mental health teams, family, patient and family involvement in service delivery or care planning
Improved Multi-disciplinary working/Specialist Roles	Developing mental health specialist roles in EOL services, liaison psychiatry in hospices, end of life care skills in clinical mental

	health practitioners, mental health ward and residential settings
Local Good Practice	Examples of locally developed good practice, goodwill between services, informal agreements
Staff training	Examples of additional training identified
Care planning	Individualised care planning
Transferable skills	Identification of transferable skills in clinical staff
Similarity of Culture	Identifying similarities between mental health and end of life care service culture
Change in perceptions	Changes in staff perceptions following exposure, experience of working with people with mental illness, people with terminal illness
Transferable knowledge	Learning from other specialities – learning disability, dementia
'Product' or Outcome	Suggestions products or specific resources to improve delivery of care

Appendix 5

a) Extract of transcript
b) Cube covers
c) Written contributions

a) Extract of transcript



Transcription Ref: JTH FG 1

we feel that we can have these conversations, like we do with everybody else.

F That is a good question.

F That's a good question, yeah. I've found with my particular patients, I didn't go down the normal route that I would go down in connection with end of life discussions, because of behavioural elements, upsetting elements and you know, the effects that it had with the family, so they didn't sort of say don't tell him what his condition is or whatever, but I just didn't go down the route that I would normally have.

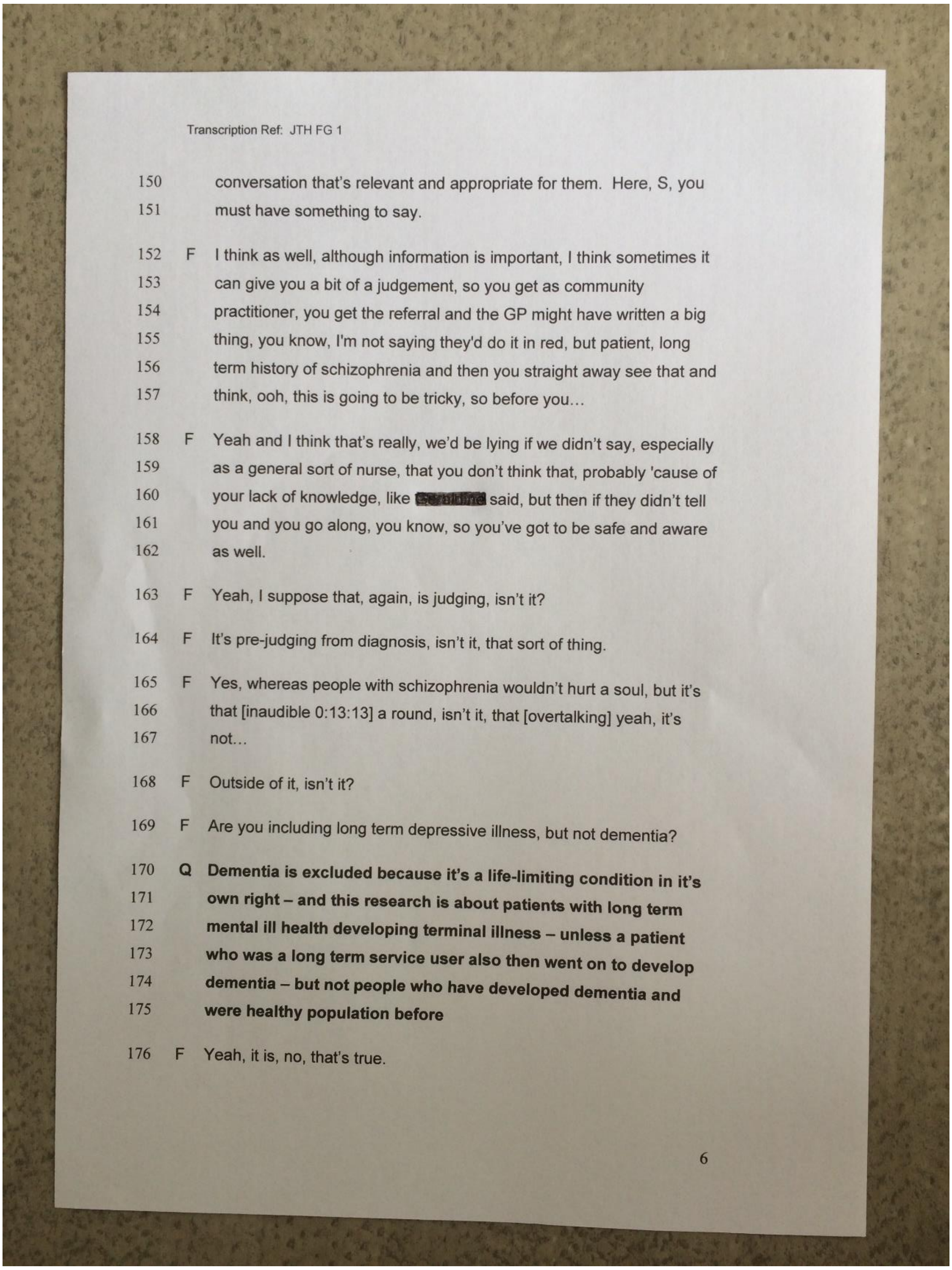
Q Is there anything that would have sort of helped with that, is there any way of kind of, that that could have been…?

F No, I just think sometimes it was kinder not to, I would have, you know, if he'd sort of said, 'oh, I've got a pain in my tummy', I wouldn't sort of say, 'yes, it's your advanced cancer now', I would have just said, 'oh, let's see what we can get for that, you know, see where the pain is' and try and deal with it in a different way than I might have done to my other patients [inaudible 0:10:57].

F I think it's quite difficult to assess insight.

F Yeah.

F I really do think it is tricky to assess people's insight, because I've certainly nursed people who knew that what they had was serious, but nobody was going to have the conversation with them about it, this is in a Mental Health Trust, but I don't think that the mental capacity interview or assessment particularly helps assess the insight of somebody with a long term mental health problem either, so they may agree to things on a superficial level but the questioning doesn't allow you to properly understand the level of insight, so that's an issue, 'cause if you can assess that, then you can have a type of



conversation that's relevant and appropriate for them. Here, S, you must have something to say.

F I think as well, although information is important, I think sometimes it can give you a bit of a judgement, so you get as community practitioner, you get the referral and the GP might have written a big thing, you know, I'm not saying they'd do it in red, but patient, long term history of schizophrenia and then you straight away see that and think, ooh, this is going to be tricky, so before you…

F Yeah and I think that's really, we'd be lying if we didn't say, especially as a general sort of nurse, that you don't think that, probably 'cause of your lack of knowledge, like [redacted] said, but then if they didn't tell you and you go along, you know, so you've got to be safe and aware as well.

F Yeah, I suppose that, again, is judging, isn't it?

F It's pre-judging from diagnosis, isn't it, that sort of thing.

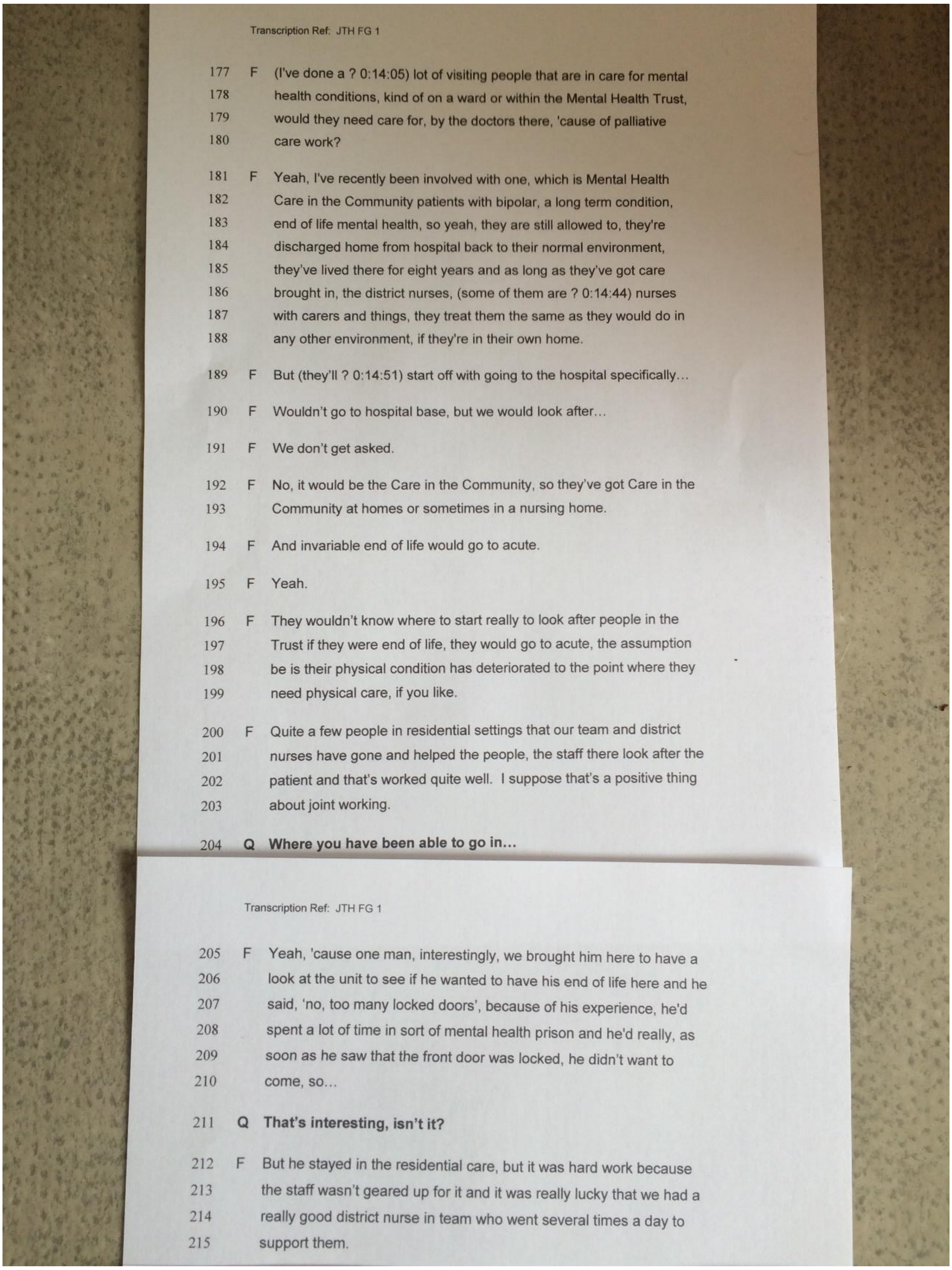
F Yes, whereas people with schizophrenia wouldn't hurt a soul, but it's that [inaudible 0:13:13] a round, isn't it, that [overtalking] yeah, it's not…

F Outside of it, isn't it?

F Are you including long term depressive illness, but not dementia?

Q Dementia is excluded because it's a life-limiting condition in it's own right – and this research is about patients with long term mental ill health developing terminal illness – unless a patient who was a long term service user also then went on to develop dementia – but not people who have developed dementia and were healthy population before

F Yeah, it is, no, that's true.



Transcription Ref: JTH FG 1

F (I've done a ? 0:14:05) lot of visiting people that are in care for mental health conditions, kind of on a ward or within the Mental Health Trust, would they need care for, by the doctors there, 'cause of palliative care work?

F Yeah, I've recently been involved with one, which is Mental Health Care in the Community patients with bipolar, a long term condition, end of life mental health, so yeah, they are still allowed to, they're discharged home from hospital back to their normal environment, they've lived there for eight years and as long as they've got care brought in, the district nurses, (some of them are ? 0:14:44) nurses with carers and things, they treat them the same as they would do in any other environment, if they're in their own home.

F But (they'll ? 0:14:51) start off with going to the hospital specifically…

F Wouldn't go to hospital base, but we would look after…

F We don't get asked.

F No, it would be the Care in the Community, so they've got Care in the Community at homes or sometimes in a nursing home.

F And invariable end of life would go to acute.

F Yeah.

F They wouldn't know where to start really to look after people in the Trust if they were end of life, they would go to acute, the assumption be is their physical condition has deteriorated to the point where they need physical care, if you like.

F Quite a few people in residential settings that our team and district nurses have gone and helped the people, the staff there look after the patient and that's worked quite well. I suppose that's a positive thing about joint working.

Q Where you have been able to go in…

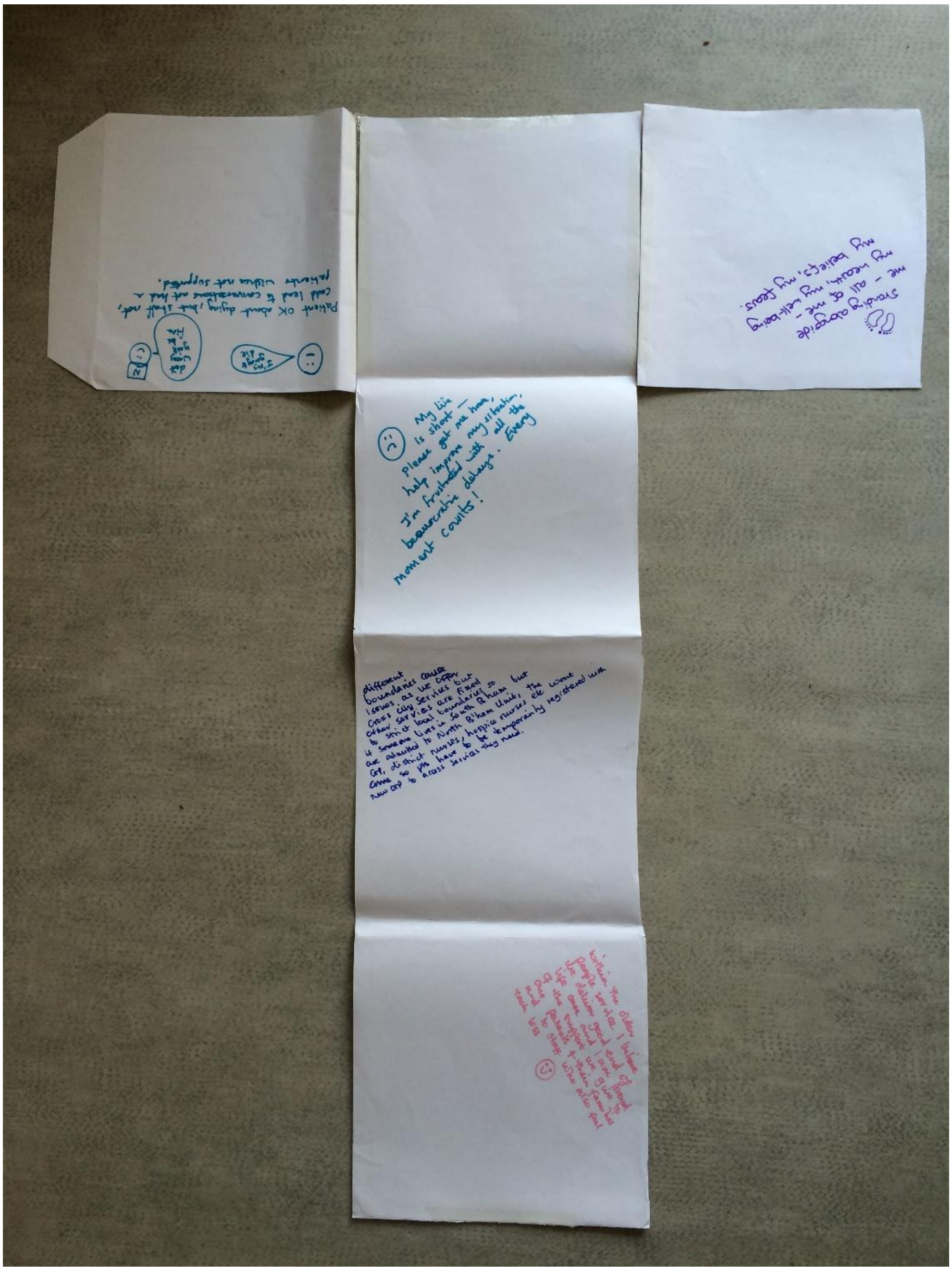
Transcription Ref: JTH FG 1

F Yeah, 'cause one man, interestingly, we brought him here to have a look at the unit to see if he wanted to have his end of life here and he said, 'no, too many locked doors', because of his experience, he'd spent a lot of time in sort of mental health prison and he'd really, as soon as he saw that the front door was locked, he didn't want to come, so…

Q That's interesting, isn't it?

F But he stayed in the residential care, but it was hard work because the staff wasn't geared up for it and it was really lucky that we had a really good district nurse in team who went several times a day to support them.

b) CUbe Covers



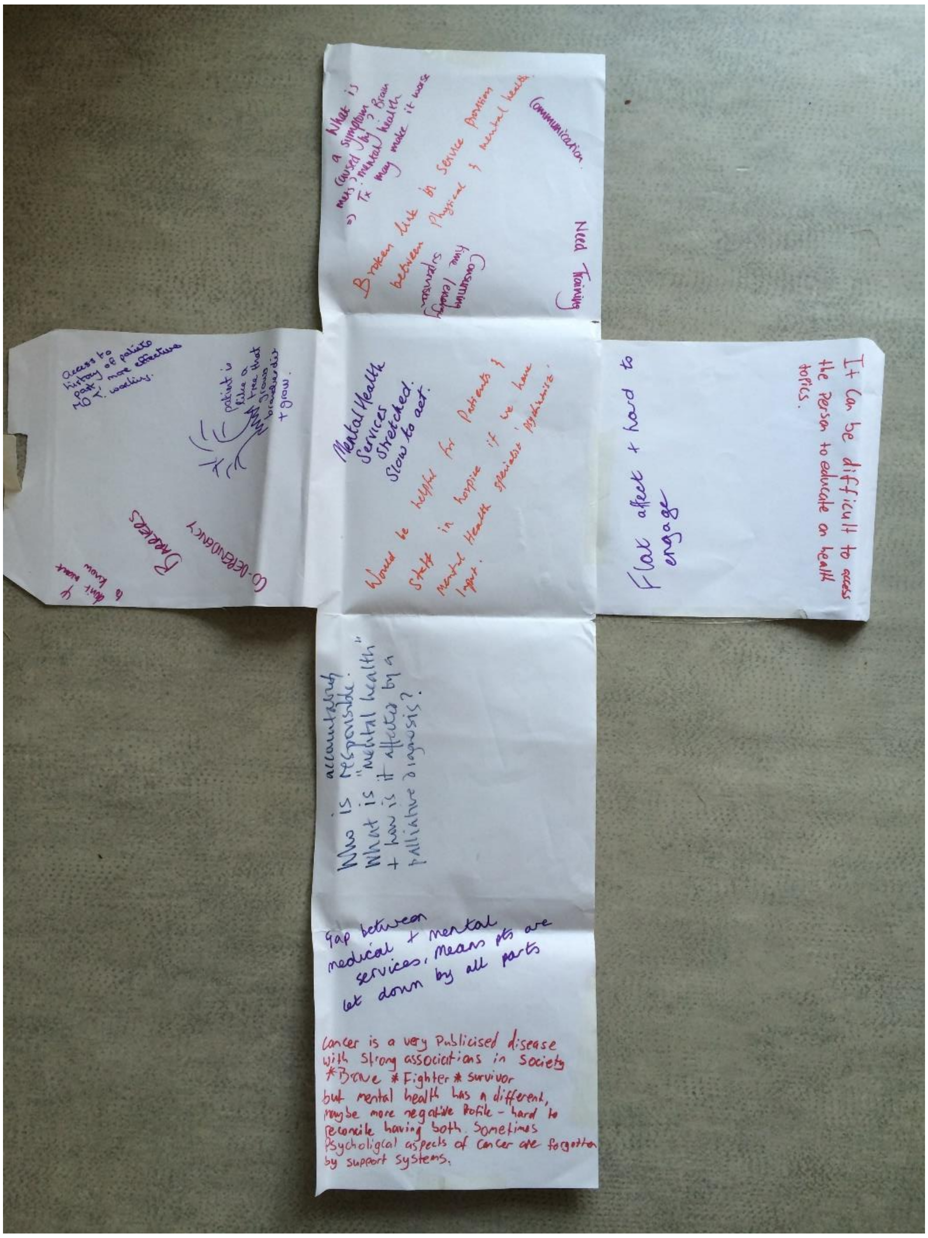
Patient OK about dying, but staff not, could lead to conversations not had & patients wishes not supported.

Standing alongside me - all of me - my health, my well-being my beliefs, my fears.

My life is short — please get me home, help improve my situation, I'm frustrated with all the beaurocratic delays. Every moment counts!

different boundaries cause issues, as we offer cross city services but other services are fixed to strict local boundaries so if someone lives in South B'ham but are admitted to North B'ham Unit, the wont GP, district nurses, hospice nurses etc come so pts have to be temporarily registered with new GP to access services they need.

Within the older people service I believe we deliver good end of life care and I am proud of the support we give to our patients + their families and to staff who also feel each loss



What is
a symptom
caused by? Brain
mets? mental health
⇒ Tx may make it worse

Broken link in service provision
between Physical & mental health.

Communication.

Need Training

Consuming
time / lengthy
supervision

Access to
history of patients
past more effective
MDT working.

patient is
like a
tree that
grows
branches
+ grow.

BARRIERS

CO-DEPENDENCY

Don't
Know
what
to

Mental Health
Services
Stretched.
Slow to act.

Would be helpful for Patients &
Staff in hospice if we have
Mental Health specialist 'psychiatrist'
Input.

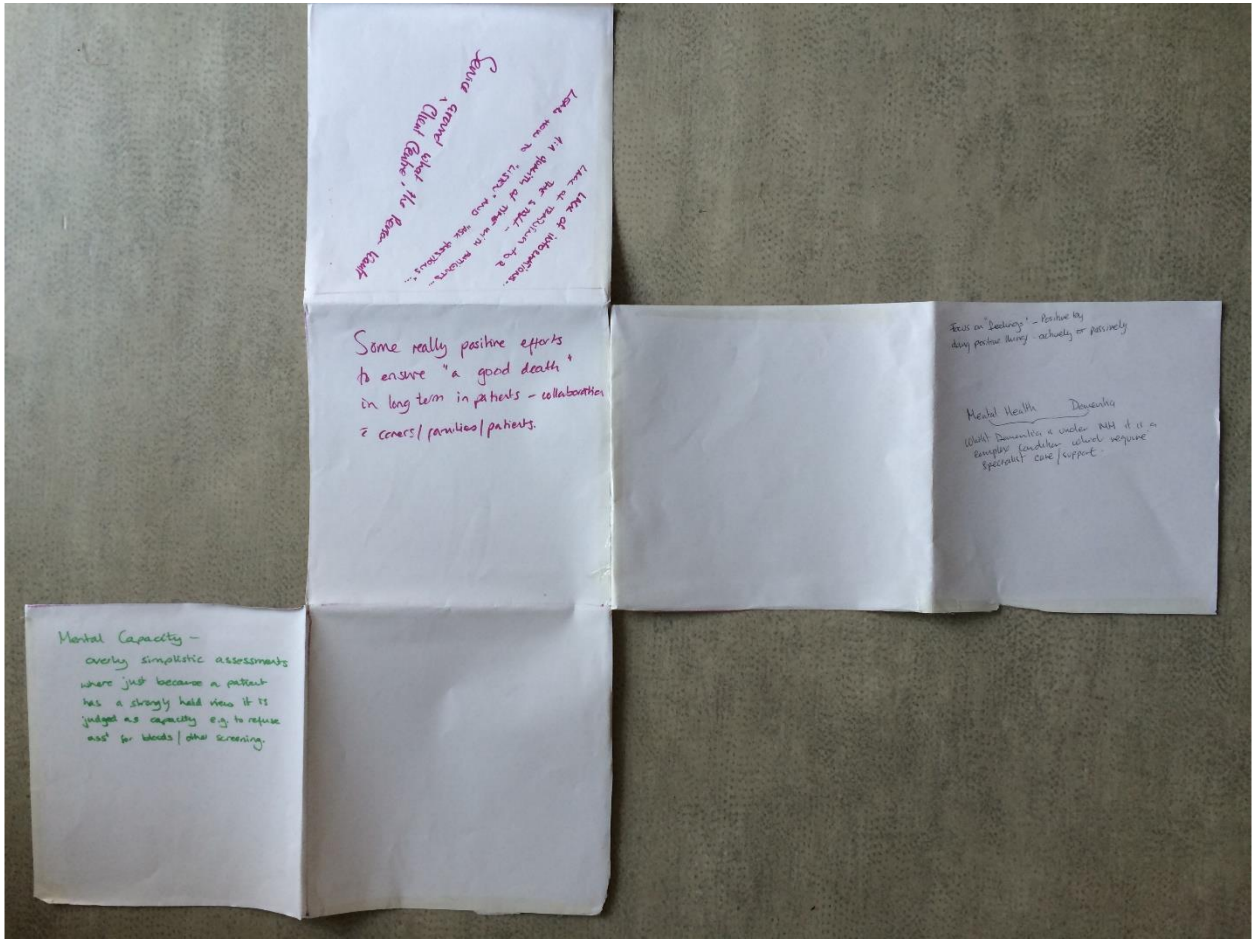
Flat affect + hard to
engage

It can be difficult to access
the person to educate on health
topics.

Who is accountable/
responsible.
What is "mental health"
+ how is it affected by a
palliative diagnosis?

Gap between
medical + mental
services, means pts are
let down by all parts

Cancer is a very Publicised disease
with Strong associations in Society
*Brave *Fighter *survivor
but mental health has a different,
maybe more negative Profile - hard to
reconcile having both. Sometimes
Psycholigcal aspects of Cancer are forgotten
by support systems.



LACK of INTERACTIONS..
LACK of TRAINING for
THE STAFF..
1:1 QUALITY OF TIME WITH PATIENTS...
LEARN HOW TO "LISTEN" AND "ASK QUESTIONS"...

Service around what 'Client Centre', the Person Wants

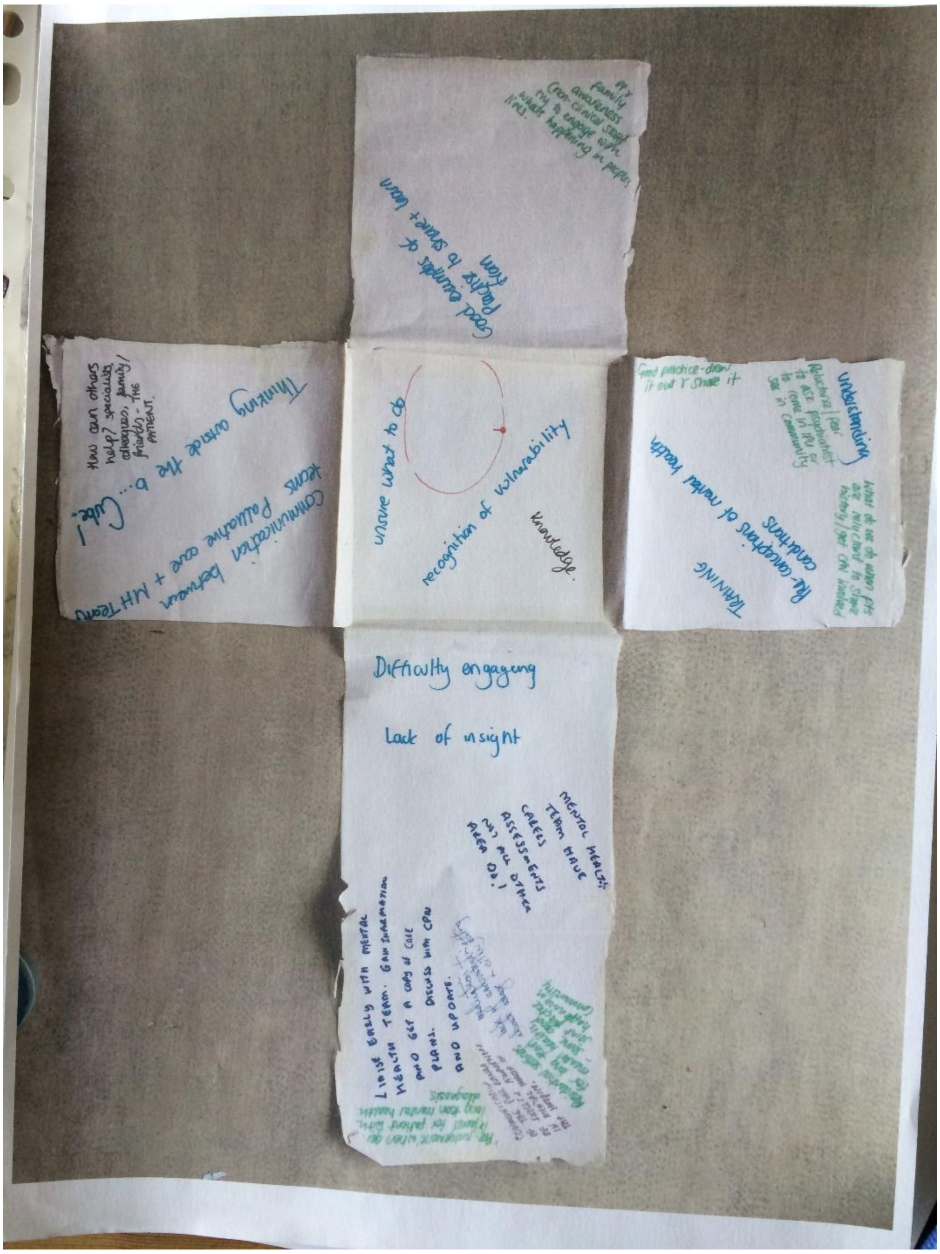
Some really positive efforts to ensure "a good death" in long term in patients - collaboration ē carers/families/patients.

Focus on "Feelings" - Positive by doing positive things - actively or passively

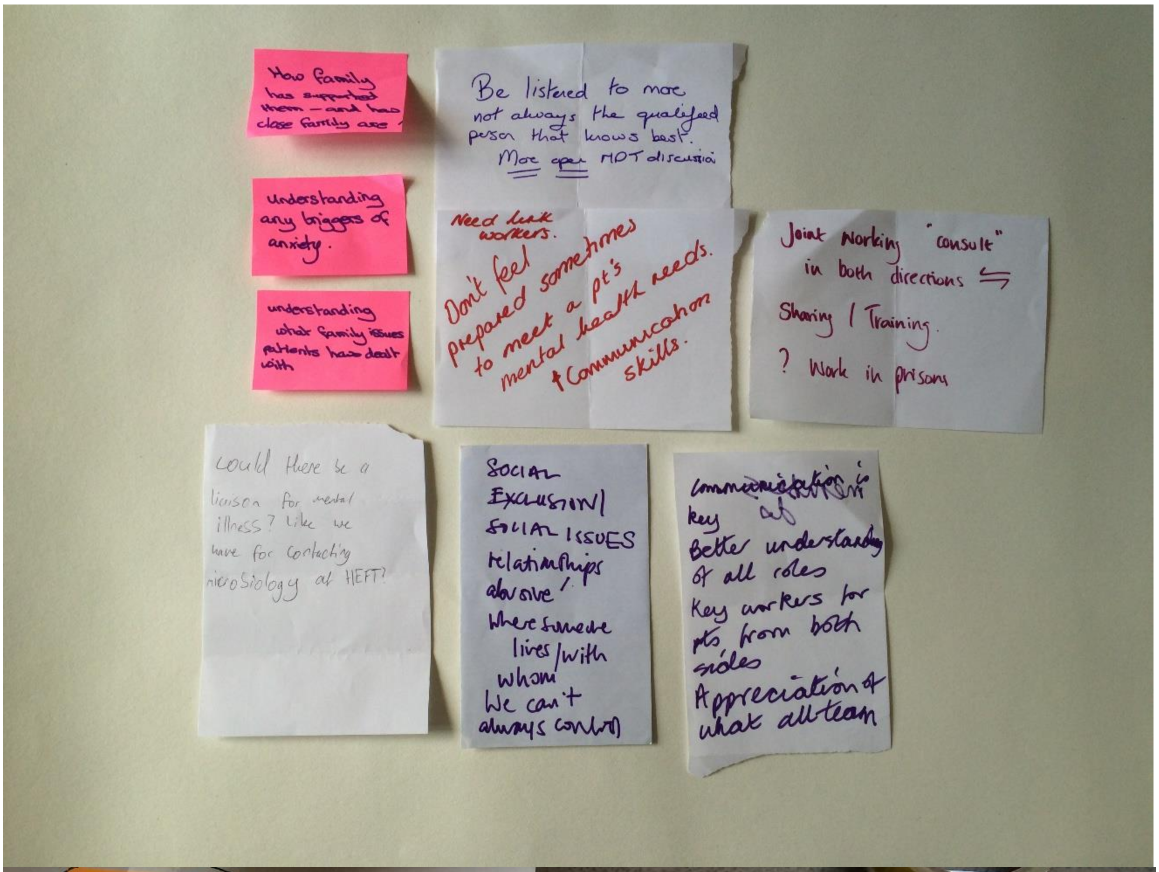
Mental Health Dementia

Whilst Dementia is under MH it is a complex condition which require specialist care/support.

Mental Capacity -
overly simplistic assessments where just because a patient has a strongly held view it is judged as capacity e.g. to refuse ass^t for bloods/other screening.


MY family awareness (non-clinical staff) try to engage with what's happening in peoples lives.
Good examples of practice to share + learn from
How can others help? specialists, colleagues, family/friends - THE PATIENT.
Thinking outside the b... Cube!
Communication between teams Palliative care + MH Teams
unsure what to do
recognition of vulnerability
knowledge.
Good practice - draw it out & share it
Understanding
Reluctance / fear to ask psychiatrist to come in IPU or see in community
What do we do when pts are reluctant to share history / get CPN involved
TRAINING
Pre-conceptions of mental health conditions
Difficulty engaging
Lack of insight
MENTAL HEALTH TEAM HAVE CARERS ASSESSMENTS AS ALL OTHER AREA DO!
LIAISE EARLY WITH MENTAL HEALTH TEAM. GAIN INFORMATION AND GET A COPY OF CARE PLANS. DISCUSS WITH CPN AND UPDATE.

c) Written contributions



How family has supported them – and has close family are ?

Understanding any triggers of anxiety.

understanding what family issues patients have dealt with

Be listened to more
not always the qualified person that knows best.
More open MDT discussion

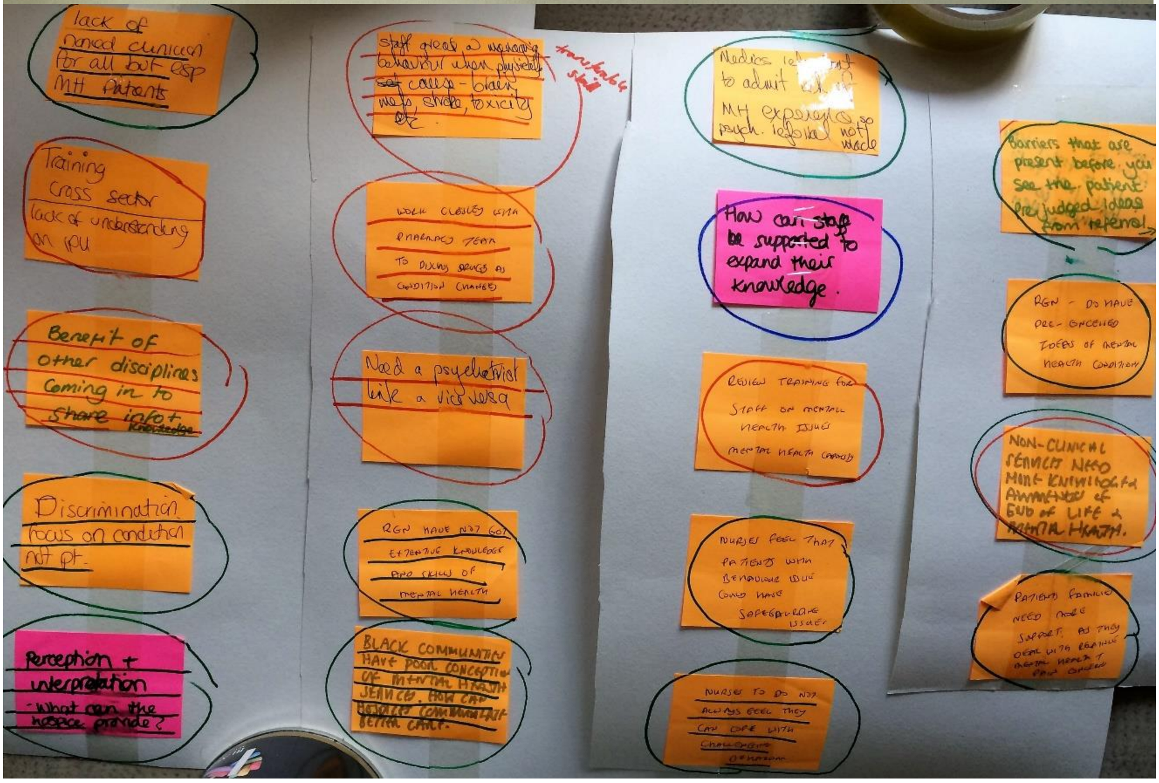
Need link workers.
Don't feel prepared sometimes to meet a pt's mental health needs.
+ Communication skills.

Joint working "consult" in both directions ⇆
Sharing / Training.
? Work in prisons

Could there be a liaison for mental illness? Like we have for contacting microbiology at HEFT?

SOCIAL EXCLUSION /
SOCIAL ISSUES
relationships abusive /
Where someone lives / with whom
We can't always control

communication is key
Better understanding of all roles
Key workers for pts from both sides
Appreciation of what all team



lack of named clinician for all but esp MH Patients

Training cross sector
lack of understanding on ipu

Benefit of other disciplines coming in to share info + knowledge

Discrimination
focus on condition not pt.

Perception + interpretation
- what can the hospice provide?

Staff great at managing behaviour when physically ~~set~~ cause - brain mets, stroke, toxicity etc.

transferable skill

WORK CLOSELY WITH PHARMACY TEAM TO DISCUSS DRUGS AS CONDITION CHANGES

Need a psychiatrist link & vice versa

RGN HAVE NOT GOT EXTENSIVE KNOWLEDGE AND SKILLS OF MENTAL HEALTH

BLACK COMMUNITIES HAVE POOR CONCEPTION OF MENTAL HEALTH SERVICES. HOW CAN HOSPICES COMMUNICATE BETTER CARE.

Medics reluctant to admit lack of MH experience so psych. referral not made

How can staff be supported to expand their knowledge.

REVIEW TRAINING FOR STAFF ON MENTAL HEALTH ISSUES
MENTAL HEALTH CAPACITY

NURSES FEEL THAT PATIENTS WITH BEHAVIOUR ISSUES COULD HAVE SAFEGUARDING ISSUES

NURSES TO DO NOT ALWAYS FEEL THEY CAN COPE WITH CHALLENGING BEHAVIOUR

Barriers that are present before you see the patient
Prejudged ideas from referral

RGN - DO HAVE PRE-CONCEIVED IDEAS OF MENTAL HEALTH CONDITION

NON-CLINICAL SERVICES NEED MORE KNOWLEDGE & AWARENESS OF END OF LIFE & MENTAL HEALTH.

PATIENTS FAMILIES NEED MORE SUPPORT AS THEY DEAL WITH RELATIVE MENTAL HEALTH + PAIN CONCERNS