Rehabilitative palliative care as a health promoting approach: A participatory action research study.

Karen Clarke
MA in Personnel and Development

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme.

April 2019

Faculty of Health and Medicine
Lancaster University

I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

Acknowledgements

This research was a journey of discovery not just about rehabilitation in palliative care, health promoting palliative care and participatory action research, but about myself as a researcher and as a senior, non-clinical manager in a hospice. The experience was enhanced by a number of collaborators who invested their time, energy and enthusiasm to allow me to learn the joy of action research. My thanks to my co-researchers: A1, A3, E2, D5, L8, O6 and S7.

I am grateful for the support I received from my academic supervisors, Professor Katherine Froggatt and Dr Sarah Brearley who enabled me to remain focussed, challenged my thinking and in doing so create a better research study. I also thank my colleagues from the 2012 PhD programme, and particularly those on the Palliative Care Cohort for being alongside me.

There are several other key people who have supported me over the last seven years: my family and parents for giving me the space and time to do what I needed to do and never complaining; the inimitable Tricia Wass for her constant eagerness and interest in what I was doing and for her unfailing support; proof-reader, Louise Carr, who somehow in her manically busy life managed to find the time, and the inclination, to scrutinise this thesis; and finally, to Martin Symons for his creativity.

Most importantly, this thesis is written in memory of: John, Jane, Terry, Diarmuid and Mick. Their wisdom and support guided me, and their spirit encouraged me. I hope they would feel proud of what they have helped to achieve in this work.

Karen Clarke, MA in Personnel and Development, *Rehabilitative palliative care as a health promoting approach: A participatory action research study*, PhD Palliative Care, April 2019.

Abstract

Health promoting palliative care views dying and death as a social phenomenon, with communities playing an integral role. As providers of palliative care, hospices are facing significant shifts in demography and illness and need to find innovative and sustainable ways to respond. Rehabilitation focuses on promoting optimal function, well-being and quality of life, but in the context of palliative care is misunderstood and under-utilised.

This research assessed whether rehabilitative palliative care offers an opportunity to integrate a health promoting approach in a UK hospice in-patient setting. Taking a participatory worldview perspective, three inquiries were undertaken. Firstly, using participatory action research, a co-operative inquiry group was established to plan and implement ways to integrate this approach. The second inquiry used thematic analysis to examine the facilitators and barriers, and thirdly a literature review assessed whether these factors were present in other studies. Following these three inquiries, the alignment and dissonance between health promoting and rehabilitative palliative care were examined.

Eight co-operative inquiry group members met 11 times between June 2015 and June 2016. Through working collaboratively, the group created a communicative space and was able to initiate change, as evidenced by a post intervention review. This was done by gaining a common understanding and developing a mutual interest in the topic, developing workshops to inform the broader multidisciplinary team and exploiting opportunities to demonstrate rehabilitative palliative care in practice. There were common facilitators and barriers in the findings from this study and the literature, many of them evident in change initiatives generally. However, some were unique including a potential conflict between a model of care focused on caring (palliative), and one based on enabling (rehabilitation). Similarities in the principles underpinning health promoting and rehabilitative palliative care were identified.

The conclusions illustrate that despite its close associations with community initiatives, a health promoting approach to palliative care can be adopted in an in-patient setting.

Table of contents

Acknowledgements 2
Abstract 3
Table of contents 4
  Tables… 9
  Figures… 9
  Key terms 10
  Abbreviations 12
Chapter One: Introduction 13
1.1 Research design 14
1.2 Background of the researcher 15
1.3 Contribution to knowledge 16
1.4 Thesis structure 17
Chapter Two: Background 20
2.1 Introduction 20
2.2 A public health approach 20
  2.2.1 Health promoting palliative care 25
2.3 Palliative care and UK hospices 26
  2.3.1 Challenges facing UK hospices and palliative care services 30
2.4 Rehabilitation in palliative care 33
  2.4.1 Benefits of rehabilitation in palliative care 34
  2.4.2 The role of rehabilitation in a hospice in-patient setting 35
  2.4.3 Rehabilitative Palliative Care 38
2.5 Conclusion 39
Chapter Three: Methodology 42
3.1 Introduction 42
3.2 Philosophical paradigm 43
  3.2.1 Ontology and epistemology 46

3.3 Methodology 47
  3.3.1 Co-operative inquiry 48
3.4 Research design 51
3.5 Methods 53
  3.5.1 Setting 53
  3.5.2 Population and sample 54
  3.5.3 Recruitment and consent 55
  3.5.4 Patient Advisory Group 56
3.6 Data collection and analysis 57
3.7 Ethical considerations 60
  3.7.1 Participant recruitment 61
  3.7.2 Establishing the co-operative inquiry group 62
  3.7.3 Undertaking fieldwork 64
3.8 Insider research 65
3.9 Quality assurance 67
  3.9.1 Reflexivity 68
  3.9.2 Authenticity 69
  3.9.3 Reliability 69
3.10 Conclusion 70
Chapter Four: Inquiry One: Participatory Action Research 71
4.1 Introduction 71
4.2 Establishing and working as a co-operative inquiry group 72
  4.2.1 Introduction 72
  4.2.2 Data collection and analysis 73
  4.2.3 Findings 80
  4.2.4 Personal reflection 88
  4.2.5 Conclusion 90
4.3 Collectively developing knowledge: rehabilitative palliative care and organisational change 91
  4.3.1 Introduction 91

4.3.2 Data collection and analysis ... 91
4.3.3 Findings ... 95
4.3.4 Conclusion ... 98
4.4 Identify, plan and implement ways to integrate rehabilitative palliative care into the hospice setting ... 99
4.4.1 Introduction ... 99
4.4.2 Data collection and analysis ... 100
4.4.3 Findings ... 102
4.4.4 Conclusion ... 111
4.5 Demonstrating rigour ... 111
4.6 Conclusion ... 113
Chapter Five: Inquiry Two: Facilitators and barriers to adopting a rehabilitative approach ... 114
5.1 Introduction ... 114
5.2 Thematic analysis ... 114
5.2.1 Data from the CIG meetings ... 116
5.2.2 Data from the evaluation form ... 119
5.3 Findings ... 119
5.3.1 Facilitators to implementing an RPC approach ... 119
5.3.2 Barriers to implementing an RPC approach ... 123
5.3.3 Factors enabling barriers to be overcome ... 128
5.4 Discussion ... 129
5.5 Conclusion ... 132
Chapter Six: Inquiry Three: Literature review ... 134
6.1 Introduction ... 134
6.2 Method ... 134
6.3 Findings ... 140
6.4 Data synthesis and discussion ... 146
6.4.1 The concept of a rehabilitative approach to palliative care ... 146
6.4.2 Different models of care ... 147

6.4.3 Resources and infrastructure ... 149
6.4.4 Teamworking ... 150
6.5 Conclusion ... 151
Chapter Seven: Rehabilitative palliative care and health promoting palliative care ... 153
7.1 Introduction ... 153
7.2 Rehabilitative palliative care in the context of health promotion ... 154
7.2.1 Create supportive environments ... 154
7.2.2 Develop personal skills ... 158
7.2.3 Reorient health services ... 159
7.3 Alignment between rehabilitative and health promoting palliative care ... 160
7.3.1 Definitions and conceptual clarity ... 160
7.3.2 Participatory models ... 161
7.3.3 Promoting independence and enablement ... 162
7.3.4 Multidisciplinary approach ... 164
7.4 Potential areas of divergence ... 165
7.4.1 Integration of enablement and caring ... 166
7.4.2 Community emphasis in health promoting palliative care ... 167
7.4.3 Death education is not addressed in RPC ... 170
7.4.4 RPC is death-denying ... 171
7.4.5 RPC perpetuates a clinical model of dying and death ... 171
7.5 Conclusion ... 173
Chapter Eight: Conclusion ... 174
8.1 Introduction ... 174
8.2 Key findings ... 174
8.2.1 Inquiry One: Participatory Action Research ... 174
8.2.2 Inquiry Two: Facilitators and barriers to adopting an RPC approach ... 177
8.2.3 Inquiry Three: Literature review ... 177
8.2.4 RPC as a health promoting approach to palliative care ... 178
8.3 Strengths and limitations of the study ... 178

8.3.1 Strengths 178
8.3.2 Limitations 183
8.4 Contribution to knowledge 184
8.5 Final conclusions 185

9. References 187

10. Appendices 200

Appendix 1: Invitation to participate in the research 200
Appendix 2: Participant Information Sheet 202
Appendix 3: Consent form 207
Appendix 4: Overview of data collection 210
Appendix 5: Ethics Committee approval for the research 216
Appendix 6: Details of the co-operative inquiry group (CIG) meetings 217
Appendix 7: Power survey 222
Appendix 8: Evaluation form 226
Appendix 9: Quotes from co-researchers (A3 and L8) 229
Appendix 10: Extract from the in-patient unit minimum data set (MDS) 231
Appendix 11: Integrated palliative outcome scale (IPOS) audit results 232
Appendix 12: “How rehabilitative is your hospice?” checklist extract 233
Appendix 13: Goal setting and action planning documents 235
Appendix 14: Goal setting and action planning documents feedback 237
Appendix 15: Workshop session plan 239
Appendix 16: Summarised feedback from the workshops 240
Appendix 17: List of nodes 245
Appendix 18: Sample of NVivo coding against the node “patient stories” 246
Appendix 19: CINAHL literature search 249
Appendix 20: Record of all database searches. 250

Tables

Table 1: Essential elements of a research paradigm and the participatory position 44
Table 2: Inquiries within the study 52
Table 3: Focus of the study and data collected 59
Table 4: Demographics of the co-operative inquiry group 80
Table 5: Co-operative inquiry and communicative space with study examples 82
Table 6: CIG and PAG responses to rehabilitation and palliative care questions 92
Table 7: "How rehabilitative is your hospice?" checklist results summary 103
Table 8: Progress informed by the goal setting and action planning documents 107
Table 9: Summarised feedback from the two workshops 109
Table 10: Demonstrating rigour in the research process 112
Table 11: Coding stages 115
Table 12: Factors enabling barriers to be overcome 128
Table 13: CINAHL search terms 137
Table 14: Inclusion and exclusion criteria 138
Table 15: Summary of papers from the literature search 142
Table 16: Applying health promotion to palliative care organisations and RPC 155

Figures

Figure 1: Detailed WHO Public Health Model 22
Figure 2: Conceptual framework for "supportive”, "palliative” and "hospice” care ... 29
Figure 3: Three main trajectories of decline at the end of life 36
Figure 4: Process of data collection and analysis 58
Figure 5: Spirals of action research 71
Figure 6: Progressive problem solving with action research 75
Figure 7: CIG Action Research Cycles 78
Figure 8: PRISMA flow diagram illustrating the literature search process 140
Figure 9: Integration of enablement and care 164
Figure 10: Evolved models of integration of enablement and care. 167

Key terms

Co-operative Inquiry Group (CIG): A group of people who come together to explore issues of concern and interest. All members of the group contribute both to the ideas that go into their work together, and also are part of the activity that is being researched.

Clinical Leaders Forum (CLF): The Hospice where this study was located had a Clinical Leaders' Forum where the Chief Executive, Deputy Chief Executive, clinical directors and professional leads from each clinical discipline met monthly to discuss clinical strategy and clinical strategic issues.

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 (NCPC, 2011a).

Health promoting palliative care is an approach focused on ensuring individuals maintain a sense control when facing the end of life and rather than death-denying recognises that the end of life will affect everyone and is always around us. It is an approach that encourages conversations about death and dying in the hope that it will be easier to plan for a good death.

Hospice is a place or an organisation that provides support to people who are dying and their families. In this thesis, when the Hospice where this study is located is referred to, it will be stated with a capital “H”. General reference to hospices will be without the capital ‘h’.

Palliative care is the active, total care of patients whose disease is not responsive to curative treatment. Palliative care takes a holistic approach, addressing physical, psychosocial and spiritual care, including the treatment of pain and other symptoms. Palliative care is interdisciplinary in its approach and encompasses the care of the patient and their family and should be available in any location including hospital, hospice and community. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death and sets out to preserve the best possible quality of life until death (European Association for Palliative Care, 2019).

Patient Advisory Group: A group of patients, from the Hospice where this study is located, who formed a group to help steer and provide the patient perspective to the research.

Rehabilitative palliative care: “a paradigm which integrates rehabilitation, enablement, self-management and self-care into the holistic model of palliative care” (Tiberini & Richardson, 2015, p.2).

Specialist palliative care: encompasses hospice care (including in-patient hospice, day services, hospice at home) as well as a range of other specialist advice, support and care such as that provided by hospital palliative care teams. People who may benefit from specialist palliative care are those whose symptoms cannot be managed in a timely way by their usual care team.

Specialist palliative care, including assessment and advice, may be provided by physicians in palliative medicine or other suitably trained practitioners, such as clinical nurse specialists, social workers, occupational therapists, physiotherapists. Other therapists may also have specialist skills in palliative care (National Institute for Health and Care Excellence, 2017).

Abbreviations

CI:	Co-operative inquiry
CIG:	Co-operative inquiry group
HCP:	Healthcare professional(s)
HPPC:	Health promoting palliative care
PAG:	Patient Advisory Group
RPC:	Rehabilitative palliative care

Word count: 40,896

Chapter One: Introduction

UK hospices face a number of challenges including: rising levels of need for palliative care to respond to the ageing population; increasing numbers of young people with life limiting conditions; increasing prevalence of diseases other than cancer; people living longer with more chronic and multiple conditions; and an ageing hospice workforce (Calanzani, Higginson, & Gomes, 2013; Gomes & Higginson, 2008). With an ageing population comes frailty and the likelihood of chronic disease with associated increasing levels of disability and dependency on informal caregivers and the health service (Hall, Petkova, Tsouros, Costantini, & Higginson, 2011). As a key provider of palliative care hospices need to ensure they are able to support these patients, and yet there is a growing body of literature that suggests that the palliative care provided in hospices, although intended to be supportive, may disable patients and reduce their ability to do things for themselves (Jennings, 2012).

There has also been criticism that palliative care is over-professionalised and/or over-medicalised (Clark, 2002; Cohen & Deliens, 2012; Karsoho, Fishman, Wright, & Macdonald, 2016) with too much emphasis on cure rather than care, and that death should be resisted, postponed or avoided. To address this there has been an international undertaking to take a public health approach to palliative care (Cohen & Deliens, 2012; Kellehear, 1999; Rosenberg & Yates, 2011; Rosenberg & Yates, 2010; Rumbold, 2011). A public health approach to palliative care argues that dying and death are a social phenomenon and that communities have an integral role to play in supporting those at the end of life (Horsfall, Leonard, Noonan, & Rosenberg, 2013; Rosenberg & Yates, 2010; Sallnow, Richardson, Murray, & Kellehear, 2015).

Based in the UK, this study explores how to integrate a rehabilitative approach into a hospice in-patient setting and whether in doing so it could be argued that this is a mechanism for introducing a public health or health promoting approach to palliative care.

1.1 Research design

Consistent with the principles of health promoting palliative care and rehabilitative palliative care (RPC), the aim of this research is to generate knowledge but to do so in an active way that involves the participants rather than them being research subjects. This in itself forms part of the inquiry: how does a group of people come together to collaboratively explore an issue and to create change? The study aimed to plan and, if possible, implement the integration of a new approach to palliative care in a hospice setting, and then consider this in the broader context of public health. This subject matter does not align with objective, scientific measurement or quantitative approaches as it is more concerned with how, working collaboratively, a new care approach can be implemented in a clinical setting. These intentions informed the participatory philosophical paradigm and action research methodology used which is discussed in Chapter Three.

The research was conducted in the United Kingdom (UK) between April 2015 and September 2018. It involved creating and working with a co-operative inquiry group (CIG) who met between June 2015 and June 2016 and this is described in Chapter Four. Once the group had stopped meeting formally the participants continued to be consulted until October 2018 when the first full draft of this thesis was shared with them. Data was collected from a variety of sources and analysed in different ways.

Within action research there are three distinct elements: its participatory character; its democratic impulse; and its simultaneous contribution to social science and social change (Meyer, 2000). It is an approach that involves others to improve their own practice which, in healthcare, can then enhance patient experience (Koshy, Waterman, & Koshy, 2011). In this context it can be emancipatory and empowering. The characteristics of participation, democracy and empowerment will be highlighted throughout this thesis.

1.2 Background of the researcher

The inspiration for this research was threefold: a background in human resource management where the highlights of my career had been transformational organisational change projects, my work as a senior manager in a hospice and an interest in public health palliative care. Within the Hospice, I was managing a team of therapists who described to me the challenges they faced in trying to gain acceptance of therapeutic interventions in the in-patient setting. Issues they described included a hostile reception when visiting the in-patient unit, a lack of communication about patients' therapy needs until discharge planning and a failure by other healthcare professionals to engage in care plans created by the therapists. Whilst supporting the therapists with strategies for dealing with this, I struggled to understand why there was such resistance.

Simultaneously, I was working with Professor Alan Kellehear as part of the shadow council of what was to become Public Health Palliative Care International (http://www.phpci.info/). I was interested in the role that hospices could play in encouraging communities to be more compassionate and talk more openly about dying whilst accepting that dying was part of living. Given the therapists' feedback, I questioned whether the Hospice was unintentionally perpetuating the perception that hospices were places where people went to die, that it was sequestering death away (Lawton, 1998) and therefore complicit in creating a death-denying society (Kellehear, 1984). I therefore wanted to explore how, in its in-patient unit, the Hospice could introduce a more rehabilitative focus that enabled people to live as well as possible with a life-limiting illness and challenge some of the perceptions about hospice care. This could have the potential of reaching more people who perhaps had previously thought hospice care had nothing to offer them.

The research was set within the organisation that I was employed by which meant that I was an 'insider' researcher (Coghlan & Brannick, 2007) who was also a senior manager. This had ethical implications and posed potential risks to the study which will be examined in Chapter Three, but more importantly it required me to be highly reflective on my own actions and behaviours and how these influenced the research. In sections 4.2.4 and 5.4 there are extracts from my journal to illustrate my reflexivity and what this meant for the study. It is this emphasis on reflexivity which also influenced my decision to write some aspects of this thesis in the first person singular.

1.3 Contribution to knowledge

The study will add to knowledge in relation to participatory research using co-operative inquiry and specifically in a hospice setting. There is also the potential for it to contribute to knowledge in relation to creating culture change in a hospice with opportunities to further explore the factors that enable and inhibit change in this context.

The research also contributes to evidence regarding how rehabilitative palliative care can be introduced to a hospice in-patient setting. Studies have focused on this approach being applied in a day service context (Round, Leurent, & Jones, 2014; Talbot Rice et al., 2014) but little knowledge exists about how it can be adopted in an in-patient setting.

The final contribution to knowledge is in relation to considering RPC as an opportunity for hospice in-patient units to adopt a health promoting approach.

1.4 Thesis structure

Participatory action research is challenging to report and does not easily conform to conventional report-writing (Smith, Rosenzweig, & Schmidt, 2010). The following explanation of how this thesis is structured is intended to guide the reader through this complexity.

Chapter Two describes the background or context for this research. It begins by explaining a public health perspective on palliative care - an international approach that has been embraced, to varying degrees, by several countries across the world. It then focuses on palliative and hospice care in a UK context and discusses some of the challenges currently being faced both at a practical and philosophical level. It concludes by describing rehabilitation in relation to palliative care and the benefits this can bring according to the literature.

The methodology is described in Chapter Three including the philosophical paradigm, participatory action research and co-operative inquiry. It then explains the approach used to undertake the research including the establishment of a Patient Advisory Group who were not research subjects but provided the patient perspective and were consulted throughout the study. Data collection and analysis is touched on briefly in Chapter Three. The approach to this depended on the phase of the research and the data that was being examined and so descriptions of data collection and analysis are included in specific Inquiries and more comprehensively in Chapter Five. Attention is paid to ethical considerations in Chapter Three as action research studies, and particularly those that are highly participatory, can pose some unique ethical issues. Similarly, challenges arise in terms of demonstrating quality and rigour in these types of studies and so this is also covered in Chapter Three.

From Chapters Four to Six, this thesis is divided into three separate Inquiries. Each component of each Inquiry is an action research cycle and therefore the activities undertaken, the data collected and analysed, the findings, and the conclusions reached are described for each. For example, Inquiry One: Chapter Four, deals with the first objective which has three parts:

- establish and work as a co-operative inquiry group (CIG), and then for the CIG to
- develop its knowledge, and
- plan how to implement a rehabilitative approach in an in-patient setting.

For each of these parts there will be a description of the data collection and analysis, findings and conclusions. With regards to data collection there is reference to concurrent analysis, which took part throughout the action research cycles and was used to inform further action, and retrospective analysis which was completed at the end.

Chapter Five – Inquiry Two explains the approach that was taken to identify the facilitators and barriers to introducing a rehabilitative approach to this setting. The emphasis here was on data collection and analysis and so full details of the retrospective thematic analysis is included. The facilitators and barriers are described before the findings are discussed and conclusions reached.

Chapter Six - Inquiry Three, is the literature review. The study was co-created by those who participated in it and therefore the timing of the literature review could only be determined once the study had commenced. There was one substantive literature search to identify the barriers and facilitators to implementing a rehabilitative approach in the context of palliative care. This took place after the CIG had concluded its actions, was undertaken independently by me in September 2017 and repeated in April 2018.

Chapter Seven assesses whether a rehabilitative approach to palliative care offers an opportunity to integrate a health promoting approach to palliative care in a hospice in-patient setting. It does this by examining the alignment as well as considering where the positions are divergent.

In Chapter Eight, the main points from this thesis are summarised, the strengths and limitations articulated, evidence of quality noted and the contributions to knowledge proposed.

Chapter Two: Background

2.1 Introduction

Within this study, there are three key elements: health promoting palliative care, hospice and palliative care in the UK and rehabilitation in palliative care. In this chapter, each of these will be discussed by providing some historical context and definitions to provide the background to the study. It is not easy to differentiate each of these topics chronologically and so I have chosen to present them according to scale, i.e. a public health approach is a global issue, palliative care (in the context of this study) relates to the United Kingdom (UK), and rehabilitation in palliative care is an approach to care.

2.2 A public health approach

A public health approach to palliative care has been advocated since the 1990's when the World Health Organisation (WHO) aimed to improve opiate availability across the world and to integrate palliative care services into mainstream healthcare (Stjernswärd, Foley, & Ferris, 2007). However, contemporary challenges such as changing demographic trends, combined with increased social isolation and inequity of access to palliative care services have prompted a re-examination of the principles of a public health approach (Sallnow et al., 2015). A public health approach is one that considers disease control and prevention alongside the maintenance and improvement of health through collective or social actions (Cohen & Deliens, 2012).

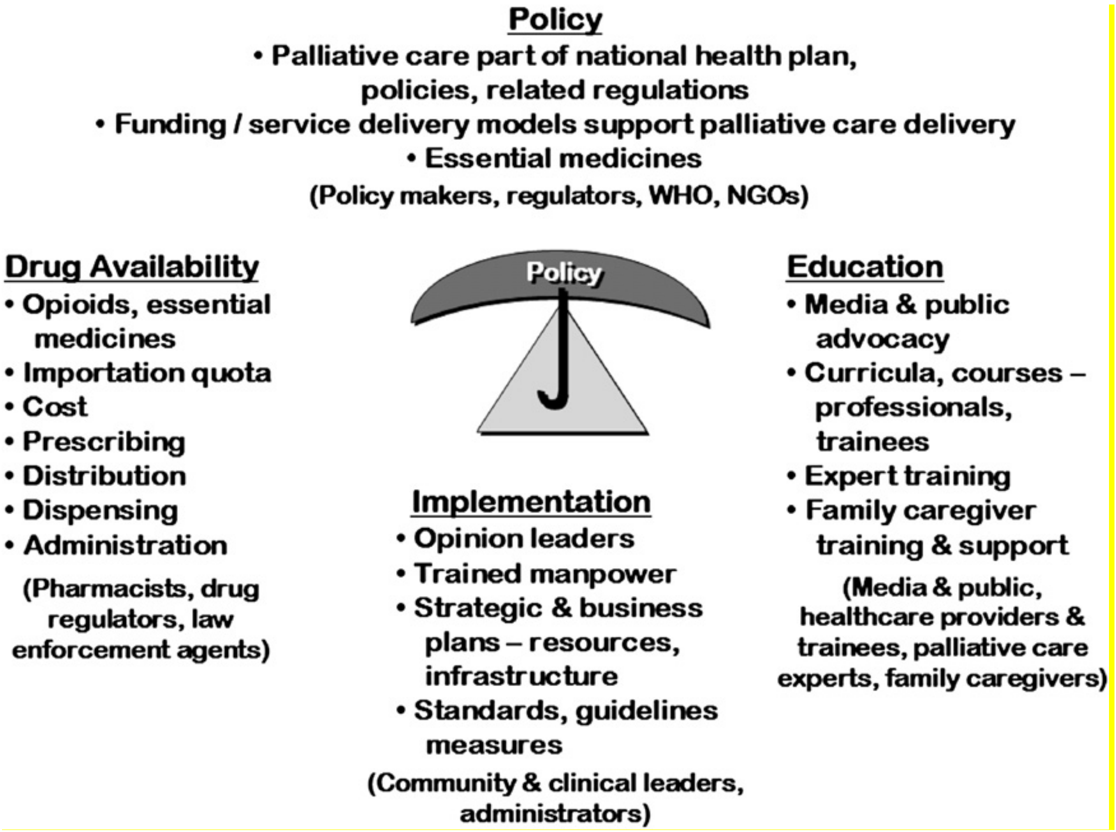
The rationale for public health to engage with palliative care is that death, dying and loss are universal experiences that have a major impact on health and wellbeing at a population level and are associated with significant burden and cost (Cohen & Deliens, 2012; Dzingina & Higginson, 2015; Gillies, 2016; Stjernswärd et al., 2007) This aligns with other public health priorities (Rao, Anderson, & Smith, 2002) and demographic, epidemiological and societal factors suggest that these issues are likely to increase in the future as the world's population continues to age (Dzingina & Higginson, 2015). There is some evidence that a public health approach to palliative care is gaining momentum (Stjernswärd et al., 2007) but there is also ambiguity around which public health approach to adopt (Clark, 2015b; Dempers & Gott, 2017b; Rumbold & Aoun, 2014) all of which share some common ground but have different scope and goals. In their integrative literature review to understand the theoretical features of the public health approach to palliative care Dempers and Gott (2017b) identified three specific paradigms from 18 studies worldwide. Their categorisation is used to illustrate the various public health approaches:

a) Population-based approach

A population-based approach focuses on palliative care at an epidemiological level and considers population data using epidemiology, health services research and policy analysis to address a health issue (Lupu, Deneszczuk, Leystra, McKinnon, & Seng, 2013) and has been demonstrated in the population-based studies of Belgium's End of Life Care Research Group (Cohen & Deliens, 2012). In their study Dempers and Gott (2017b) allocated three studies to this category but suggested that this was because they did not fit into either of the other two suggesting that this approach is the least defined of all.

b) WHO approach

The WHO approach aims to integrate palliative care into all levels of society through: appropriate policies, adequate drug availability, education of health care workers and the public, and implementation (Stjernswärd et al., 2007) to address the core concerns of reach and service provision (Dempers & Gott, 2017b). Figure 1 illustrates the four components of the WHO Public Health Model (Stjernswärd et al., 2007) which are set within the context of the culture, disease demographics, socioeconomics, and the health care system of the country concerned.



(Stjernswärd et al., 2007)

Figure 1: Detailed WHO Public Health Model

Whilst the WHO is credited with being proactive in palliative care development in resource poor countries, there are questions about how effective this model is in tackling the development barriers that exist and its relevance in more affluent countries (Cohen & Deliens, 2012).

c) Health promotion

In 1986, the first international conference on health promotion took place in Ottawa, Canada. It defined health promotion as:

> “the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities” (WHO, 1986, p.1).

The Ottawa Charter (WHO, 1986) describes the five pillars of health promotion as: build healthy public policy; create supportive environments; strengthen community action for health; develop personal skills and reorient health services. In 1997, the WHO Jakarta Declaration suggested an alternative paradigm to the biomedical model of healthcare to one that endorsed the partnership between the community and healthcare professionals. This required a culture shift by healthcare professionals to engage with communities as possessors of expert knowledge and to recognise the need to share this knowledge and its power in partnership with communities (Rosenberg, Mills, & Rumbold, 2016). Since then a health promotion approach has been used successfully in fields such as HIV and cardiovascular disease (Sallnow et al., 2015).

The most prevalent theme in Dempers and Gott’s (2017b) study was a health promotion approach (as conceptualised by the authors) where studies referred to the importance of community. This accords with Sallnow et al. (2015) who suggested that the dominant interpretation of health promotion within end of life care has been through strengthening the community action pillar of the Ottawa Charter (WHO, 1986) and concerted efforts of community engagement. In the UK, some hospices are adopting this approach by engaging with schools and working directly with community groups (Paul & Sallnow, 2013).

It could be argued that community engagement, advocated by a health promoting approach improves palliative care reach - a goal of the WHO approach, and so health promotion and WHO approaches are not mutually exclusive. The WHO approach tends to be system oriented whereas health promotion is socially oriented (McIlfatrick et al., 2013) but social participation and community ownership is referred to in the WHO Public Health Strategy for Palliative Care (Dempers & Gott, 2017b). Stjernswärd et al (2007) also allude to this shared ground in stating that effective public health strategies must be incorporated into all levels of health care systems and involve the community through collective and social action. However, whilst population-based and WHO approaches are focused at an international or national level, health promotion interventions can be done at a local level, e.g. falls prevention strategies for people with dementia; promoting positive mental health and wellbeing among carers; or improving health literacy among people with life-limiting illness (Gillies, 2016). These are appropriate strategies for a hospice, the setting for this study, to consider. Health promotion is also an asset rather than deficit based model recognising resources and wellness rather than deficits and illness (Benzein & Saveman, 2008) which is aligned with a rehabilitative approach. For these reasons, health promotion is the public health approach that will be adopted for this study. This is done in the knowledge that the predominant health promotion approach in the UK concerns community engagement whereas this research focuses on the in-patient setting. This will be explored in Chapter 7.

2.2.1 Health promoting palliative care

The two fields of health promotion and palliative care were integrated using the key principles of palliative care, the key action areas of the Ottawa Charter and the foundational work of Saunders (1987) to create the concept of health promoting palliative care (Kellehear, 1999) The goals of health promoting palliative care are to:

a. provide education and information for health, death and dying;
b. provide social support at both personal and community levels;
c. encourage interpersonal reorientation;
d. encourage reorientation of palliative care services;
e. combat death-denying health policies and attitudes (Kellehear, 1999).

In being adopted, a health promoting approach addresses the underdeveloped social aspects of conventional palliative care (Kellehear, 1999) to: complement clinical approaches, restore social and pastoral interventions, allow diversity among clients, expand understanding of health and reclaim a holistic perspective (Rumbold, 2011). A participatory relationship between the healthcare professional (HCP) and the patient acknowledges that the patient is the expert in their illness who can identify their own needs and direct their own self-help (Kellehear, 1999). The individual works in partnership with the HCP to decide what support they need and how; the HCP does not dictate or assume. In health promoting palliative care the HCP adopts a facilitating role and listens to the concerns and goals of the patient which in turn gives them support and control. Yet it also acknowledges that some may wish to assume a dependent ‘sick role’ but emphasises that this is a *choice* and not an assumption made by a HCP. In the traditional sick role, patients are assumed to be “in need” and that they will be “compliant”; the HCP “does”, is perceived to be the expert, and dispenses advice.

Three core characteristics of health promoting palliative care (HPPC) are:

- **Participation**: There is an aspiration that organisations will participate in the development and/or uptake of public policy relating to palliative care and the support of dying people (Kellehear, 1999). HPPC also advocates that communities will work collaboratively to improve end of life care locally and that palliative care should be reformed within a participatory model of health (Rumbold, 2011).
- **Democracy**: Participatory social relations includes the relationship between the patient and the HCP (Rumbold, 2011). This is not a hierarchical relationship where the HCP is dominant but a democratic relationship where knowledge and expertise are acknowledged and shared.
- **Empowerment**: In democratising the relationship between the HCP and the patient, a health promoting approach is one that empowers people. By educating, organising equipment, praising and building confidence patients are empowered therefore enabling them to remain in control but also relieving the burden on carers which in turn alleviates suffering and promotes health (Buckley, 2002; Pegg & Tan, 2002). In HPPC, there is a call for communities to feel empowered to set their own health priorities.

2.3 Palliative care and UK hospices

According to the World Health Organisation (WHO):

> "Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2018, p.1).

Palliative care is explicitly recognised under the human right to health (WHO, 1986) and should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.

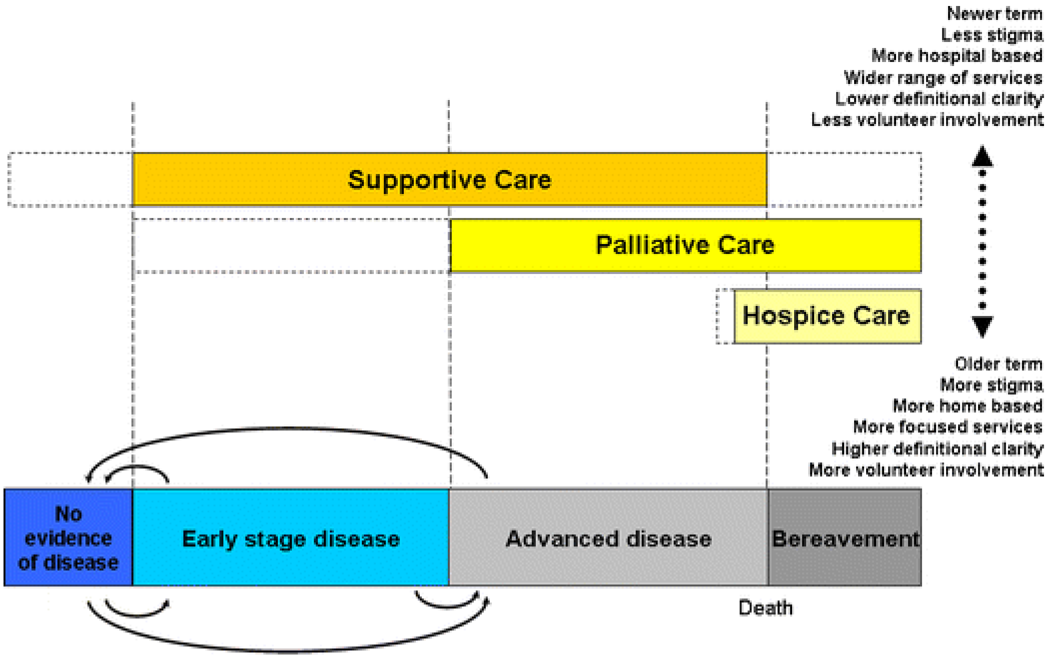
The term "palliative care" was first proposed by Balfour Mount in 1974 who was inspired by the work of Dame Cicely Saunders who founded St Christopher's Hospice, London in 1967 which is recognised as the start of the modern UK hospice movement (Clark, 2002). In the 1980's the formal medical subspecialty of Palliative Medicine was established in the UK (Fallon & Smyth, 2008). Through the leadership of Dame Cicely Saunders, the hospice movement condemned the neglect of those who were dying in society whilst seeking to reframe death as a natural phenomenon rather than a clinical failure. It argued that high quality pain and symptom management should be available to all who needed it and that palliative care offered an alternative to the growing arguments in favour of euthanasia (Clark, 2015a).

In the UK, hospices aim to provide palliative care to all those with a life limiting illness, their relatives and family carers, including bereavement support, in several settings: in-patient unit, at home, in care homes or via day services. The hospice's multidisciplinary teams are expert in caring for dying people and are considered to provide *specialist* palliative care as they work solely within this field. This is distinct from HCP such as GPs and district nurses who provide palliative care as part of a broader range of support and do not necessarily have specialist qualifications in this area.

Within this field terminology can be complex, challenging and confusing. In their systematic review Hui et al.(2013) found 24 definitions for “palliative care” and 17 for “hospice care”. The International Association for Hospice and Palliative Care (IAHPC) presented a new global definition for palliative care in January 2019 which was rejected by the European Association of Palliative Care (EAPC) because terms such as ‘serious health related suffering’ were too ambiguous and complex; the proposed definition did not sufficiently reflect the complexity of palliative care, specifically in the overlap between specialist and generalist approaches; and certain aspects of palliative care such as rehabilitation, public health and compassionate community approaches were omitted (European Association of Palliative Care, 2019).

Whilst the term palliative medicine has been widely understood and accepted it has been less easy to establish a clear and consistent description for the support that it provided by the multidisciplinary palliative care team (Fallon & Smyth, 2008) and at which stage of someone’s illness which type of care is being provided. The conceptual framework in Figure 2, developed by Hui et al. (2013) illustrates how ‘supportive care’, ‘palliative care’ and ‘hospice care’ can be understood.

The stages of illness are depicted at the bottom and were identified as being the key distinguishing factor for determining the type of care being provided. The size of the boxes for supportive, palliative and hospice care are proportionate to the patient population accessing that type of care. Hospice care sits within palliative care. The dashed lines indicate that the scope of the different types of care are not rigid and can be provided at different stages of illness. The palliative care section is clearly defined by a coloured box but has an expanded dashed line to reflect an increasing amount of literature suggesting that palliative care should start early (Temel et al., 2010) and/or from the time of diagnosis (Hui et al., 2013; Murray et al., 2017). Arguably this is also true for UK hospice care, but this model reflects an international position and the models of hospice care vary across the world.



(Hui et al., 2013, p.683)

Figure 2: Conceptual framework for "supportive", "palliative" and "hospice" care

The terms end of life, terminally ill and terminal care share similar meaning: progressive life-limiting disease with a prognosis of months or less but differ in their application.

According to Hui et al. (2014) “end of life” defined a particular time frame whereas “terminally ill” described a patient's condition, and “terminal care” characterised the care delivered to these individuals. The UK End of Life Care strategy (Department of Health, 2008) suggests that the end of life is the last year of life whereas terminal care pertains to the last days of life. In this thesis the term life-limiting illness will be used unless a different term is specified by an author.

2.3.1 Challenges facing UK hospices and palliative care services

A lack of understanding of the terminology or a misunderstanding of what hospice and palliative care means to an individual are some of the challenges that UK hospices face. This can mean that those who could benefit from their services fail to access them and patients are not referred or are referred late. There are also other societal and demographic changes that are affecting hospices and palliative care services:

2.3.1.1 An ageing population and workforce

There will be rising levels of need for palliative care to respond to the ageing population (Gomes & Higginson, 2008). The number of people who may need palliative care in the UK is growing more than previously predicted with the number of people expected to die rising by 25% between 2014 and 2040 (Etkind et al., 2017).

The likely increases in demand and the changing profile of palliative care patients comes at a time when the health and social care workforce is ageing and facing significant recruitment challenges (NCPC, 2011b). Furthermore, for most of their working lives, the majority of people working in hospices have focused on caring for those with cancer (Calanzani et al., 2013) and may be ill-equipped or lacking the confidence to support those with a non-malignant diagnosis.

2.3.1.2 Increasing prevalence of conditions other than cancer

By 2040, 53% of people dying will be over the age of 85 and between 25-50% of them will have frailty (Etkind et al., 2017). Frailty is a "distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves" (British Geriatric Society, 2014, p.1). This can have an impact on people maintaining activities of daily living and people decline from being independent to increased dependence (Tiberini & Richardson, 2015) resulting in feelings of loss: loss of control, identity, authority and purpose with resulting depression, anxiety, hopelessness or frustration (Mahler & Verney, 2016). Whilst the palliative care team effectively manages symptom control for those who are dying from cancer (Ellershaw, Peat Sj Fau - Boys, & Boys, 1995) these skills may not easily translate into supporting frail older people (Nicholson & Richardson, 2018).

In addition to living longer and with frailty, people are living with, and dying from, chronic illness and multiple morbidities and so will have a different set of health needs (Calanzani et al., 2013). Increasing prevalence of other diseases (e.g. cardiovascular and respiratory) means that palliative care needs to extend beyond cancer (Murray & McLoughlin, 2012).

2.3.1.3 Lack of family caregivers

Palliative care providers and hospices can only provide a finite amount of support and rely heavily on families and informal carers to support someone nearing the end of their life. There is evidence that the model of society has changed, with families being more geographically dispersed and fewer children being born, leading to increased dependence on health and social care services rather than a reliance on family caregivers (Gomes & Higginson, 2008; Payne, 2010).

Palliative care has also come under criticism from a philosophical perspective. In their critique of palliative care, Randall and Downie (2006) suggested that the Asklepion tradition, which stresses the importance of giving individual attention to each patient, their stories and their values, was being overlooked by healthcare professionals adopting the Hippocratic techniques of modern medicine. The medicalisation of death and dying has been widely discussed in the literature (Clark, 2015a; Cohen & Deliens, 2012; Karsoho et al., 2016) with claims that the dominant medical view is that death should be resisted, postponed or avoided and that this philosophy has crept into palliative care. This has resulted in an over-emphasis on ‘symptom control’, to the detriment of psychosocial and spiritual support (Kearney, 1992). Concern has also been expressed that paternalism exists within palliative care (Dempers & Gott, 2017a; Rosenberg, Horsfall, Leonard, & Noonan, 2018) which can stifle patient autonomy and empowerment and lead to palliative care becoming over-professionalised (Randall & Downie, 2006). Hospices have also been criticised for abandoning their heritage and being reintegrated back into mainstream healthcare systems rather than holistically meeting the needs of dying people within their social context (Rosenberg & Yates, 2010).

To address some of these concerns there has been a growing interest in other models of hospice care - Hospice Enabled Dementia Care (Hospice UK, 2015) Age-Attuned

Hospice Care (Nicholson & Richardson, 2018) and the focus of this study Rehabilitative Palliative Care (Tiberini & Richardson, 2015) and A Public Health Perspective on End of Life Care (Cohen & Deliens, 2012).

2.4 Rehabilitation in palliative care

There is evidence to suggest that although diagnosed with an advanced, life-limiting illness, palliative patients want to remain independent and to focus on life and living (Carter, MacLeod, Brander, & McPherson, 2004; Reeve, Lloyd-Williams, Payne, & Dowrick, 2010; von Post & Wagman, 2017). Patients describe maintaining normality as an important way of preserving dignity and self-identity (Johnston, Rogerson, Macijauskiene, Blaževičienė, & Cholewka, 2014), and physical function and independence are also high priorities (Cheville, 2001; Cotterell, 2008; Yoshioka, 1994). A focus on rehabilitation within palliative care has evolved as a means of supporting patients to achieve this (National Institute for Clinical Excellence, 2007).

In relation to palliative care, the term rehabilitation may appear incompatible (Cheville, 2001) but in this context rehabilitation is

> "the process of helping a person to reach the fullest physical, psychological, social, vocational, and educational potential consistent with his or her physiological or anatomical impairment, environmental limitations, desires, and life plans" (Javier & Montagnini, 2011, p.638).

However, this definition fails to acknowledge an important aspect of palliative rehabilitation which is that it aims to enable participation in meaningful activities whilst simultaneously acknowledging and preparing for death (Bye, 1998).

It was also evident in Dame Cicely Saunders' original vision for modern palliative care who said that the work of all the professional team is:

> "enable people to live until they die, at their own maximum potential, performing to the limit of their physical activity and mental capacity, with control and independence wherever possible" (Saunders, 2004, p.9).

Similarities have been identified in the characteristics of rehabilitation and palliation: symptom-oriented; take an integrated, holistic multidisciplinary approach; are creative in problem-solving to achieve improved quality of life; and recognise the patient in the wider context of their social, lived-in world (Cheville, 2001; Santiago-Palma & Payne, 2001). A further similarity is that both aim to improve, whilst maintaining a balance between, function and comfort depending on the patient's goals (Mahler & Verney, 2016).

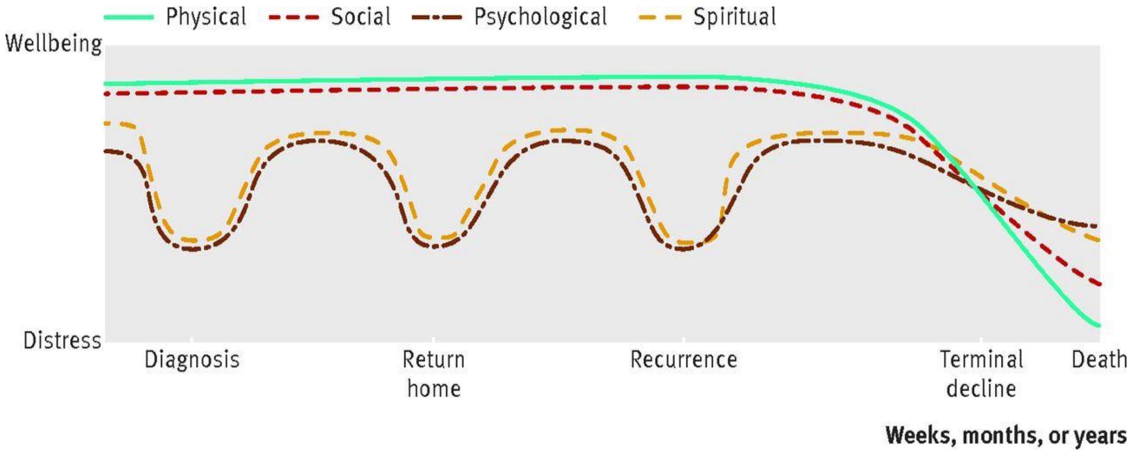
2.4.1 Benefits of rehabilitation in palliative care

The benefits of rehabilitation for those with advanced cancer has been widely discussed in the literature (Javier & Montagnini, 2011; Oldervoll et al., 2011; Scialla, Cole, Scialla, Bednarz, & Scheerer, 2000; Yoshioka, 1994) and palliative rehabilitation has been proven to be beneficial for patients with symptoms such as breathlessness, pain and fatigue and for other conditions including frailty (Crocker et al., 2013; Matthew Maddocks et al., 2016) chronic obstructive pulmonary disease (COPD); (McCarthy et al., 2015; Resqueti et al., 2007) and heart failure (R. Taylor et al., 2014). There is also some evidence that the benefits of adopting a rehabilitative approach extends beyond the patient and their family to the broader health economy. Healthcare costs are significantly elevated in the last year of life due to a combination of factors: increased hospital admissions, more frequent GP visits, additional social care costs (Georghiou & Bardsley, 2014; Hazra, Rudisill, & Gulliford, 2017; Lynn & Adamson, 2003). For patients aged over 65 years, severe disability and functional decline were associated with increased hospital stays (A. Kelley, Ettner, Morrison, Du, & Sarkisian, 2012) and a failure to regain function in older people in the three months after a hospital admission was identified as a significant predictor of being institutionalised within the next 12 months (Portegijs, Buurman, Essink-Bot, Zwinderman, & de Rooij, 2012). These studies indicate that addressing functional decline may reduce healthcare need and costs and/or reduce the need for long-term care home support. In addition to the direct costs to health and social care services, there are also indirect costs associated with people being cared for at home by informal caregivers - family members and friends who may be unable to work because of their caregiving responsibilities.

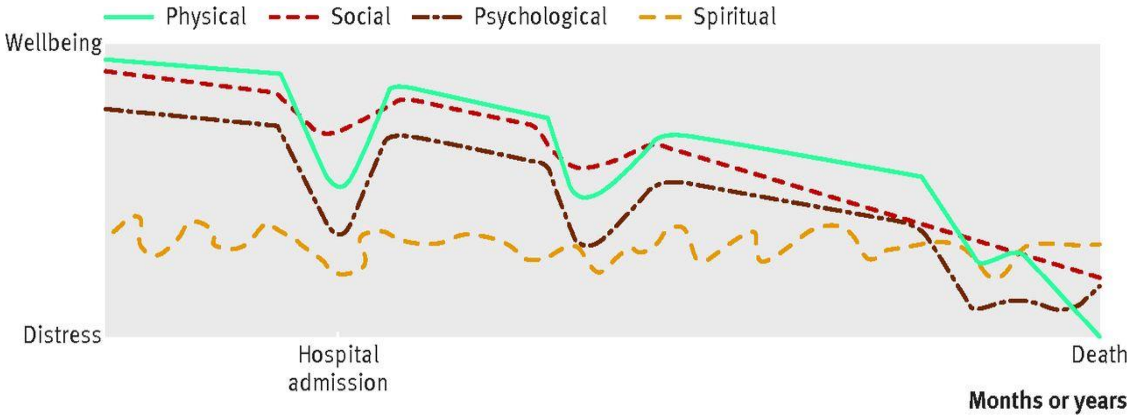
2.4.2 The role of rehabilitation in a hospice in-patient setting

Within a UK hospice in-patient unit, patients spend prolonged periods of time in bed, often recovering from an exacerbation of their illness, and this can reduce their functional independence, decondition them, increase their disability and have an impact on their quality of life (Javier & Montagnini, 2011; Santiago-Palma & Payne, 2001). Furthermore, as Figure 3 illustrates, each group of patients will have different needs depending on their illness.

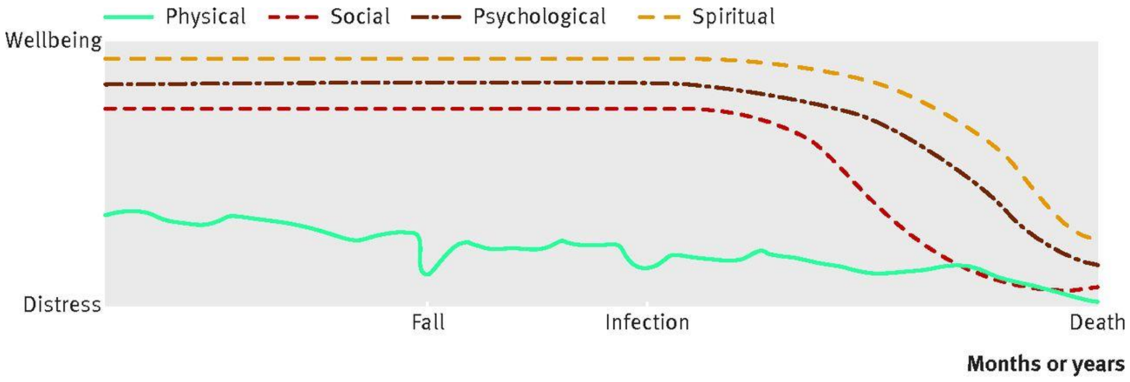
The disease trajectories for cancer, organ failure and physical/cognitive frailty show considerable variation in terms of function over time. With organ failure (Figure 3b) for example, although there is a persistent decline, the unpredictable exacerbations are recoverable from. This demands a different approach from the care team who, in the a: Wellbeing trajectories in-patients with conditions such as cancer causing rapid functional decline



b: Wellbeing trajectories in-patients with intermittent decline (typically organ failure or multimorbidity)



c: Wellbeing trajectories in-patients with gradual decline (typically frailty or cognitive decline)



(Murray et al., 2017, p.5)

Figure 3: Three main trajectories of decline at the end of life

hospice in-patient setting, may be more familiar with the inexorable decline of cancer shown in Figure 3a (Murray & McLoughlin, 2012). For people who are elderly and frail, rehabilitation has been considered beneficial in identifying losses and developing strategies or goals to address them (Crocker et al., 2013).

Most people wish to die at home (Khan, Gomes, & Higginson, 2013) which means that discharge from a hospice is now more common. Therefore, an in-patient admission must support and maintain the patient's independence and functional ability to enable them to be successfully discharged home with as good a quality of life as possible. When discharged home the burden of care often falls to a family member and so maintaining an individual's independence during an in-patient admission not only improves their quality of life but can also reduce the burden of care for the caregiver (Santiago-Palma & Payne, 2001). The fear of being a burden to others has been recognised as one of the main concerns that underlies patients' requests for death-hastening acts amongst people nearing the end of life and deemed to be more difficult for the caregiver to cope with than the patient's physical impairment (McPherson, Wilson, & Murray, 2007). Retaining as much functional independence may ameliorate the patient's perceptions of hopelessness and despair and relieve some of the burden for the caregiver ensuring that this is manageable and therefore increasing the likelihood that someone can remain at home to die (Proot et al., 2003).

Despite its benefits there are criticisms of adopting a rehabilitative approach to palliative care. With its emphasis on enablement, self-management and self-care, it could be argued that rehabilitation is death-denying which is at odds with the in-patient setting where many patients are admitted for terminal care (Department of Health, 2008). Clearly articulating that in the context of palliative care, rehabilitation is about participating in meaningful activities whilst acknowledging and preparing for death (Bye, 1998) will be an important aspect of this study.

This emphasis on promoting independence could also be perceived as cost saving (see 2.4.1). This makes a compelling argument given the current and future financial constraints in healthcare, and in the hospice setting, where most of the funding comes from charitable donations, the economic contribution should not be overlooked. However, this should be considered as an additional and indirect benefit of rehabilitation rather than the driver for it. Patients' goals and needs are the priority.

Rehabilitation is traditionally seen as the responsibility of allied healthcare professionals and often clinical staff are unaware of the role they could play in this ((Department of Health, 2008). This may present some challenges for engagement and also potential conflict within the multidisciplinary setting of the in-patient unit where no healthcare discipline dominates.

Although identified in the NICE guidelines (National Institute for Clinical Excellence, 2007), there is a lack of evidence to support rehabilitation in palliative care (Eva & Payne, 2014; Wosahlo & Maddocks, 2015). This may mean that some clinicians will be reluctant to engage with the approach as they are not convinced of its value or efficacy. Notwithstanding this, although the healthcare professional may recognise its benefit, that does not guarantee that the patient will engage with it (M. Maddocks, Mockett S Fau - Wilcock, & Wilcock, 2009).

2.4.3 Rehabilitative Palliative Care

A growing interest in the role that rehabilitation could play in palliative care resulted in the introduction of an approach called Rehabilitative Palliative Care. Launched in July 2015, "Rehabilitative Palliative Care: Enabling people to live fully until they die" (Tiberini & Richardson, 2015) introduced the concept of 'rehabilitative palliative care' which was defined as: "a paradigm which integrates rehabilitation, enablement, self-management and self-care into the holistic model of palliative care" (Tiberini & Richardson, 2015, p.2). Many of the ideas and concepts in this document are not new but this publication has raised the profile of rehabilitation in palliative care in the hospice sector and 'Rehabilitative Palliative Care' has been incorporated into national guidance: Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 (National Partnership for Palliative and End of Life Care, 2015) and Age-Attuned Hospice Care (Nicholson & Richardson, 2018).

"Palliative rehabilitation", "rehabilitative approaches" and "rehabilitative palliative care" all appear in this thesis. The former reflects that the phrase palliative rehabilitation care predated rehabilitative palliative care, and rehabilitative approaches was the term used in the literature search to ensure that studies which did not refer to palliative rehabilitation or RPC were not excluded. However, the core aspects of each are the same and therefore the predominant term used will be RPC.

2.5 Conclusion

This chapter has introduced health promoting palliative care as a global movement originating from the 1990's but gaining momentum now due to increasing populations, the perceived professionalisation of death and dying, more social isolation and inequity of access to services (Sallnow et al., 2015). A health promoting approach focuses on education and empowerment and encourages people to become active participants in their own health.

In the UK, it was explained that the modern hospice movement arose in the late 1960's in response to perceived failings in the healthcare system to adequately care for those who were dying but has recently come under criticism for becoming more aligned to mainstream healthcare, perpetuating a medical-model, and adopting a paternalistic approach to patient care. An ageing population who are living with increased co-morbidities is also putting pressure on hospice and palliative care services.

At a service level, an approach to palliative care that includes rehabilitation was outlined concluding with the introduction of rehabilitative palliative care (RPC) in 2015. In this study, the focus is on introducing a rehabilitative approach to a hospice in-patient setting in order to provide an approach that maximises independence, promotes self-management, and supports patients with conditions other than cancer. In doing so it could address some of the challenges facing UK hospices: reduce the pressure on specialist palliative care resources, reduce caregiver burden and reduce healthcare costs. A further question is whether, in addition to this, adopting RPC in an in-patient setting is modelling health promoting palliative care.

In assessing whether RPC offers an opportunity to integrate a health promoting approach to a hospice in-patient setting, this study will:

1. Establish a co-operative inquiry group to work together to:
    a. collectively develop their knowledge about rehabilitative palliative care;

    b. identify, plan and implement ways to integrate rehabilitative palliative care into a hospice in-patient setting;

2. Identify the facilitators and barriers to adopting a rehabilitative approach in this setting;
3. Review the literature to assess whether these factors were present in other studies focussed on integrating a rehabilitative approach to palliative care;
4. Examine whether rehabilitative palliative care, adopted in a UK hospice in-patient setting reflects a health promoting approach to palliative care.

Objectives 1) and 2) will involve participatory action research with a co-operative inquiry group (CIG). The knowledge gained and reported in these sections reflects the shared understanding of the CIG who, in this methodology, are co-researchers and co-subjects (Heron & Reason, 1997). To retain the authentic voice of the research these sections will be written in the first person. This is also intended to demonstrate self-reflection and self-awareness (Hockley, 2006) - both integral features of action research but also emphasises that I was an instrument of the research and not detached from it (Coghlan & Brannick, 2005). Other sections will be written in the third person.

Chapter Three: Methodology

3.1 Introduction

There are some key themes within health promoting palliative care and rehabilitation that helped to inform the approach to the research: a strong emphasis on working with people and empowering them, and a move away from a paternalistic approach to care giving to one that is more democratic. To research this subject matter using a positivist approach, where the staff were passive participants with no control over the changes being introduced, would have felt incongruent with these principles and so a research methodology was sought that aligned with the values of the topics under consideration. This chapter focuses on the methodology and methods used to undertake this research.

Methodology refers to the framework within which research is conducted, and methods are the tools or techniques used. Both are underpinned by a set of beliefs that guide the approach and decisions made about how the research is conducted. This is sometimes referred to as a "worldview" (Creswell, 2014; Koshy et al., 2011; Reason, 1998) or more commonly as a "paradigm" (Braun & Clarke, 2013; Flick, 2009; Koshy et al., 2011; Mertens, 2007). Alignment between the research subject, methodology and paradigm ensures cohesion and congruence in the study (Creswell, 2014) and enhances its trustworthiness.

This research seeks to engage a group of individuals firstly to understand and then to implement a new model of hospice care. It is therefore change oriented and highly participatory. These principles underpin the research.

3.2 Philosophical paradigm

In addition to being change oriented this study was intentionally participatory and as such resonates with a participatory paradigm. Table 1 illustrates the key elements of a participatory paradigm.

A participatory worldview position aims to empower those who are oppressed to engage collaboratively to improve their position in society (Guba & Lincoln, 1994; Kemmis & Wilkinson, 1998). Its unique elements are described as context bound and involving action and participation which is designed to change local situations (Reason & Bradbury, 2013). Whilst the co-researchers in this study are not oppressed, neither are they in positions of power within the organisation. However, the issue of where the power lies within this research is complex as it could be argued that as clinicians they have the power of knowledge in both their clinical expertise and patient experience. This will be explored later.

The study is therefore located within the participatory paradigm and recognises that this requires a flexible approach to the research. The means of gathering and analysing data could only be determined once the CIG had agreed what needed to be done and how, therefore enabling them to adopt the most appropriate method, technique and procedures to deliver the outcomes they were seeking.

Table 1: Essential elements of a research paradigm and the participatory position

Research paradigm element	**Participatory position – Transformation based on democratic participation between researcher and subject**
Ontology: • The worldviews and assumptions in which researchers operate in their search for new knowledge (Schwandt 2007, p.190) • The study of things that exist and the study of what exists (Latsis, Lawson and Martins, 2007) • What is the nature of reality? (Creswell, 2007).	• Participative reality: subjective-objective reality, co-created by mind and the surrounding cosmos (Guba and Lincoln, 2005, p.195) • Freedom from objectivity with a new understanding of relation between self and other (Heshusius, 1994, p.15) • Socially constructed: similar to constructive, but do not assume that rationality is a means to better knowledge (Kilgore, 2000, p.54) • Subjective – objective reality: Knowers can only be knowers when known by other knowers. Worldview based on participation and participative realities (Heron and Reason, 1997).
Epistemology: • The process of thinking. The relationship between what we know and what we see. The truths we seek and believe as researchers (Bernal, 2002; Guba and Lincoln, 2005; Lynham, Webb-Johnson, 2008; Pallas, 2001)	• Holistic: "Replaces traditional relation between 'truth' and interpretation' in which the idea of truth antedates the idea of interpretation" (Heshusius, 1994, p.15) • Critical subjectivity in participatory transaction with the cosmos; extended epistemology of experiential, propositional, and practical knowing; co-created findings (Guba and Lincoln, 2005, p.195)

• What is the relationship between the researcher and that being researched? (Creswell, 2007).	• Critical subjectivity: understanding how we know what we know and the knowledge's consummating relations. Four ways of knowing: (1) experiential, (2) presentational, (3) propositional, (4) practical (Heron and Reason, 1997).
Methodology: • The process of how we seek out new knowledge. The principles of our inquiry and how inquiry should proceed (Schwandt, 2007 p.190) • What is the process of research? (Creswell, 2007).	• Political participation in collaborative action inquiry, primacy of the practical; use of language grounded in shared experiential context (Guba and Lincoln, 2005, p.195) • Use deconstruction as a tool for questioning prevailing representation of learners and learning in the adult education literature; this discredits the false binaries that structure a communication and challenges the assertions of what is to be included or excluded as normal, right or good (Kilgore, 2001, p.56) • Experiential knowing is through face-to-face learning, learning new knowledge through the application of the knowledge • Democratisation and co-creation of both content and method • Engage together in democratic dialogue as co-researchers and as co-subjects (Heron and Reason, 1997).

Source: Adapted from Lincoln et al. (2011, p. 102-111)

3.2.1 Ontology and epistemology

The ontological and epistemological elements of the participatory position are outlined in Table 1. Ontology and epistemology invite reflection upon how the social world should be studied and the nature of social entities (Bryman, 2012). Ontological perspectives consider whether or not reality exists entirely separately from human practices and understandings, on a spectrum from realism, where reality is entirely independent of human ways of knowing, to relativism, where reality is dependent on human knowledge and interpretation (Braun & Clarke, 2013). Epistemology considers how knowledge can be known ranging from positivism, a straightforward perception of the world and a human's perception of it, to constructionism or interpretivism where knowledge is socially constructed (Ritchie & Lewis, 2003).

The participatory position assumes that although individuals are autonomous (subjective) they are involved in a participatory relationship with the given reality (objective). This means that a participatory approach has a subjective-objective ontology (Lincoln et al., 2011); (Reason, 2004). In the context of this study, the Hospice in-patient unit is a known entity (objective) but how it functions depends on the interactions and knowledge of those who work within it and so this is subjective. This paradigm also assumes that knowledge is created through active participation (subjective epistemology) and has an extended epistemology of experiential, propositional, practical and knowing. These are described as:

- **Experiential knowing** which comes through direct face-to-face encounters; it is knowing through new insights as a result of engaging with a project

- **Presentational knowing** which comes from experiential knowing, and provides expression through forms of imagery such as poetry and story, drawing, sculpture, movement and dance
- **Propositional knowing** "about" something, is intellectual knowing of ideas and theories and is expressed in spoken or written form
- **Practical knowing** is knowing "how to" do something, as applied to everyday life and work, and is expressed in a skill, knack or competence and supported by a community of practice (Heron & Reason, 2008).

3.3 Methodology

A participatory action research (PAR) study was undertaken based on the participatory paradigm with its subjective-objective ontology and subjective epistemology as outlined above and a flexible approach to data gathering and analysis. Lewin (1946) is credited with being the founder of action research and adopting the term (Carr & Kemmis, 1986; Greenwood & Levin, 2006; McNiff, 2013). Lewin (1946) claimed that change undertaken in a democratic way, involving the voluntary participation of the individuals concerned, was more effective than change imposed autocratically by those in positions of power. Action research has been adopted by several researchers within palliative care (Hockley, 2006) and is “a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed an improvement and involvement. It is problem-focused, context specific and future-oriented” (Waterman, Tillen, Dickson, & de Koning, 2001, p.iii).

PAR is a specific form of action research and has common characteristics with it such as using cycles of action and reflection, and being open-ended and developmental

(McNiff & Whitehead, 2002). Some argue that it is the degree and level of participation that distinguishes PAR from action research or the expertise of the researcher (Hockley, Froggatt, & Heimerl, 2013), whereas others suggest the difference lies in what they aim to achieve. They both strive to problem-solve, are democratic and equitable; provide a voice to participants; and are egalitarian and transformative (Carr & Kemmis, 1986; Coghlan & Brannick, 2005; Meyer, 2006; Williamson, Bellman, & Webster, 2012) but in addition PAR attempts to help people to explore their reality in order to change it (Heron & Reason, 2006; Kemmis & Wilkinson, 1998). PAR is more of an interventionist approach than action research with the intention of empowering people by helping them construct and use new knowledge (Reason, 2006). When research participants do more than simply collaborate and become key stakeholders involved in decision-making at every stage, communities of inquiry will emerge and in this respect the research moves into becoming a co-operative inquiry (CI). The key characteristics of PAR are that it is empowering, democratic and participatory (Carr & Kemmis, 1986; Coghlan & Brannick, 2005; Ingleton & Davies, 2007; Lewin, 1951; Meyer, 2006; Reason, 2006; Williamson et al., 2012).

3.3.1 Co-operative inquiry

Whereas in positivist forms of research the roles of researcher and subject are mutually exclusive, i.e. the researcher contributes the thinking and the subject acts, in co-operative inquiry (CI) the participants think and act collaboratively (Reason, 1991). In this empowering approach, the lines between researcher and participant dissolve to the extent that they become co-researchers and co-change agents who are united in achieving a common goal (Hart, 1995; Heron & Reason, 2006; McNiff & Whitehead, 2006). Essential aspects of CI are that individuals become involved in the decision-making process of the research and the subsequent implementation of any changes (Williamson et al., 2012). The process is evolutionary and iterative rather than being prescribed by the researcher from the outset (Morrison & Lilford, 2001). This collaboration reflects a democratic approach by breaking down some of the boundaries between professional and lay knowledge (Ingleton & Davies, 2007). Doing research in this active and collaborative manner means that knowledge is generated by individuals through social processes and does not exist independently (McNiff & Whitehead, 2002) thus supporting the participatory subjectivist epistemology.

Heron and Reason (2001) suggest that the defining features of CI are:

a. All participants are as involved as possible as co-researchers in all research decisions;
b. The interplay between action and reflection is explicit and intentional;
c. Attention is paid to the validity of the inquiry and its findings;
d. The inquiry method is wide-ranging and can be informative and transformative. It is open-minded;
e. There is a range of skills suited to all-purpose experiential inquiry;
f. The full range of human sensibilities is available as an instrument of inquiry.

In CI the different ways of knowing (Heron & Reason, 2008) (see 3.2.1) become intentional and will be more valid if the four ways are congruent with each other: if knowing is grounded in experience, expressed through images and stories, understood through theories, and expressed in worthwhile action (Heron & Reason, 2008). In the context of this research, the involvement of others who are also HCPs enriches the research by providing different ways of knowing. In their role as co-researchers, HCPs identify issues and suggest solutions relating to the research based on their experience – experiential knowledge. The new insights gained are then understood at a theoretical level – propositional knowing; then, as the inquiry progresses they apply their learning to the day to day tasks they are undertaking – practical knowledge.

In considering how a co-operative inquiry is established and functions, it is helpful to consider Habermas' (1996) description of a 'communicative space'. He suggested that this space created *solidarity* between the participants who share their understandings with each other and that this understanding and the decisions reached, by *consensus*, gave those decisions *legitimacy* (Kemmis & McTaggart, 2005). A communicative space needs to be established that articulates an issue of concern, allows participants to *voice divergent views* in a *democratic context*, permits the *mutual understanding* and the evolution of new practices which arise and are tested through *authentic engagement* (Carr & Kemmis, 1986). The process of PAR is one of collaborative inquiry aimed at reaching a mutual understanding and consensus that is not enforced by those in positions of power and therefore opens up a communicative space (Kemmis & McTaggart, 2005). Some argue that a communicative space is central to this form of inquiry and influential in the degree of success (Wicks & Reason, 2009).

CI is an evolving and iterative process (Coghlan & Brannick, 2005) taking place over a period of time and employing a range of both qualitative and quantitative data collection approaches. It has four phases:

a. coming together to examine an area of mutual interest;
b. initiating the activities that have been agreed;
c. becoming fully immersed in these activities and the experiences they bring;

d. coming together to share knowledge and experience (Heron & Reason, 2001).

Its underpinning principle is that good research is *with* people rather than *on* people (Heron & Reason, 2001) and there is an alignment here with the approaches of health promoting palliative care and rehabilitative palliative care.

3.4 Research design

The aim of this research is to undertake participatory action research (PAR), via a co-operative inquiry, to integrate a rehabilitative approach palliative care in a hospice in-patient setting and in doing so assess whether it offers an opportunity to integrate a health promoting approach. PAR does not lend itself to established report-writing conventions (Smith et al., 2010) but wherever possible those conventions will be used. In addition, there are four characteristics present in the most effective writing about PAR: a clear structure; inclusion of key elements of project design: how it was initiated, who was involved, what the process was; conveying the co-researchers' experience and voices through the use of quotations and addressing the challenges and pitfalls of the project (Smith et al., 2010). To enable these characteristics to be reflected in this thesis, Table 2 outlines the three inquiries that were undertaken and by whom. In writing this thesis both the first and third person is used depending on whether it is reporting the work of the CIG, the activities I undertook independently or discussing the literature.

Table 2: Inquiries within the study

Inquiry: Chapter	**Detail**	**Participants**
Inquiry One: Chapter Four	The focus of Inquiry One was to answer the research question: "*How can a rehabilitative approach be integrated into the provision of palliative care within a hospice in-patient setting?*" This involved three stages which will be reported as Inquiry One: to establish a co-operative inquiry group, who would work together to collectively develop their knowledge about rehabilitative palliative care, and then identify, plan and implement ways to integrate rehabilitative palliative care into this setting.	Co-operative inquiry group
Inquiry Two: Chapter Five	Inquiry Two addresses the research question, "*What are the facilitators and barriers to integrating a rehabilitative approach with palliative care according to health care professionals?"* The emphasis is on data collection and analysis and so full details of the retrospective thematic analysis is included.	Researcher and reviewed with co-researchers
Inquiry Three: Chapter Six	Inquiry Three is a literature review to respond to the question, *"What are the facilitators and barriers to integrating a rehabilitative approach with palliative care according to healthcare professionals?*".	Researcher

The following sections describe the methods used specifically in relation to Inquiries One and Two.

3.5 Methods

3.5.1 Setting

The research was based in a 15-bedded hospice in-patient unit in the south of England which in 2013 moved to a new building. Having been located in a quiet residential area for 28 years, the new building was situated on one of the town's main 'A' roads, positioned between a further education college and a retail park. This change of location heralded the start of a new relationship between the Hospice and its local community leading to an overt public engagement strategy. The aim was to challenge some of the taboos and fear of hospices and to raise awareness that hospices were places where people lived well and engaged in normal day to day activities. What was striking about the new building was the lack of a reception desk in a tall, light-filled area known as 'The Street' in which visitors were welcomed by one of 126 volunteer hosts. The Street had a café at its heart, with live music, commissioned artwork and opportunities to interact with an artist in residence. In September 2014 the Hospice delivered a masterclass "Embedding Vision and Changing Culture" as part of Help the Hospices (now known as Hospice UK) series of Masterclasses to showcase practice and offer contemporary and innovative perspectives on the challenges which many hospices were facing.

At a national level and following the work of the Commission into the Future of Hospice Care (2013), hospices were being challenged to consider their future and plan strategically to meet the changing needs of the people they supported (Calanzani et al., 2013), as discussed in 2.3.1. Many hospices identified that the predominant case mix for day services was elderly patients, those in their last year of life and primarily with a cancer diagnosis. In ensuring the day services were accessible to younger people with diagnoses other than cancer, hospices looked to redesign their services by combining a therapeutic and social model. In this Hospice's new 'Wellbeing' centre, social, therapeutic and interventionist approaches to patient care were provided. In-patients were encouraged to also use its facilities and therapists were expected to become more involved in supporting in-patients.

For many employees and volunteers the relocation and changes to their everyday work were significant. In contrast, for the in-patient unit team, the move was less of a transformational change. The cohort of patients they supported did not change significantly but the facilities provided were improved and expanded. The overt community engagement agenda and the proactive introduction of therapies on the in-patient unit felt destabilising and challenging to a team who had been used to delivering care in a quiet location isolated from the hustle and bustle of daily life and who had traditionally seen their role as taking care of patients. Some team members used an expression 'tucking-up' which was described as keeping patients tucked-up in bed because they were believed to be too poorly to do anything else. An awareness of these issues led to this research.

3.5.2 Population and sample

The study population was all Hospice-based staff and volunteers. However, nurses and therapists who worked in, or supported, the in-patient unit were recruited purposively as this allowed certain groups of people who had direct relevance to the research question to be sampled (Bryman, 2012) and ensured a broad range of perspectives relating to in-patient care was captured. Volunteers, who supported in-patients, were also recruited purposively, as they could bring the perspective of someone who was indirectly involved in-patient care and may also have had personal experience of caring for someone at the end of life.

The sample size was influenced by the work of Heron and Reason (2001) who suggested that groups of up to 12 people worked well and that a group of fewer than six was too small and would lack the variety of experience. A smaller group may have been easier to manage and enabled more engagement from participants but ran the risk of becoming non-viable if people failed to attend or dropped out. A larger group would have been more challenging to control, and some participants may have felt overwhelmed and reluctant to engage. Taking all of this into consideration, the minimum number of participants was set as six and the maximum was 15 with the ideal being eight as this would allow two people each from nursing, therapies and volunteering plus two others. The upper limit was set at 15 to ensure that all those who wanted to participate were able to do so.

3.5.3 Recruitment and consent

Personal invitations (Appendix 1) were sent to nurses (n=36), therapists (n=5) and volunteers (n=108) inviting them to attend an Information Session to:

a. gain an understanding of what the research was about and why representation from certain occupational groups was important;
b. explain what PAR and being part of a CI involved;
c. be reassured that the decision about whether to participate was entirely voluntary and would have no bearing on their employment, or volunteering, with the Hospice;

d. access a participant information sheet (Appendix 2).

Aside from the practicalities, the Information Sessions were also designed to capture people’s curiosity and interest and highlight the importance of this research (Reason, 2002). This was done via an interactive session with the aid of a PowerPoint presentation. After attending the Information Session, reading the participant information sheet and asking any questions, attendees were invited to join the CIG. A decision on this could either be made at the Information Session or within the following week. All those who expressed an interest in joining were given a consent form (Appendix 3). There was a further opportunity to ask questions before confirming their decision to be involved and signing the consent form based upon the information that was known at the time.

Once they had given consent to participate, to retain the anonymity of the participants they were given an identification which comprised of the initial of their first name and a number according to when they signed the consent form. These were used throughout the study.

3.5.4 Patient Advisory Group

The focus of the research was how to implement a new model of care and it did not directly involve patients. To ensure the patient perspective was integrated into the study an advisory group of patients, drawn from the Hospice’s patients’ forum, was established to support the research in an advisory capacity. This meant that patient members were informed of the research and how it would be undertaken, asked for a steer on how to proceed and then given progress reports. Patients were invited via letter to attend a meeting to learn more about what was involved. Five people attended that meeting, and all subsequently agreed to form the Patient Advisory Group (PAG). A further patient heard about the group from a CIG member and also joined. The first meeting took place on 7 August 2015 and the PAG met bi-monthly thereafter for one hour for a total of four meetings.

3.6 Data collection and analysis

Due to the complexity of this study and the different ways data was collected and analysed, this section only introduces the principles underpinning data collection and analysis within action research and this study. Inquiry Two, Chapter Five focuses on data collection and analysis in detail when it considers the facilitators and barriers to adopting a rehabilitative approach in this Hospice. In addition, each specific Inquiry will have its own data collection and analysis sections.

In action research, data is generated through participation, observation, problem-solving, decision-making and through the interventions undertaken as part of the project (Coghlan & Brannick, 2005). Data collection is iterative and, particularly with participatory action research, is not pre-determined as it involves all the participants in data generation (McIntosh, 2010). With insider research the data also comes from the researcher being actively involved in the organisational processes that relate to the project (Coghlan & Brannick, 2005). In recognition that action research is cyclical, the process of gathering, analysing and reflecting on the data collected was ongoing rather than being a one-off activity at the end. Data was shared by all participants and used to refine action and influence smaller changes as the project progressed (Hockley & Froggatt, 2006; Koshy et al., 2011). These characteristics are unique to action research

(Koshy et al., 2011) and lead to a rich variety of both qualitative and quantitative data, collected by all participants which provided a deeper understanding and rigour to the research (M. Kelley & McKee, 2012; Koshy et al., 2011).

Data was collected at different times and for different purposes, and Figure 4 represents the three ways that that data was collected and analysed. An overview of the data collected throughout the study can be found at Appendix 4. Collecting and analysing information took place within the CIG meetings to inform and plan the actions that would take place, and outside the meetings. This constituted concurrent data analysis identified as being essential to keep the process going (Hockley, 2006; Titchen, 2000); it is an analytical practice that enables the participants to review actions to inform new activity.

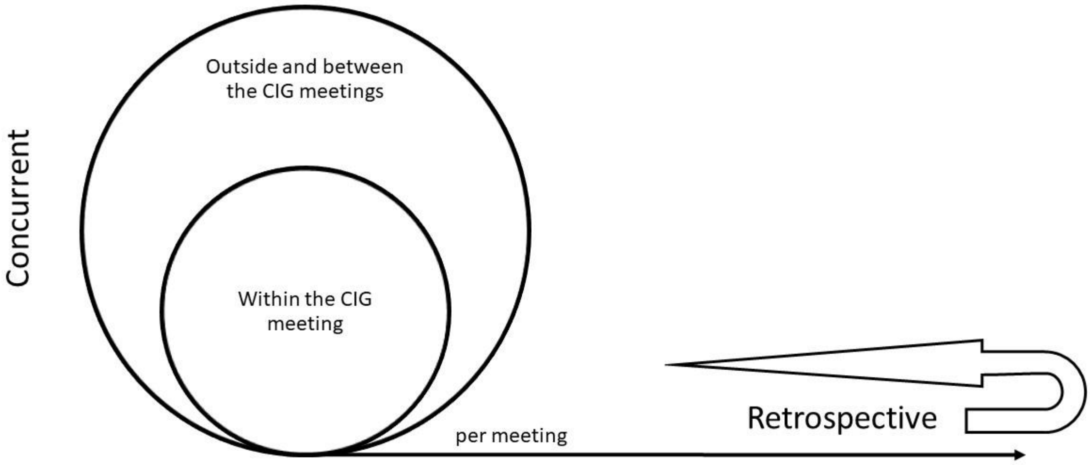


Figure 4: Process of data collection and analysis

The final data collection and analysis took place retrospectively by the CIG collectively and then by me independently. Titchen (2000) and Hockley (2006) describe a similar process of concurrent and retrospective analysis in their action research studies. The quantitative data was analysed using descriptive statistics and the qualitative data was analysed thematically as part of the retrospective analysis.

As part of the retrospective analysis, and aligned with the participatory nature of this research, the CIG was invited to review the notes of all the CIG meetings and their own journals (if they had kept them) and to share their perceptions of what had taken place. This ensured that there was shared ownership of the data interpretation and has been referred to as 'collaborative theorising' (Lather, 1992, p.57). This not only enhances the rigour of the research (Coghlan & Brannick, 2005), involving the CIG in the analytical process also meant it improved its authenticity (Koshy et al., 2011). Table 3 illustrates what data was collected and analysed for which aspect of the study and where this is reported in this thesis.

Table 3: Focus of the study and data collected

Area of focus	**Data collected**
Inquiry One: Establishing and working as a co-operative inquiry	• Concurrent data from the CIG meetings • Feedback from questionnaire gathering demographic data from CIG • Feedback from the power survey completed by the CIG
Inquiry One: Developing knowledge	• Feedback from evaluation form completed by CIG members • Notes from the 11 CIG meetings

Inquiry One: Planning how to integrate a rehabilitative focus	• Feedback from evaluation form completed by CIG members • Analysis of the "How rehabilitative is your hospice?" checklist completed pre-and post-intervention and reviewed by CIG (Tiberini & Richardson, 2015) • Analysis of the goal setting and action planning documents (Tiberini & Richardson, 2015) • Feedback from the RPC workshops • Notes from the 11 CIG meetings
Inquiry Two: Identification of the facilitators and barriers	• Thematic analysis of the CIG notes from 11 meetings • Feedback from evaluation form completed by CIG members • Experiential thematic analysis to gain the participants' perspectives
Inquiry Two: Steps taken to address any barriers	• Thematic analysis of the CIG notes • Feedback from evaluation form completed by CIG members

Full details of the approach to data analysis will be reported in Inquiry Two, Chapter Five which considers the facilitator and barriers to implementing a rehabilitative approach in a hospice in-patient setting.

3.7 Ethical considerations

Ethical approval was granted by the Faculty of Health and Medicine Research Committee at Lancaster University on 21 April 2015 (Appendix 5).

Ethical research ensures that the researcher does no harm, does not breach confidentiality, does not distort the data, ensures the participants are fully informed of what the research entails and participate voluntarily (Coghlan & Brannick, 2005).

However, undertaking participatory action research, with its close relationship between the researcher and participants or co-researchers, presents some unique ethical challenges and conducting research within one's own organisation can compound these issues. The following three considerations were adopted to guide this research and ensure that it remained ethical:

- ensuring that confidentiality and anonymity was preserved given the close relationship between all participants in the research
- ensuring informed consent was obtained despite the research process being iterative, and participants not knowing in advance what may be required of them
- avoiding harm to participants given that the outcome of the research was not known, and they would continue to work in the organisation once the research was concluded (Williamson & Prosser, 2002).

When considering the ethical issues surrounding this research, it should be recognised that I, my role and how I conducted myself were key factors. Therefore, I have chosen to write the following section in the first person, rather than describe myself in the third person. The key ethical issues are described according to the research phase they arose within: participant recruitment, establishing the co-operative inquiry group and undertaking the fieldwork.

3.7.1 Participant recruitment

Due to the small number of therapists employed by the organisation, some may have felt under pressure to participate in the research to avoid the risk that therapists would not be represented. However, the subject matter was rehabilitation, a subject familiar to the therapists and therefore likely to be of interest to them. I trusted and anticipated that the therapists would want to be involved and that this would overcome any sense of obligatory participation.

Participants may have also felt that because I was a senior manager a failure to participate would reflect badly on them or be detrimental to their ongoing employment. Within the organisation there was already an established culture of working across hierarchical boundaries e.g. front-line clinicians working with directors in developing clinical strategy which was commented on during a Care Quality Commission (CQC) inspection: “there was positive culture at the Hospice where people felt included and consulted” and “the managers at the Hospice were seen as part of the team” (Care Quality Commission, 2015, p.14). Staff had also reported that they felt there was an open culture which encouraged discussion and challenge. I hoped that this culture would assuage any perception that a failure to participate would reflect poorly on the individual. However, to prevent the above issues arising, the recruitment material was carefully worded to avoid anyone feeling under pressure to participate, to emphasise that a decision to participate was entirely voluntary and that a decision not to participate would not be detrimental to them. The consent form also included a statement asking participants to confirm that their decision to participate was not influenced by fear of the implications of a decision not to participate.

3.7.2 Establishing the co-operative inquiry group

Once established, there was the potential for there to be conflict between opposing views held by members of the CIG particularly as they came from different healthcare disciplines. From an ethical perspective, conflict had the potential to cause harm to participants personally or by damaging their working relationships. My role was to ensure that everyone was valued for the experience, concerns and perspective that they brought (Brydon-Miller, 2008) and I had responsibility for ensuring a healthy and respectful group dynamic. This was achieved by:

- establishing ground rules with the group from the outset
- challenging any inappropriate behaviour during the meeting and encouraging group members to do the same
- encouraging group members to reflect on their own behaviour and the impact of other people's behaviour on them at meetings
- following up any disagreements outside the meeting to try to resolve them
- adjourning or concluding the meeting if significant conflict arose.

As the participants were co-researchers and therefore responsible for constructing the study, they could only give consent for what was known and/or anticipated before the study. Identifying other future, potential risks that they could be exposed to was difficult (Froggatt, Heimerl, & Hockley, 2013). To ensure the participants were as well-informed as possible with regards consent, I explained this at the Information Session, in the participant information sheet and on the consent form. Initial written informed consent was given by all participants from the outset; however, the CIG participants could change, and the research could impact on individuals not initially identified (Costello, 2003) which meant that constant vigilance in relation to consent was required. Discussing it at every CIG meeting ensured that any potential issues in relation to consent were identified. As activities and interventions were planned, we undertook an assessment to identify what, if any, further written consent was required and, if necessary, the steps for achieving this recorded. This ensured that participants could renegotiate their consent if an unexpected event occurred, and I was then reassured that the individual was fully aware of what they were agreeing to. We also acknowledged that with PAR we all had equal responsibility for the findings and consequently the individual, political and organisational consequences of the project (Williamson & Prosser, 2002).

3.7.3 Undertaking fieldwork

The collaborative nature of action research and the prolonged period of time spent working together required a relationship between the co-researchers built on trust, mutual respect, long-term commitment and a willingness to work together (Brydon-Miller, 2008). Because these relationships develop, the validity of the research can be enhanced because respondent bias is reduced (Costello, 2003) as the participants are more likely to provide truthful information rather than feel they should respond in a particular way (Robson, 2002). However, a counter-argument suggests that because of these long-standing and trusting relationships, a sense of informality can emerge (Hockley & Froggatt, 2006) which could expose me to claims of bias. To avoid this, I ensured ongoing reflection and engagement using a journal and with support from academic supervisors. This also added to the rigour of the research.

I also had a responsibility, along with my co-researchers, of protecting the anonymity of the participants who were doing in-organisation research. It was likely that their colleagues would know they had become involved in the study and their individual identities could not be completely disguised (Williamson & Prosser, 2002). To address this, CIG members were anonymised in written material, and the CIG agreed how they would report progress to the wider organisation. Outside of the CIG, I was unable to guarantee that participants of the CIG would preserve confidentiality (Hockley &

Froggatt, 2006). To mitigate any potential breach, participants were asked on the consent form to agree to preserving the confidentiality of the discussions at the CIG, the ground rules for the research were discussed at the outset, confidentiality was a regular agenda item at the meetings and I encouraged members of the CIG to discuss issues amongst themselves as well as with me if they had any concerns regarding confidentiality.

3.8 Insider research

In addition to recognising and managing the ethical issues surrounding this research, I also had to acknowledge the fact that I was a senior manager conducting research in my own organisation. An ‘insider researcher’ is an established member of an organisation who is undertaking research in that organisation as opposed to someone who temporarily joins the organisation for the purposes of the research and only remains for the duration of it (Brannick & Coghlan, 2007). Whilst insider research can present many challenges such as the potential for role conflict and informal relationships developing, it has the benefit that the researcher is grounded in the organisation’s structure and politics which means that the research is undertaken in ways that conform to the political conditions within the organisation. Rather than compromise the project, these factors are more likely to enhance it (Coghlan & Shani, 2008). There is an argument that insider research will ensure the issues identified in 3.7 are resolved more satisfactorily than if the research was being undertaken by an external person. This is because an insider researcher has a vested interest in the outcome of the research and will be impacted by the same issues that may arise as the other participants. Outsider researchers do not have the same compulsion which could mean the participants are more vulnerable (Meyer, 1993). Some of the issues being an insider researcher presented for me, and the degree to which my experience supports the above assertions, will be discussed in 4.2.4 and 5.4.

The advantages to me being an insider researcher and a senior manager were that I had the authority to change practice (Williamson & Prosser, 2002), and it was also more likely that the findings would be extended to other settings within the Hospice, the study would be properly resourced, and the change would occur (Hart, 1995). However, because of my seniority there was a power imbalance between me and the co-researchers and because I had initiated the research, I could be perceived as the research 'expert' (Andrews, McInerney, & Robinson, 2013) which could disempower participants. Some of these issues were mitigated by the fact that I was a non-clinician whereas many of the participants had the clinical expertise or knowledge of working with patients needed for the research. In addition, I did not undertake a formal literature review of rehabilitation in palliative care prior to starting the research as I wanted to learn from and with the CIG to understand collectively this concept. This meant that knowledge in relation to the subject matter was generated collaboratively rather than being provided by me which helped to overcome any potential power imbalance, furthered the democratic process and enhanced participation, all critical features of action research (Meyer, 2000). Furthermore, I had never undertaken action research before and I emphasised that, whilst I may have a basic theoretical understanding of it, the practice was new to me and we would be learning together.

When a researcher has a dual role, consideration also needs to be given to dealing with information that arises through the research that, as a manager, I should act upon (Coghlan & Shani, 2008). I decided that unless full consent to make a disclosure had been given by all parties, such information would remain confidential. I felt conflicted by this and so to avoid making either role untenable, I made my duals roles, as a manager and as a researcher, clear via dialogue and continuous renegotiation with the CIG, superiors and colleagues (Coghlan & Shani, 2008).

Being cognisant of and attentive to the ethical issues surrounding the research and the impact I, as an insider researcher, had on the study are some of the ways of ensuring quality in the research as they enhance its authenticity (Coghlan & Brannick, 2007). Further ways of demonstrating quality in an action research study will now be discussed.

3.9 Quality assurance

Within the positivist paradigm, quality is usually addressed through assessing the validity and reliability of the research (Badger, 2000) but the relevance of these concepts to action research is questionable when there is greater attention paid to the underpinning values of the research, the role of the researcher and rigour in the research process (Froggatt, 2013). Furthermore, it is argued that action research should be judged within the criteria of its own terms (Coghlan & Brannick, 2007) and that what constitutes rigour in action research is different to rigour in traditional scientific research (Zuber-Skerritt & Fletcher, 2007). Within the participatory paradigm the appropriateness of reliability and validity is further questioned on the basis that due to its participatory nature, truth is subjective and multifactorial rather than being singular and objective (McNiff & Whitehead, 2002) and the researcher is not detached but rather is an essential and integral component of the research (Coghlan & Brannick, 2007). The framework that will be used to judge the quality of this action research study is as follows:

a. Extent to which worthwhile practical purposes are addressed;
b. Levels of democracy and participation;
c. Different forms of knowledge engaged with during the study based on fourfold epistemology: experiential, presentational, propositional and practical knowledge (Heron & Reason, 2001);
d. Extent to which the research has been and continues to be responsive and developmental (Reason, 2006).

In addition to these, attention was also paid to other measures that can be used to demonstrate quality and rigour: reflexivity, authenticity and reliability. These are described here and are reflected throughout the study.

3.9.1 Reflexivity

My dual role as an insider researcher and a senior manager could affect the validity of the data presented (Koshy et al., 2011). Remaining cognisant of this, and demonstrating that self-awareness, demanded reflexivity which is a concept used to explore the relationship between the researcher and the object of the research (Coghlan & Brannick, 2007). Reflection should be done systemically to ensure the continual awareness of the impact of “one’s own theoretical and methodological presuppositions” (Coghlan & Brannick, 2005, p.6). Systemic reflexivity can be further categorised into: epistemic – focused on the researcher’s belief system; and methodological – assessing one’s own impact on the research setting as a result of carrying out the research (Johnson & Duberley, 2000). In this research both epistemic and methodological reflexivity took place mainly through my journal, kept as part of the data collection, which not only supported me to be reflexive but also enhanced the trustworthiness of the study (Hockley & Froggatt, 2006). Trustworthiness can also be judged by how acceptable the claims to knowledge are to those who were co-researchers in the study (Koshy et al., 2011) and engaging other's perspectives to triangulate the data has been discussed in the literature as a means of establishing rigour (Coghlan & Brannick, 2007; Cotterell, 2008) and to offer a degree of authenticity (Koshy et al., 2011).

3.9.2 Authenticity

Authenticity means that the results are "valid and reliable if they are recognisable and authentic to the people involved in the research" (Zuber-Skerritt & Fletcher, 2007, p.423). Criteria for assessing authenticity include: the extent of involvement of participants, the degree to which their views have changed, their understanding of other people's views and whether participants have been encouraged and empowered to change (Guba & Lincoln, 1994). Transparency in describing the setting and the reported experience of those collaborating in the research and therefore the degree to which the reader can engage with the study is another means of establishing authenticity (Cotterell, 2008; Titchen, 1995). This aligns with a view that the quality of participatory action research can be assessed by the extent to which the principles underpinning the research have been adhered to (Froggatt, 2013; Reason, 2006).

3.9.3 Reliability

Within positivist studies a measure of quality is reliability, but this can be problematic in action research studies because the studies are specific to a certain context and cannot be replicated (Hockley, 2006). However, there may be aspects of an action research study that can be replicated, and it is that aspect of reliability that action researchers should be cognisant of and able to demonstrate that the study is generalisable and applicable in other similar situations in accordance with the ethics of the original research (Robson, 2002). There are certain aspects of this study that could be replicated e.g. workshop session plans referred to in Chapter Four and the mechanisms used for gathering feedback referenced in Chapters Four and Five.

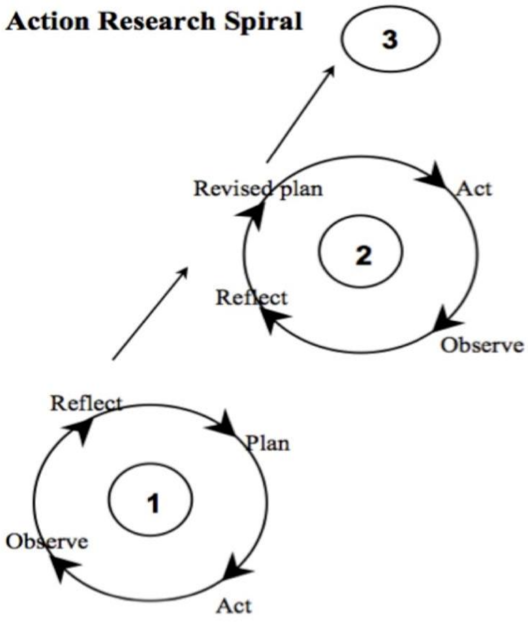
3.10 Conclusion

This chapter has outlined where the research is located paradigmatically, the factors that influenced the epistemological and ontological position for the research and how this informed the approach to the research. It explained that a participatory action research methodology was used via co-operative inquiry and then described the setting, population, and recruitment strategy before broadly setting out the approach to data collection and analysis. Ethical considerations and the factors relating to insider research were then outlined, before the ways of assuring a quality study were set out.

Chapter Four: Inquiry One: Participatory Action Research

4.1 Introduction

This chapter will focus on Inquiry One: establish and work as a co-operative inquiry group, collectively develop knowledge regarding rehabilitative palliative care and organisational change, and then identify, plan and implement ways to integrate this into a hospice setting. The chapter is written in the first person as the activities involved me and the CIG. It is divided into three sub sections so that each of the above activities can be described separately using the data collected and analysed, the findings, and the conclusions. Each activity was an action research cycle, but even within those activities there were other cycles of plan, act, observe and reflect taking place, see Figure 5.



(Zuber-Skerritt, 2001, p.20)

Figure 5: Spirals of action research

4.2 Establishing and working as a co-operative inquiry group

It was important that time was spent establishing the co-operative inquiry group and ensuring that we were clear about our purpose. The previous chapter explained the approach that was used to establish the co-operative inquiry group whereas this section describes how it evolved from inception to undertaking cycles of action research.

4.2.1 Introduction

The CIG met 11 times between 25 June 2015 and 7 June 2016. Although it met on an ad hoc basis after that, this was the period when it was formally involved in action research. The details of the meetings can be found at Appendix 6. As I was a full participant in the CIG group I use the terms ‘we’, ‘our’ and ‘us’ when referring to the CIG.

At the first meeting, the stages of co-operative inquiry the CIG agreed were based upon Heron and Reason’s (2001) framework (3.3.1):

a. collectively develop our knowledge about what a rehabilitative approach meant and about organisational change;
b. actively participate in planning how to integrate a rehabilitative focus into hospice palliative care, paying particular attention to the facilitators and barriers to this approach;
c. lead on the actions that would be agreed as part of the plan including through our everyday work where we would initiate action, then observe and record the outcomes of our own and others’ behaviour;

d. meet regularly to review progress, adapt or amend plans where appropriate and to agree how the study should be evaluated.

In addition, the CIG agreed the format, frequency, dates and ground rules for future meetings. We also agreed that each meeting would be chaired by a different member of the group thus aligning with the participatory approach adopted and therefore democratising the research process, enabling personal growth and development and enhancing ownership of the research (Williamson et al., 2012). To conclude the first meeting, the CIG planned the agenda for the next meeting and who would chair it. After the first meeting, we began to work in accordance with the cycles of action research: plan, act, observe and reflect (see Figure 5).

Within CI there is an interplay between reflection and action (Heron, 1996). To do too much of the former is considered theorising and of the latter is activism, so a balance needs to be struck between the two (Heron & Reason, 2006). In September 2015, there was a concern raised that the CIG was moving into the action phase without considering organisational change theory. This was addressed and, as it relates to the CIG developing their knowledge, is reported in section 4.3.

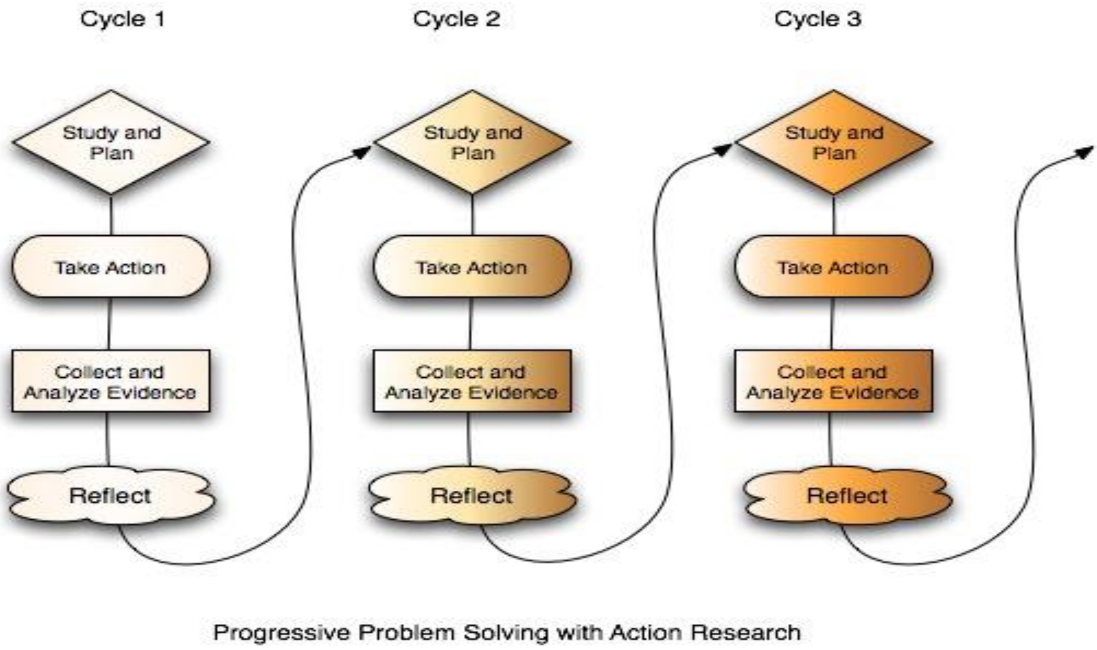
4.2.2 Data collection and analysis

Demographic data about the individuals who consented to join the CIG was collected via a form which was circulated to the group at the first meeting. Once completed the form was returned to me and I collated the results. During this action research phase, both concurrent and retrospective data was collected and analysed.

4.2.2.1 Concurrent data collection and analysis

I kept a journal which provided me with a prompt to be reflective (C. Taylor & White, 2000). It was used to log thoughts or emotions during an interaction, or following a meeting or an incident, as well as a tool to help me to work through certain aspects of the research and its progress. Keeping a journal was not a natural technique for me and, on reflection, the entries were not as regular or fulsome as I would have liked, but it did describe some of the apprehension I felt at certain times in the research and some of the challenges of action research. The CIG was invited to keep a reflective journal, but this did not form part of the data collection. It was intended to be a tool for them to capture their thoughts and reflections using the same method that I had. Evidence from the meeting notes revealed that the group was reflective which could be due to their work in palliative care where ongoing, regular reflection is encouraged.

In the meetings, the CIG reviewed what had taken place since the last meeting, planned what action to take and how this would be assessed. The first three meetings broadly focused on planning the research, meetings four to seven were during an active phase of the project, and meetings eight to 11 predominantly focused on reviewing the research. However, even within these distinct phases there were smaller action research cycles of planning, acting and reflecting taking place. These activities also reflect the phases of CI (Heron & Reason, 2001) described in 3.3.1. Whilst Figure 5 shows the action research cycles as spirals, Figure 6 shows them taking place in a more linear fashion (Riel, 2010). This version has been adapted for Figure 7 which shows how the CIG collected data, analysed it and then used it to plan the actions it would take.



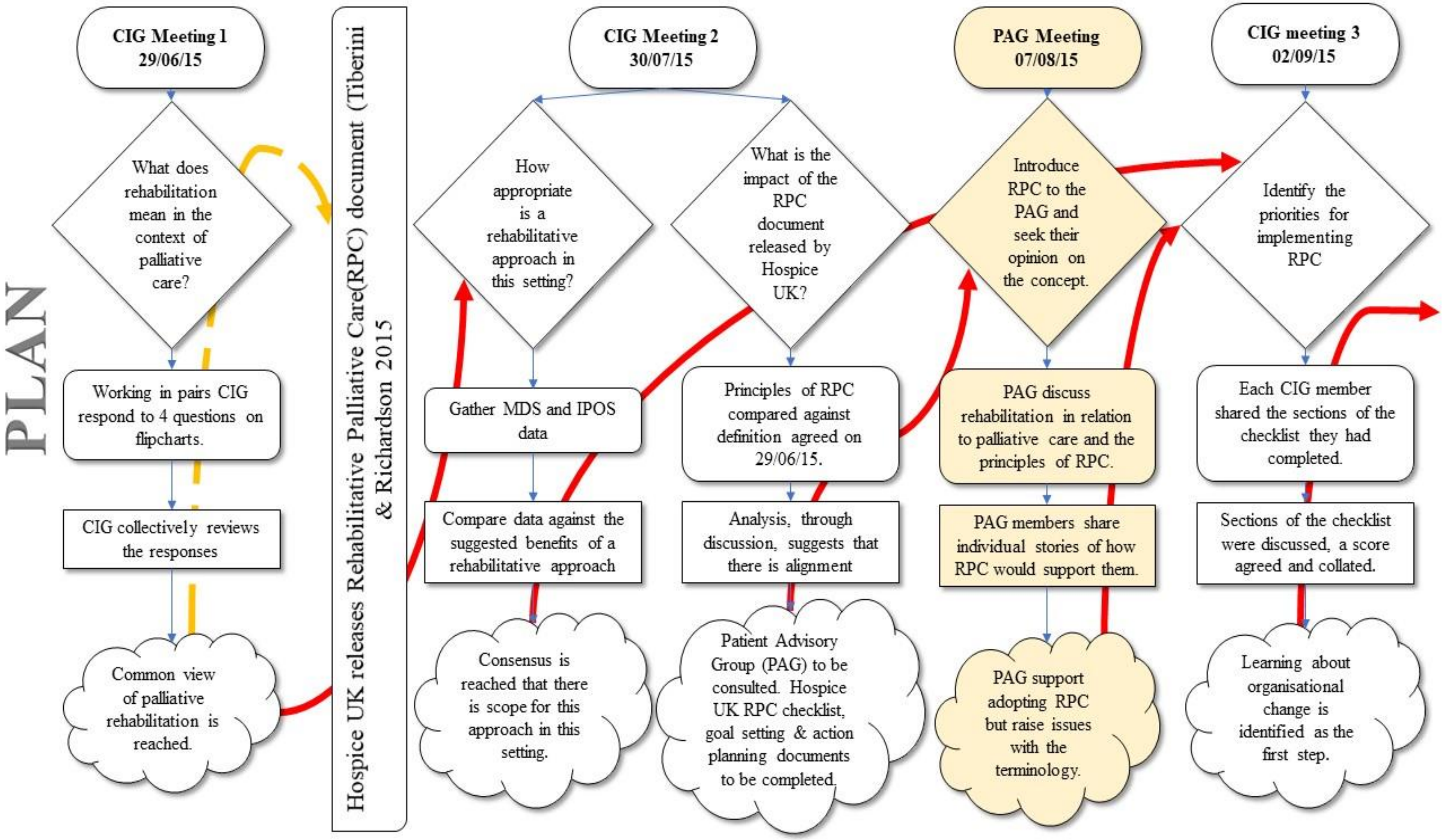
(Riel, 2010, p.2)

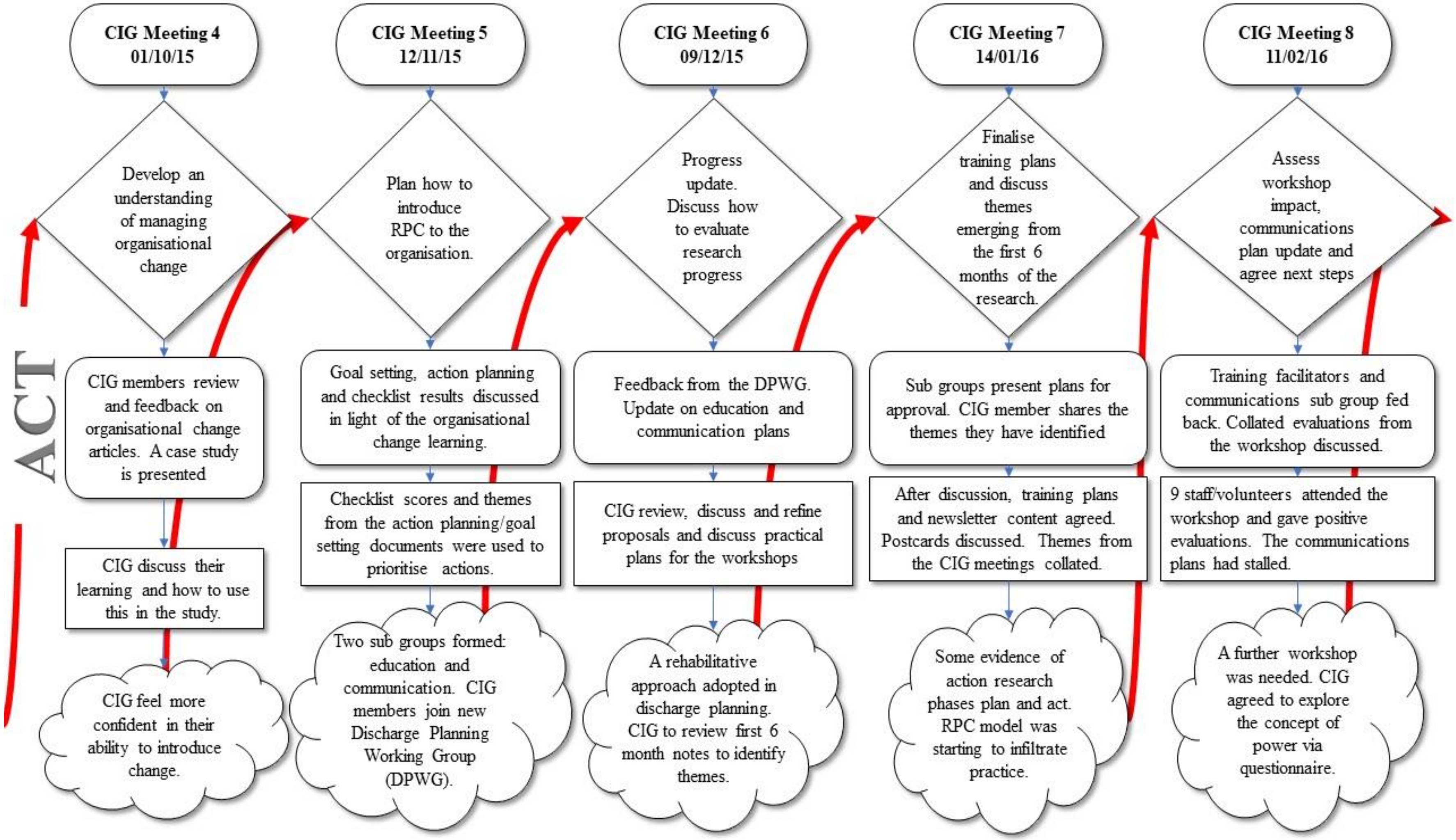
Figure 6: Progressive problem solving with action research

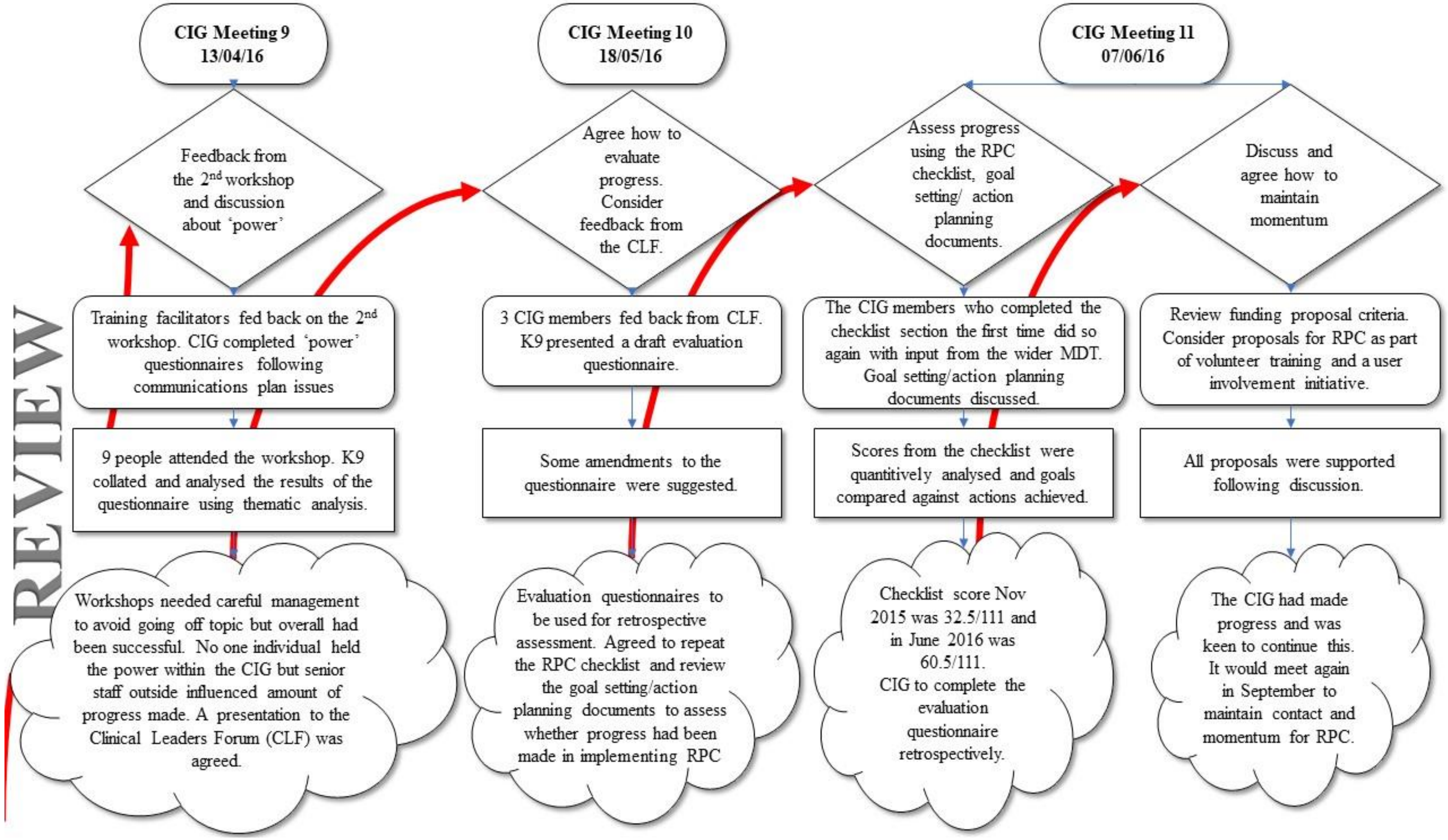
There is one activity included which relates to the Patient Advisory Group, not the CIG, and so this is highlighted in a different colour. The red arrows show how one phase was carried forward to the next activity and the following symbols have been used to reflect the phases:

Study and plan: ◇ Take action: ▢

Collect and analyse evidence: ▭ Reflect/Review: ☁


PLAN
CIG Meeting 1 29/06/15
What does rehabilitation mean in the context of palliative care?
Working in pairs CIG respond to 4 questions on flipcharts.
CIG collectively reviews the responses
Common view of palliative rehabilitation is reached.
Hospice UK releases Rehabilitative Palliative Care(RPC) document (Tiberini & Richardson 2015
CIG Meeting 2 30/07/15
How appropriate is a rehabilitative approach in this setting?
Gather MDS and IPOS data
Compare data against the suggested benefits of a rehabilitative approach
Consensus is reached that there is scope for this approach in this setting.
What is the impact of the RPC document released by Hospice UK?
Principles of RPC compared against definition agreed on 29/06/15.
Analysis, through discussion, suggests that there is alignment
Patient Advisory Group (PAG) to be consulted. Hospice UK RPC checklist, goal setting & action planning documents to be completed.
PAG Meeting 07/08/15
Introduce RPC to the PAG and seek their opinion on the concept.
PAG discuss rehabilitation in relation to palliative care and the principles of RPC.
PAG members share individual stories of how RPC would support them.
PAG support adopting RPC but raise issues with the terminology.
CIG meeting 3 02/09/15
Identify the priorities for implementing RPC
Each CIG member shared the sections of the checklist they had completed.
Sections of the checklist were discussed, a score agreed and collated.
Learning about organisational change is identified as the first step.


ACT
CIG Meeting 4 01/10/15
Develop an understanding of managing organisational change
CIG members review and feedback on organisational change articles. A case study is presented
CIG discuss their learning and how to use this in the study.
CIG feel more confident in their ability to introduce change.
CIG Meeting 5 12/11/15
Plan how to introduce RPC to the organisation.
Goal setting, action planning and checklist results discussed in light of the organisational change learning.
Checklist scores and themes from the action planning/goal setting documents were used to prioritise actions.
Two sub groups formed: education and communication. CIG members join new Discharge Planning Working Group (DPWG).
CIG Meeting 6 09/12/15
Progress update. Discuss how to evaluate research progress
Feedback from the DPWG. Update on education and communication plans
CIG review, discuss and refine proposals and discuss practical plans for the workshops
A rehabilitative approach adopted in discharge planning. CIG to review first 6 month notes to identify themes.
CIG Meeting 7 14/01/16
Finalise training plans and discuss themes emerging from the first 6 months of the research.
Sub groups present plans for approval. CIG member shares the themes they have identified
After discussion, training plans and newsletter content agreed. Postcards discussed. Themes from the CIG meetings collated.
Some evidence of action research phases plan and act. RPC model was starting to infiltrate practice.
CIG Meeting 8 11/02/16
Assess workshop impact, communications plan update and agree next steps
Training facilitators and communications sub group fed back. Collated evaluations from the workshop discussed.
9 staff/volunteers attended the workshop and gave positive evaluations. The communications plans had stalled.
A further workshop was needed. CIG agreed to explore the concept of power via questionnaire.



Feedback from the 2nd workshop and discussion about 'power'

Training facilitators fed back on the 2nd workshop. CIG completed 'power' questionnaires following communications plan issues

9 people attended the workshop. K9 collated and analysed the results of the questionnaire using thematic analysis.

Workshops needed careful management to avoid going off topic but overall had been successful. No one individual held the power within the CIG but senior staff outside influenced amount of progress made. A presentation to the Clinical Leaders Forum (CLF) was agreed.

Agree how to evaluate progress. Consider feedback from the CLF.

3 CIG members fed back from CLF. K9 presented a draft evaluation questionnaire.

Some amendments to the questionnaire were suggested.

Evaluation questionnaires to be used for retrospective assessment. Agreed to repeat the RPC checklist and review the goal setting/action planning documents to assess whether progress had been made in implementing RPC

Assess progress using the RPC checklist, goal setting/ action planning documents.

The CIG members who completed the checklist section the first time did so again with input from the wider MDT. Goal setting/action planning documents discussed.

Scores from the checklist were quantitively analysed and goals compared against actions achieved.

Checklist score Nov 2015 was 32.5/111 and in June 2016 was 60.5/111. CIG to complete the evaluation questionnaire retrospectively.

Discuss and agree how to maintain momentum

Review funding proposal criteria. Consider proposals for RPC as part of volunteer training and a user involvement initiative.

All proposals were supported following discussion.

The CIG had made progress and was keen to continue this. It would meet again in September to maintain contact and momentum for RPC.

Figure 7: CIG Action Research Cycles

Figure 7 does not just show what the CIG did to establish itself and begin working together, as our activities did not fall neatly into distinct phases. Other aspects of the research are reported here as they provide an overview of action research in practice and provide some insight into data collection and how it was used to inform actions. Also, it is not possible to show the action research cycles as data collection without revealing the findings, as this is part of the concurrent data collection and analysis.

Further reflection often took place at the beginning of the following meeting, as part of the process of "reflect and plan" (Zuber-Skerritt, 2001) . These cycles of action and reflection in a disciplined way helped to develop understanding (Hynes, 2013) and were aligned with the repeated process of gaining and applying knowledge and reflecting upon it that HCPs go through to improve patient care (McIntosh, 2010). This iterative process was repeated several times during the months that the CIG met.

4.2.2.2 Retrospective data collection and analysis

Following a discussion about a decision not to include an article in the newsletter (which will be described in 4.2.4) I compiled and emailed a short, written survey to the CIG to gather their perspectives about power within the group and the organisation (Appendix 7). By this time one CIG member had left the organisation and so six were sent out and returned. The responses to the questionnaire were collated by me. The quantitative data was analysed using descriptive statistics and the qualitative data analysed thematically using Braun and Clarke's (2013) method.

At the end of the action research cycles, in June 2016, CIG members completed a form to evaluate the research project (Appendix 8). I created it and it was sent out electronically to six people and five were returned; one individual was on maternity leave and did not return the evaluation form. The returned forms were collated and analysed by me. The results are reported as findings in this thesis according to which aspect of the study they relate to and so some findings are reported here as they relate to this action research cycle.

4.2.3 Findings

The findings reported here relate to establishing and working as a CIG.

4.2.3.1 Descriptive data about the CIG

In addition to myself, five clinicians, two volunteers and one non-clinical manager consented to become part of the CIG as shown in Table 4.

Table 4: Demographics of the co-operative inquiry group

ID	Age	Ethnic group	Role	Length of service
S7	61-70 years	White	Manager	2-5 years
D5	61-70 years	White	Volunteer	1-2 years
A1	31-40 years	White	Therapist	2-5 years
N4	61-70 years	White	Volunteer	1-2 years
A3	31-40 years	White	Therapist	6 mths - 1 year
E2	31-40 years	White	Manager/Therapist	2-5 years
O6	25-30 years	White	Nurse	6 mths - 1 year
L8	25-30 years	White	Manager/Therapist	2-5 years
K9	41-50 years	White	Manager	6-10 years

One volunteer left after the second meeting due to health reasons and a discussion took place about whether he should be replaced. The consensus view was that no other volunteers had expressed an interest in joining the CIG and the group was already established. However, it was agreed that D5 would keep the volunteers updated and seek their views via the volunteer Host Liaison meetings. A1 resigned in January 2016 having secured a new post elsewhere.

4.2.3.2 Establishing and working as a co-operative inquiry

In considering the findings in relation to establishing and working as a co-operative inquiry, three issues will be considered: (a) establishing a communicative space and the retrospective analysis of the (b) power survey and the (c) evaluation form.

a. Establishing a communicative space

It is evident from Figure 7 that there were multiple and repetitious action cycles which illustrate rigour (Coghlan & Brannick, 2005) and reflect a key feature of action research, in that small-scale changes took place as the project progressed offering a sense of momentum for the change (Lewin, 1951). The CIG was established and worked as a co-operative inquiry for over a year and in doing so seemed to reflect the characteristics of a communicative space referred to in 3.3.1.

There are some practical factors that influence whether a communicative space has been created (Kemmis & McTaggart, 2005) and O6's description of how she felt the group worked suggests that these practical issues were addressed: "The group were productive and focused during meetings to maximise the time available; meetings always ran to time and there was well directed discussion" (O6: evaluation form). To assess whether

Table 5: Co-operative inquiry and communicative space with study examples

Co-operative inquiry features (Heron and Reason, 2001)	**Examples from the PAR**	**Communicative space characteristics (Kemmis and McTaggart, 2005)**
All participants are as involved as possible as co-researchers in *all* research decisions	• CIG characteristics identified in the evaluation form: *supportive* (L8, S7); *enthusiastic* (L8, D5), *collaborative* (L8, A3), *motivating* (L8), *responsible* (A3, O6) and *participative* (A3, O6). A key enabler was the "Determination and motivation of the CIG group, collaboration" (S7). • Thematic analysis suggested a joint problem-solving approach, collaborative working, mutual respect: "You and D5 are really important to us. We need that support from you to figure it out" (L8: CIG, 29/06/15) and empowerment: "this group was empowering people (us) to come up with something to take to the organisation as a whole" (A3: CIG, 10/01/15). • Managers and staff felt comfortable in being open with the group: "I didn't challenge when I thought that" (E2: 30/07/15); "I'm struggling from a management point of view…..." (L8: CIG, 02/09/15); "I'd felt bamboozled after the last meeting when the group had launched into how it was planning to do it; I feel the need to put the brakes on" (A3: CIG, 02/09/15).	• Solidarity • Voice divergent views in a democratic context

	• A ‘safe’ space “..it felt like a really honest meeting and was an example of how safe the space created by the group felt” (L8: CIG, 14/01/16). “I was getting anxious, wondering about what would happen next and then the group had this meeting where things were put into perspective.” (D5: CIG, 14/01/16). “..there was that validation that it was ok for people to say what they thought and to be thinking a certain way and that K9 was alongside the group” (L8: CIG, 14/01/16). • S7 summarised the group’s involvement by saying, “although it is K9’s PhD it doesn’t really feel like it is; everyone is throwing in an opinion, deciding what to do (CIG, 02/09/15).	
Interplay between action and reflection is explicit and intentional.	• ‘*Has the inquiry been too superficial and taken on a role of service development rather than research*?’ (Journal entry 10/12/15) • “The reason I was interested in participating in the research was to learn about organisational change and to understand how you could change the culture of an organisation... I don’t feel that this had been tackled at all and that instead the group has dived in to looking at what rehab was in palliative care which is important, but not what I had expected to be doing. This I find frustrating” (E2: 02/09/15). • “We started it, we doubted it, we questioned it, we debated it” (L8: CIG, 14/01/16). • Reflection outside the meeting: “I’ve been thinking about this a lot since the session” (A3: 30/07/15)	• Legitimacy • Authentic engagement
Attention is paid to the validity of	• There’s “a sense that people are feeling overwhelmed at the moment and that there are a lot of groups going on, is this a priority?” (E2: CIG, 12/11/15). Is it “the right time to be	• Authentic engagement

the inquiry and its findings.	thinking about delivering teaching?” (L8: 12/11/15) “Do we just need to give it some time; are the CIG trying to push it too much?” (A3: CIG, 11/02/16). “From the volunteer perspective, is it clear enough why the volunteers are being included in this?” (L8: CIG, 09/12/15).	
There is a range of skills suited to all-purpose experiential inquiry.	• Individuals took responsibility for aspects of the research project: S7 established a resource library, each member chaired a meeting, CIG members joined ‘spin-off’ groups, some presented the CIG’s work.	• Democratic context • Authentic engagement

a co-operative inquiry was established, its features will be aligned with quotes and examples from the study and the characteristics of a communicative space in Table 5. One of the co-operative inquiry characteristics is that the method is wide-ranging and can be informative and transformative; it is open-minded. This has not been referred to specifically in Table 5 as each Inquiry Chapter will report on the breadth of methods used to inform the research.

In Table 5, it is reported that E2 described the frustration that she felt about the approach that the CIG was taking. The fact that E2 was able to share her frustration indicates that she felt able to voice a potentially divergent view and that she was engaging authentically with the research reflecting a communicative space (Kemmis & McTaggart, 2005). It is suggested that a communicative space defuses the often-powerful voice of management (Hockley, 2013) and this is discussed in 4.2.3.2.b. However, power dynamics within the CIG and in the wider organisation was a topic that we discussed which was prompted by the Chief Executive’s decision not to include an article about RPC in the internal newsletter which will be reported in 4.2.4.

b. Power survey

Once they had been collated and analysed, I shared the results from the power survey (Appendix 7) with the group to ensure rigour in the research process. They demonstrated that the shared view of the CIG was that the organisation encouraged engagement from staff and volunteers irrespective of traditional hierarchical structures. L8 suggested that the way the CIG had been constructed, based on inclusivity, was an example of this. The consensus was that everyone in the CIG had the opportunity to exercise influence, but the co-researchers relied on me to initiate and facilitate engagement in the research (Andrews et al., 2013). However, it was noted that the CIG quickly became self-sufficient, developed autonomy and confidence, and became increasingly independent of me (A3, D5, L8, O6, E2). Managers were not considered powerful in the group, despite four being present. D5, E2 and S7 said that initially I held the power but then the therapists, who had a greater knowledge of the subject matter, became more dominant (S7, A3). L8 said the occupational therapist and nurse had the most influence and O6 said that all members exercised equal influence.

Outside the CIG, there were perceived difficulties relating to a lack of engagement by those who could influence change, i.e. the Chief Executive, the senior managers and senior clinicians. It was felt that there was "limited scope for new ideas to be introduced without the go ahead from these people" (E2) and there was, "the insecurity that nothing fruitful will come of this work without senior buy in, especially from the chief exec" (L8). S7's view was that clinical staff and clinical managers had the autonomy to effect change when it related to patients and there was some evidence of CIG members working with their colleagues to change current practice. This, and maintaining the position that a rehabilitative approach was simply an enhancement of current best practice, were some of the mechanisms CIG members adopted to make change happen despite not having engagement from the senior team. It was also perceived that there was a strong and traditional nursing element within the organisation and it was purported that a lack of nurses within the CIG meant it did not have credibility with senior, clinical managers. At times, the CIG felt it did not have enough power to fully implement change as it was dependent on the power and influence of others (Mitchell, Agle, & Wood, 1997).

c. Evaluation form

According to the responses from the evaluation form (Appendix 8), when asked what they had learnt personally and professionally from being a co-researcher in this project the CIG comments included: working as a multidisciplinary team (O6), appreciating how interesting research could be (S7) and a greater understanding of roles within the Hospice (D5). In the extract below A3 describes how he engaged with the research on a personal level to initiate change, both personally and professionally (Heron & Reason, 2006; Kemmis & Wilkinson, 1998) and, in accordance with PAR, was able to construct and use new knowledge (Reason, 2006):

> “I have become more aware of what it takes to implement a new way of working in an organisation. …. I look at the inclusive way we tried to bring this about as a successful model for organisational change.
>
> I have had to take on the responsibility of organising and delivering training … and I gained a lot from that …. I feel I have advanced my skills in teamwork and understand more in terms of what I can offer a group such as the CIG. I have become more confident in my own abilities to contribute to a team and a project. I have also learned a lot about my own communication style (which has benefited me both personally and professionally). The experience has also given me the chance to be a bit more confident when expressing my views” (A3: evaluation form) (This quote is provided in full at Appendix 9).

L8’s feedback also demonstrates the breadth of learning she gained from being part of the research:

> “I have learnt much about the process of change and influencing change… It has been really useful in helping me see how my team fit in with the rehabilitative palliative approach and where best to focus their influence. This project group has given me a designated time to explore this safely without the impact of other work load” (L8: evaluation form) (This quote is provided in full at Appendix 9).

There were also examples of others developing their own knowledge and skills and in doing so reflecting (Heron & Reason, 2001) ways of knowing:

- O6 and A3 both volunteered to facilitate the workshops despite never having done this before: introducing a new topic to the organisation and delivering to an audience of clinical staff, volunteers and managers - presentational knowledge
- S7 demonstrated an understanding of the need to be rigorous in the research process and proposed supplementing the meetings with reading. She volunteered to collate relevant resources – propositional knowledge.
- L8 said, “Personally: I have learnt to adapt my communication skills….these can be often interpreted as overbearing and this group format has given me a chance to work on this characteristic” (evaluation form) – practical knowledge.

4.2.4 Personal reflection

The findings above illustrate what other members gained from being part of the CIG and I will now share some learning of my own which demonstrates how conflict can arise when undertaking insider research and being a senior manager.

I had taken steps to ensure that, within the CIG, my role was a as co-researcher and not a senior manager and this was acknowledged by the CIG: “K9 from the start was always clear that her role was as a researcher and when she has intervened it has been in the capacity as the facilitator” (L8: evaluation form); “K9 was very keen from the beginning that she should be seen as the research leader and not as a senior manager, which showed that she was taking into account how her position in the Hospice may impact the research” (O6: evaluation form). However, when the Chief Executive decided not to include the rehabilitative article in the newsletter there was an expectation that I would assume my senior management role to address this. My journal records the incident and is an example of epistemic and methodological reflection (Johnson & Duberley, 2000):

> “*When I became aware that the article had not been agreed, I decided not to intervene and maintained my role as a researcher and not the Deputy Chief Executive (DCE). Throughout the project I had adopted and maintained the role of a CIG member as opposed to the DCE as this was the essence of the participatory approach the group had created. I felt that in this context I couldn’t choose to adopt the DCE role just because things had not gone according to plan. Neither did I feel I should make unilateral decisions about how to deal with this when every other decision had been made collectively*” (KC: Journal, 12/02/16).

In responding in this way, I was not fulfilling my role as an insider researcher by working behind the scenes to reduce resistance (Reason & Bradbury, 2013). However, to have acted differently would have, in my mind at the time, damaged the integrity of the research and undermined the values underpinning it. It would also have blurred the boundaries between the two roles that I had kept distinct; that of a researcher and that of a senior manager. On reflection, however, should the same scenario happen again, I would probably attempt to maintain the integrity of both roles and respond as a senior manager *and* a researcher. This is because I now feel more confident fulfilling both roles, and of my responsibility and ability to act in the best interests of the CIG without assuming a management stance. If another member of the CIG had had the opportunity to address this issue with the Chief Executive, I think they would have done so which suggests that perhaps my actions were not in the best interests of the CIG. Nevertheless, because of my actions, the CIG had to consider, collectively and critically, how to respond to the Chief Executive's decision rather than rely on my position of authority to resolve the problem. In doing so, they developed their own skills in problem-solving, worked collaboratively, and were empowered to take responsibility for the problem and the solution which resulted in more robust communication at all levels of the organisation and in doing so reflected several attributes of PAR (Carr & Kemmis, 1986; Coghlan & Brannick, 2005; Meyer, 2006; Williamson et al., 2012).

4.2.5 Conclusion

The examples in Table 5 suggest the features of a co-operative inquiry (Heron, 1996; Heron & Reason, 2001) were evident in the work of the CIG who created a communicative space and by doing so facilitated change. However, on reflection the CIG may have been so good at establishing a communicative space it became insular and detached from the rest of the organisation. If that was the case, then that perceived impenetrability may have created suspicion and resistance which led to some of the barriers that the CIG felt it faced, particularly from senior staff which will be discussed on Chapter Five.

4.3 Collectively developing knowledge: rehabilitative palliative care and organisational change

The second phase of Inquiry One was for the CIG to collectively develop our knowledge of rehabilitative palliative care. As the action research progressed, the CIG agreed that a focus on the theory of organisational change was needed. This is reported here as it relates to the CIG developing knowledge.

4.3.1 Introduction

An initial phase of co-operative inquiry is for the group to come together to examine an area of mutual interest (Heron & Reason, 2006) and so the first task for the CIG was to develop a shared understanding of what rehabilitation in palliative care meant and then assess its relevance in this setting. However, there were some concerns from E2 and A3 that the group was not attending to the research aspect of action research and was instead focusing on action. It was therefore agreed, at meeting three, that the CIG also needed to develop knowledge regarding organisational change theory.

4.3.2 Data collection and analysis

4.3.2.1 Rehabilitative palliative care

To ensure the CIG had a mutual understanding of rehabilitation in palliative care, working in pairs, we considered four questions written on individual flipcharts and then wrote our response on the flipchart paper (29/06/15). After considering one question we moved on to the next flipchart question and wrote our response under those who had considered the question before us – a snowball technique. The handwritten flipcharts were then transcribed by me and the responses from the CIG are shown in Table 6. A similar exercise was undertaken with the PAG (07/08/15).

Table 6: CIG and PAG responses to rehabilitation and palliative care questions

Question	**CIG response (29/06/15)**
What does the term “palliative rehabilitation” mean?	Not dying in hospice, dying at home Allowing patients to take control at end of life – quality of life Allowing people to live well until they die – under their own terms Active participation in meaningful activities to enhance quality of life Small individualised realistic goals Patient – centred care Holistic care – emotional, spiritual and physical Not giving up on the patient = dying Not enhancing the sick role
	Patient Advisory Group response (07/08/15)
	Keep people active, mobile and free from pain Positive attitude Skills to manage your condition Not just physical support Lack of understanding of the term palliative - terms are contradictory Rehabilitation sounds positive and dynamic.
	CIG response (29/06/15)
What is “palliative rehabilitation” not?	Curative Compulsory Unrealistic Really intense Clinician-led – it involves patients, carers and families Enforced on a patient

	Not necessarily about increasing function, can be adjusting & accepting Clinicians taking over Dehumanizing About physio Disempowering
What would a patient or family member think or understand by the term [palliative] rehabilitation?	Fix it/ Cure it/ Prolong life Gym/exercise Lifestyle changes to enhance longevity “Inappropriate” “Physios do rehab” Rehabilitation = walking Helping people achieve important improvements and goals Making people feel more ‘normal’/independent Make patient feel empowered/important – it’s not just dying No idea – what does it mean? Intimidated by the medical profession, feel can’t ask/challenge.
What other words or phrases could be use instead of “palliative rehabilitation”?	“Live well” Enabling Patient-centred goals Promoting independence Supporting appropriately Not just medical care Maximise abilities Look after whole person not the disease Control – encourage to take control/allowed to be in charge Functional approach Empowerment Promoting resilience

The results from the discussion about palliative rehabilitation with the CIG and the PAG were used to inform what the CIG needed to do to gain conceptual clarity, so it was part of the concurrent analysis.

The CIG wanted to assure itself that there was some evidence to support introducing a rehabilitative approach in this setting. Two organisational documents were analysed to determine this: Minimum Data Set (MDS) and an internal audit of the Integrated Palliative Outcome Scale (IPOS). The National Council for Palliative Care (NCPC) collated the MDS annually from hospices, and reports for 2013/14 and 2014/15 for the in-patient unit (IPU) at this Hospice were collected from the Hospice's records and reviewed by the CIG. The MDS was used to understand the profile of patients being admitted to the in-patient unit in a year, e.g. age, diagnosis, length of stay, outcome from admission, number of deaths etc. (Appendix 10).

IPOS is a component of the Outcome, Assessment and Complexity Collaboration (OACC), an internationally validated tool for measuring patient outcomes launched in 2013. It was introduced to the Hospice's in-patient unit in 2015 and used to assess the degree to which the team had addressed the concerns of patients by asking them to identify their main issues on admission, and then repeating this three to five days later, and again upon discharge. As part of an audit, in June 2015, the responses from 30 patients were collected by IPU nurses, collated by one of the junior doctors and presented at an Audit feedback meeting. Clinical CIG members collected hard copies of the audit presentation and photocopied it for the CIG to consider (Appendix 11). The information from the MDS and IPOS audit were considered by the CIG as part of the concurrent analysis and were used to inform whether a rehabilitative approach was appropriate in this setting.

4.3.2.2 Organisational change

In response to the concern that the CIG had not considered organisational change theory, it was agreed that I would source an organisational change article for each CIG member to critique and present to the group at the next meeting. The CIG members' notes on these articles were shared in the resource folder. In addition, I presented a case study of an organisational change project I had been involved in.

4.3.3 Findings

4.3.3.1 Rehabilitative Palliative Care

Through their experience and my reading, the clinical staff and I had some understanding 'palliative rehabilitation'; the therapists were more conversant in it than others. The volunteers and non-clinical individuals had less knowledge but after some discussion a shared understanding of palliative rehabilitation was achieved which was that it was an intervention that was driven by the patient goals and was not simply about improving functional ability, although this was an aspect of it. Shortly after the first CIG meeting a document, endorsed by Hospice UK, "Rehabilitative Palliative Care: Enabling people to live fully until they die" (Tiberini & Richardson, 2015) was launched. Whilst this was based on 'palliative rehabilitation' the CIG felt that RPC placed more emphasis on the role of the multidisciplinary hospice team in providing a culture of enablement for patients to achieve their priorities rather than therapy-led interventions. We thought that this more clearly recognised the roles that volunteers, non-clinical staff and lay people could play. It was also perceived to have more emphasis on participating in meaningful activities such as socialising and eating and enjoying food rather than a more interventionist activities. We concluded that RPC was congruent with the CIG’s original understanding of palliative rehabilitation and a concept that resonated with the aims of the research and so was the term adopted.

When consulted about it, the PAG also responded positively to the concept of RPC. One member said she felt reassured that, “there was not going to be a strong emphasis on exercise and activity, but more emphasis on small goals that would enable people to feel better” (JM: PAG 07/08/15). Another said that his family were constantly trying to “wrap him up in cotton wool” (DM: PAG, 15/10/15) which made dealing with his illness even more difficult to cope with. He said he hoped that adopting this approach and involving families would encourage them to be more supportive.

Using the data from the MDS and the IPOS audit, the CIG needed to assess whether RPC was appropriate for this setting. Based upon the clinical staff’s experience and knowledge, the CIG used the MDS data to make some assumptions about which patients might be most amenable to this approach, e.g. according to the MDS, approximately 48% of patients returned home after an in-patient admission. It was important for these patients to have the same levels of mobility/independence when they went home as when they arrived in the Hospice. The MDS also showed there was a steady increase in admissions for patients with heart failure and respiratory conditions. These illnesses often had acute exacerbations followed by some improvement (Figure 3b) and we felt that a rehabilitative approach might benefit both these groups of patients to gain a degree of functionality after an acute episode.

According to the IPOS audit of 30 in-patients, *mobility* and *weakness* scored quite highly and did not decrease very much during patients' admissions. This suggested that the current focus of in-patient care was not sufficiently addressing these issues. The CIG felt a rehabilitative approach could make a positive contribution to this.

4.3.3.2 Organisational change

The CIG meeting focussing on organisational change took place on 1 October 2015 and seven journal articles were discussed. The key findings were that:

- Resistance to change should not be demonised and that conflict should be celebrated and used as an impetus for change (R. Thomas & Hardy, 2011)
- Managers' engagement with change was often superficial and nurse leaders' identities were affected during organisational change (Salmela, Eriksson, & Fagerström, 2013)
- John Kotter's model of organisational change was considered very relevant to this study as alignment could be seen with some of the activities we were planning (Kotter & Schlesinger, 2008)
- Poor management of change leaves organisations worse off than no change and that the psychological contract comes under duress during change (Burnes, 2003)
- Change needed to adopt an engineering and psychological approach, those contributing to or affected by the change must be involved and where possible rewarded and that change was operational; transformation was strategic (Graetz, 2006)

- Barriers to effective organisational change were previously thought to be cost, workload and legislation, but contemporary thinking suggested it was management and culture (Hoag, Ritschard, & Cooper, 2002)
- Nurses would benefit from knowledge of change theory (Shanley, 2007).

The learning about organisational change was an important aspect of the study as it was used, as part of the concurrent analysis, by the CIG to inform plans throughout the remaining months of the research.

4.3.4 Conclusion

The CIG engaged at a conceptual level with the topic of rehabilitation in palliative care and, at a very early stage in the research process, grappled with a refreshed concept (described as rehabilitative palliative care) in a constructive and positive way and achieved consensus. This demonstrates some of the features of co-operative inquiry described in Chapter Three (Heron & Reason, 2001) and reflects authenticity in that the participants were prepared to review their position based on new information (Guba & Lincoln, 1994). This process also ensured that we had a mutual understanding of the subject matter and provided a foundation upon which to build our knowledge which would assist us in assessing whether RPC was relevant in this setting.

The CIG seemed to create a space that aligned with Habermas' theory of a communicative space. Table 5 showed that its characteristics of solidarity, an ability to voice divergent views, legitimacy, authentic engagement and a democratic context could be evidenced by our interactions.

Having considered the information from the MDS and IPOS, we concluded that it would be appropriate to plan to implement a RPC approach to the Hospice's in-patient unit. Through undertaking further action research cycles our knowledge of RPC developed and staff and volunteers were able to put this knowledge into practice in their day to day activities demonstrating Heron and Reason's (2001) extended epistemology, and research in action (Lewin, 1948).

In addition to developing our own knowledge about organisational change and action research, the CIG participated in generating knowledge about how to integrate a rehabilitative approach into a hospice in-patient setting and therefore contributed to the evidence-base on this subject whilst implementing change. This reflects the key components of action research: democratic impulse, participatory in nature and contributing to social science and social change (Meyer, 2000). It also contributes to creating an evidence base for this work (Halkett, Ciccarelli, Keesing, & Aoun, 2010; Runacres, Gregory, & Ugalde, 2017).

4.4 Identify, plan and implement ways to integrate rehabilitative palliative care into the hospice setting

The final phase of Inquiry One was for the CIG to identify, plan and implement ways to integrate rehabilitative palliative care into the Hospice in-patient setting.

4.4.1 Introduction

Having gained conceptual clarity of RPC, satisfied itself that this approach was relevant in this setting and learnt some of the principles of organisational change the CIG planned, and began to implement, a rehabilitative approach. This section demonstrates that a wide range of data was used to inform the plans and assess how effective they had been including checklists, action planning and goal setting documents, session plans and feedback from workshops, and more formally through the evaluation form. In addition to using their influence as clinicians to enact change on the in-patient unit, and joining groups such as the Discharge Planning Working Group, the two main activities the CIG engaged in were developing a RPC workshop and a communications plan.

4.4.2 Data collection and analysis

4.4.2.1 Checklist

The CIG used the "How rehabilitative is your hospice checklist?" (Tiberini & Richardson, 2015) to measure how rehabilitative the Hospice's approach was prior to and post activities developed by the CIG (extract at Appendix 12). The CIG first assessed the Hospice in September 2015, prior to undertaking any activities, and repeated it in June 2016. Each ‘domain’ was assessed by the same CIG member on both occasions in consultation with the wider multidisciplinary team. The feedback from individual CIG members who had completed the checklist was reviewed collectively at the September 2015 CIG meeting and collated by A1. This formed part of the concurrent analysis and used to inform where the CIG needed to prioritise activities. The checklist was repeated in June 2016 by the same individual who had completed it the first time. It was also done in consultation with other members of the multidisciplinary team to achieve consensus. The results were collated by L8 and used as part of the retrospective analysis to determine whether change had taken place.

4.4.2.2 Goal setting and action planning

In September 2015, the CIG considered the Hospice's current position in relation to RPC and what we aspired to achieve using a goal setting and action planning document developed as part of the launch of the Rehabilitative Palliative Care document (Tiberini & Richardson, 2015) (Appendix 13). The goal planning document asked:

- What is the current reality and the future vision?
- What internal and external factors must we consider?

The action planning document asked:

- What were the key drivers, the evidence and the economic value of change? What evidence was there for change?
- Who were the key stakeholders who needed to be on board?
- What steps needed to be taken, by whom and when?

CIG members completed the goal setting and action planning documents independently and this was then discussed collectively, and one version produced by A1 following the meeting in October 2015 (Appendix 14). This was reviewed in May 2016 and formed part of the retrospective analysis to help assess whether change had taken place.

4.4.2.3 Workshops

The CIG developed and delivered two workshops on RPC for in-patient unit staff and volunteers in January and March 2016. A sub group of the CIG (S7, L8, K9, A3 and O6) developed the workshop plan (Appendix 15), formulating this into a lesson plan that was shared and refined by the wider group and signed off in January 2016 prior to the first workshop. Participants attending the workshops were asked to provide feedback on how useful and relevant the workshops had been by completing an evaluation form, by hand, at the end of the workshop. The questionnaire responses from participants at the workshops were collated by A3 and O6 who delivered the workshop. The feedback was shared and discussed with the CIG.

4.4.2.4 Evaluation form

At the end of the project the CIG was asked, via an evaluation form (Appendix 8), what changes had occurred as a direct result (impact) of the project. The manner in which this data was collected and analysed has previously been reported and the findings are stated in the relevant sections of this chapter.

4.4.3 Findings

These findings relate to how the CIG identified, planned and implemented ways to introduce a rehabilitative approach.

4.4.3.1 Checklist

A summary of the "How rehabilitative is your hospice?" checklist results is shown in Table 7. During the nine months between the first and second assessment, progress was deemed to have been made in relation to: Focus on function - an increase of 11; and Enablement - an increase of 10.5. The overall score increased from 32.5/111 to 61.5/111 which according to the CIG was as a result of:

- different members of the multidisciplinary team undertaking patients' functional assessments and documentation rather than this only being the role of the therapists
- changes to the induction programme for new staff including junior doctors to ensure they understood a rehabilitative approach
- increases in the number of proactive, early referrals being made to the therapists

Table 7: "How rehabilitative is your hospice?" checklist results summary

			Score	
	Heading	**Summary**	**Sept 2015**	**June 2016**
1.	Person-centred goal setting	• Multidisciplinary support is focused around person-centred goals for each patient • 'Parallel planning' is used to introduce 'uncertainty' and actively plan for several possible outcomes	2.5/10	2.5/10
2.	Focus on function	• Functional assessment is established as a core component of palliative care holistic assessment • Function is explicitly documented in patients' notes • Symptom control is routinely contextualised in relation to patients' function • Proactive early referrals are made to allied health professionals for specialist rehabilitation input	5/18	16/18
3.	Enablement	• Patients and families are supported to understand and expect that hospices provide enablement focused support which gives them maximum choice and participation • Patients are supported to maintain their normal routines of daily life as closely as possible while in the hospice • All members of the multidisciplinary palliative care team integrate principles of enablement in their daily practice and support of patients • Hospices create enabling environments	5.5/25	16/25

		• Hospices practice proactive discharge planning • Patients in the community are offered models of palliative care support that optimise choice, normalcy and independence		
4.	Supportive self-management	• Self-management strategies are actively incorporated across all hospice support services • Patients are supported to take informed and optimally managed risks	10.5/20	12/20
5.	Strategic direction	• Rehabilitative Palliative Care is an explicit priority in hospices' strategic direction	1/6	2.5/6
6.	AHP expertise and leadership	• Hospices invest in allied health professional expertise and leadership	6/12	7/12
7.	Education	• Hospices educate and train staff to understand and competently deliver enablement-focused Rehabilitative Palliative Care	0/14	2/14
8.	Recruitment and workforce planning	• Hospices proactively identify gaps in workforce skillsets and undertake targeted recruitment to build rehabilitative experience and knowledge across multidisciplinary teams	2/6	3.5/6
	Total		**32.5/111**	**61.5/111**

- improved support for patients to maintain their normal routines of daily living while at the Hospice with Host volunteers being actively encouraged to support this
- proactive discharge planning beginning once a patient was admitted (unless their admission was for terminal care) and undertaken by all members of the multidisciplinary team.

There was anecdotal evidence that there had been an increase in awareness amongst patients' families about what enablement focused support was, but this could not be quantified. However, the results also demonstrated that less progress had been made in relation to:

- Strategic direction: the CIG had not been able to influence a change in approach such that RPC became an overt strategic priority for the Hospice
- Education: Although the CIG had run two workshops, education and awareness raising of RPC was not integrated into the Hospice's education programme. However, from October 2016 RPC was incorporated into employees' mandatory training and into the "Excellence in Volunteering" programme for volunteers. Specific 'goal setting' workshops for clinical staff were run three times during the summer of 2017
- Recruitment and workforce planning: aligned with the fact that RPC had not yet been included as a strategic priority, nor had it been considered as part of workforce planning. Some progress had been made in terms of including it in the person specification for clinical roles.

4.4.3.2 Goal setting and action planning

By using the goal setting and action planning documents in September 2015, CIG members had identified several issues regarding RPC. These have been extracted, in Table 8 and aligned with comments made in May 2016 to reflect that the CIG agreed that progress had been made with regards to discharge planning, the team's appetite for change, interest in RPC, training in RPC and engagement of senior staff. Direct quotes are included to bring the voice of the co-researchers into this thesis (Smith et al., 2010).

4.4.3.3 Workshops

18 people attended the two workshops: seven volunteers, nine nurses, a nurse manager and a non-clinical manager. Summarised feedback from participants is shown in Table 9 and more detail is provided in Appendix 16. It demonstrates an increased awareness of the concept of RPC and how it could benefit Hospice patients. There is also some self-awareness from some participants that they needed to adapt the way they worked to facilitate this approach and that volunteers had a key role to play in it.

4.4.3.4 Evaluation form

The most significant feedback from the evaluation form was that the CIG felt that there had been a change of practice on the in-patient unit and by other members of the multidisciplinary team which would benefit patients: "Staff are more aware of the concept of RPC and we are starting to see changes in clinical practice on IPU" (O6: evaluation form); "Therapy team members are more aware of the concept and therefore able to support patients better on IPU and lead to a more tailored discharge planning process and rehab input." (L8: evaluation form).

Table 8: Progress informed by the goal setting and action planning documents

Weakness	**Improvement identified**	**CIG Comments in May 2016**
Poor at setting patient centred goals in a multidisciplinary way	Better communication at multidisciplinary team (MDT) meeting; greater involvement of the MDT in goal setting	**A3**: "I can think of several recent IPU admissions that have benefitted from a wider understanding of RPC and the more pro-active goal setting that has come about as a result. Ultimately this has got people home more quickly and they have been more confident about returning home."
Late to start discharge planning	Discharge Planning Working Group (DPWG) established and discharge planning now more proactive.	**L8**: "the need to look at discharge planning was instigated by the in-patient unit which was better than the CIG initiating something; it felt organic and exciting."
Occupational therapy referrals for discharge planning only	Appropriate referrals were now being made and in a timely manner	**A3**: "a better understanding of what OT is from the wider team which has made my life easier! I feel more part of the ward team and more able to communicate my ideas more easily. I had felt like a bit of an island working across IPU, wellbeing and the community but feel more like I am part of each team now and I really feel this project has helped that."
Some reluctance to change	Appetite for change	**D5**: "I think there's an appetite for change; people aren't resistant." **A3**: "I agree, O6 or I now had a reporting slot at every discharge planning meeting to update on what is happening at the CIG and people are interested

		in what is happening and how the work of the CIG can be continued after the research phase has finished." **L8**: "the volunteers have embraced it but also said how under-utilised they are; this approach would make them feel listened to."
No training around RPC	Two workshops run, integrated into volunteer training, incorporated into mandatory training from Sept 2016.	**O6**: "Following the training sessions, I feel that both volunteers and staff are more aware of the RPC approach and more open to using it in their practice, with the word 'rehabilitation' being used more on the ward." **S7**: because of this project there has been "positive feedback from staff as a result of the training, inclusion (of RPC) in mandatory clinical training for September 16, (RPC) established as an integral part of the volunteer training."
Concerns about staff perceiving this to be additional workload	Staff keen to hear more about the CIG's work and integrate it into daily practice	**O6**: "people had volunteered to be part of the discharge planning group and therefore they were keen to see change and improvement happen."
Need to influence key stakeholders	Senior managers were now engaged, and the researcher was scheduled to present the CIG's work at the July Board Meeting.	**E2** "the PR Officer spoke to me because the next edition of 'Reaching Out' (external newsletter) would focus on changing attitudes and she would like it to feature a piece on rehabilitative palliative care linked to a patient story. This felt like a positive step." **L8**: "at the end of the (CLF) meeting it was agreed that this would be revisited so as not to lose momentum. It felt positive."

Table 9: Summarised feedback from the two workshops

Question	Yes/ No	Comments	
		1st group	2nd group
Do you feel you understand what RPC is?	ALL RESPONDENTS ANSWERED YES TO ALL QUESTIONS	• Training was very thorough • Better understanding of what it (RPC) hopes to achieve • It has been around a while and I have worked with it • It was explained well • Consider language and adapt to individual patients • Improvement of life and living standards despite medical problems • Very informative session which enabled a wide-ranging discussion.	• Session made it easy to understand • Explained and discussed • The discussions helped • Scenarios we talked about helped.
Do you feel that RPC is relevant to you and the way you		• Requires greater thought and flexibility • Need to develop how hosts can deliver this • Everyone has goals however small they are • Need to spread the word and answer questions raised • Encourage patients to reach their goals no matter how small	• As an ex nurse I feel I have skills that could be utilised • Already involved in discharge planning and enabling patient choice • To promote my knowledge within my role • Need to step back more and empower patients • Volunteers have a role to play as new projects develop.

undertake your role at the Hospice?		• Communication between groups needs to be better. As a host, I’d like more involvement with IPU • A lot of patients have the aim to get home, this approach enables them to do this • We all want to help our patients to meet their goals and live to their maximum potential for as long as possible • Everyone has a goal we can work toward.	
Do you feel some elements of RPC are already in place at the Hospice?		• We work every day to improve quality of life • There is an awareness and we do some things well but there are challenges (staffing and time) • We encourage patients to do things for themselves, e.g. preparing for discharge • The MDT approach to discharge planning • We have a good system of MDT planning and discussion • Goal setting • Resources at the Hospice need to be used more effectively • Some aspects in place but not structured or consistent.	• Physiotherapists and Occupational Therapists are here, there is a gym, a shared dining area • Multidisciplinary team input to achieve patient goals • Yes, but we can do more • A varied team able to support people in different ways • MDT all working together • Evident in link between discharged ward patients and wellbeing • Yes, we have an MDT approach.

Other feedback was that there was engagement across the organisation including from senior management: there is now “an understanding that RPC is inclusive and not just the responsibility of therapists” (A3: evaluation form) and “Following the training sessions, I feel that both volunteers and staff are more aware of the RPC approach and more open to using it in their practice, with the word ‘rehabilitation’ being used more on the ward” (O6: evaluation form), and that multidisciplinary teamworking had improved: there’s now “a closer more integrated team with more direct team working between nurses and therapists”, “more discussion from all members of the team … about the holistic approach to assessing or planning interventions” (A3: evaluation form) and “Volunteer colleagues have become more involved in care and are aware of the changing role of hospices”, “it seems that the multidisciplinary team, including volunteers are working more closely” (D5: evaluation form).

4.4.4 Conclusion

The findings presented here and in the associated appendices demonstrate that the CIG did plan and implement change. In doing so, we became cognisant of factors that supported its introduction and those that did not which will be examined in the Inquiry Two.

4.5 Demonstrating rigour

In clearly explaining the approach adopted to undertaking the research including the data analysis process, the authenticity of the research is enhanced (Cotterell, 2008; Titchen, 1995). In judging the quality of action research Heron and Reason (2001) suggest that different forms of knowledge should be engaged throughout the study. In the findings shown in Table 5, there are examples of the different ways of knowing, in particular experiential and practical knowing and other indicators of quality:

- the fact that the CIG challenged assumptions and interpretations through reflection and dialogue adds to the study's legitimacy (Coghlan & Brannick, 2005)
- participants questioned their own assumptions and listened to the perspectives of others which reflects rigour (Coghlan & Brannick, 2005; Reason, 2006)
- the group also reflected quite naturally and in this respect action research mirrors clinical practice (Hart, 1996) and therefore adds to authenticity.

As further evidence of rigour, aspects of Inquiry One have been mapped against Coghlan and Brannick's (2007) criteria (Table 10):

Table 10: Demonstrating rigour in the research process

Coghlan and Brannick criteria	**Examples from the study**
Multiple and repetitious action research cycles: diagnosis, planning, acting and evaluation, and how these are recorded as a true representation of what was studied.	Figure 7 illustrates the action research cycles the CIG undertook. This was supplemented by comprehensive meeting notes which were validated by the CIG at each meeting.
Challenging and testing own assumptions and interpretations	To illustrate my own reflections, extracts from my journal are provided (4.2.4/5.4). One of the first activities the CIG undertook was to test its assumptions about whether a rehabilitative approach was appropriate for

throughout the study through reflection.	this setting (4.3.2). Table 5 includes examples of how the CIG reflected and questioned assumptions.
Accessing different views which may confirm or contradict interpretations.	The PAG provided a different perspective and more importantly, that of a patient. The wider organisation was consulted about how rehabilitative the Hospice was, and senior managers were presented with updates and plans on how the research was progressing. There is evidence that some of their feedback meant a different approach was required or some initiatives did not succeed. Throughout the study my findings were shared with the CIG for validation or otherwise.

4.6 Conclusion

This chapter has explained the action research cycles, data gathering and analysis and conclusions from the first phase of Inquiry that the co-operative inquiry group (CIG) undertook. Where relevant there has also been some discussion about key issues. It demonstrates that the CIG was established and in Table 5 that this reflected the characteristics of co-operative inquiry (Heron & Reason, 2001) and a communicative space (Kemmis & McTaggart, 2005). The CIG also collectively developed its knowledge of rehabilitative palliative care and organisational change and was able to use this to plan how to implement a rehabilitative approach in the Hospice in-patient setting. Evidence was then presented to suggest that this implementation had been successful and changes in practice had started to take place. The final section of this chapter provided details of how rigour could be demonstrated through the activities that were undertaken as part of this Inquiry.

Chapter Five: Inquiry Two: Facilitators and barriers to adopting a rehabilitative approach

5.1 Introduction

This chapter explains the Inquiry that took place to understand the barriers and facilitators the CIG faced when trying to implement a rehabilitative approach to the Hospice in-patient setting. The data was gathered from the notes of the CIG meeting which were then thematically analysed, and then combined with feedback from the CIG via an evaluation form that highlighted the barriers and facilitators from their perspective.

5.2 Thematic analysis

In this research the views of those responsible for care delivery was an important factor. To analyse this type of information Flick (2009) advocates thematic analysis which is a method for identifying, analysing, and reporting patterns (themes) within data (Braun & Clarke, 2006) or ‘winnowing’ the data (Creswell, 2014). In their systematic review of data analysis in action research studies in nursing, Waterman et al. (2001) found that there was a broad range of analytical methods used with thematic analysis being the most common (although 37% of studies had no information regarding data analysis). A *theme* is a category identified by the analyst through their data that:

- relates to their research focus (and quite possibly the research question);
- builds on codes identified in transcripts and/or other field notes; and
- provides the researcher with the basis for a theoretical understanding of his/her data that can make a theoretical contribution to the literature relating to the research focus (Bryman, 2012, p.580).

I undertook the thematic analysis using a seven-stage process of coding and analysis (Braun & Clarke, 2013) outlined in Table 11 but with an additional step at stage four where the coding was rationalised. The columns on the right illustrate which stages were completed as part of the concurrent and retrospective analyses. Also, the CIG reviewed the dataset, as part of *experiential* thematic analysis: an analytical process that enables the data to be considered from the participants' perspective (Braun & Clarke, 2013). This aligned with the participatory intent of the study and is also congruent with Heron and Reason's (2001) extended epistemology - experiential.

Table 11: Coding stages

Stage	Thematic analysis	Concurrent	Retrospective
1	Transcription	X	
2	Reading and familiarisation, taking note of items of potential interest	X	X
3	Coding complete across dataset		X
4	Rationalisation of codes		X
5	Searching for themes		X
6	Reviewing themes	X	X
7	Defining and naming themes		X
8	Writing and finalising analysis		X

Source: Adapted from Braun and Clarke (2013, p.202).

The notes from the CIG meeting provided the majority of the data used to identify what the facilitators and barriers were. I collected data to inform this part of the study from the evaluation form that CIG members completed at the end of the action research phase which has been reported previously.

5.2.1 Data from the CIG meetings

Some of the data from the CIG meetings was used concurrently to inform other areas of the study as part of the smaller action research cycles reported at Figure 7, but I also used it retrospectively to identify facilitators and barriers. Using Braun and Clarke's (2013) approach outlined in Table 11, the process of coding and analysing the data will now be described in detail.

5.2.1.1 Transcription

Between 30 June 2015 and 7 June 2016 there were 11 CIG meetings all of which were audio recorded; I took supplementary notes and captured points of interest in my journal. I transcribed the notes of the meeting and then shared them with the CIG to check for accuracy and completeness. This enabled me to become familiar and fully engaged in what would become the primary dataset and so was a good investment of time and initiated the data analysis process. Points of interest were noted as "Comments" usually in my journal.

5.2.1.2 Reading and familiarisation

The recordings were transcribed as soon as possible after every meeting to ensure that the conversations were recalled contemporaneously while fresh in my memory. Whilst this gave me an opportunity to get an in depth understanding of the data, each set of notes was considered in isolation so did not allow me to consider the breadth of the data set in its entirety. To address this, prior to commencing any coding, I read all the notes from the CIG meetings together and noted points of interest.

5.2.1.3 Coding complete across dataset

An inductive approach to the retrospective data analysis was undertaken. Inductive analysis is data driven and is a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions (Braun & Clarke, 2006).

After a thorough read and familiarisation of the transcripts, I imported them into NVivo software and coded them. Coding involves categorising the data of interest and then assigning tags to those categories (Bryman, 2012). I undertook coding based on the following principles:

- on what I expected to find based on past literature and common sense
- what was surprising and unanticipated
- the unusual, which may be of conceptual interest to the readers (Creswell, 2014).

Once coded, the content was captured under 'nodes', as described in the NVivo software. A list of the nodes can be found at Appendix 17. A sample of NVivo coding against the node "patient stories" is shown at Appendix 18.

5.2.1.4 Rationalisation of codes

Once all the notes had been coded, I reviewed the nodes, and made some refinements, e.g. the terms 'constructive debate' and 'questioning' had been used to code data but contained much of the same material and were subsequently merged under one node -

questioning. Some nodes were deleted as I deemed them insignificant having only coded one item of text to them, e.g. innovation. This reduced the number of nodes and enabled themes to begin to be identified more clearly. I decided not to revisit the coding once I had rationalised it and the CIG had reviewed it. My journal at the time states: "*I want the data to remain as unfiltered as possible and do not want to recode it. I have compared my initial findings with that of the group and if I recode it now, I think there is the potential for subjectivity and bias*." (Journal entry: 5/01/16).

5.2.1.5 Searching and reviewing themes

Themes relating to change became evident quite quickly and, informed by the organisational change literature and my prior knowledge, were classified into 'facilitators' and 'barriers'. Other nodes needed some further review before being aggregated with others, e.g. the theme of 'patient stories' was reviewed, and some text reclassified as relating to rehabilitation as an approach whilst other text was classified as a facilitator for change.

5.2.1.6 Defining and naming themes

Once this process had been concluded there were eight primary nodes, 49 when child nodes were included. These eight nodes became known as the key themes and would appear as major findings in the study supported by quotes and specific evidence.

5.2.1.7 Writing and finalising analysis

Having undertaken this process, to meet the dual intention of action research to 'act' but also to produce rigorous research and to generate knowledge, I needed to consider the data in two ways: the action that had taken place and the research findings. These findings are reported under the relevant Inquiry phase.

5.2.2 Data from the evaluation form

As discussed in 4.2.2.2, the evaluation form was analysed by me without the use of software and the results reported in the relevant sections of this chapter.

5.3 Findings

This section will present what the CIG considered the facilitators and barriers to integrating a rehabilitative approach to be and interpretations made by me based on the thematic analysis of the CIG meetings. This process of synthesising different views helps to ensure rigorous research (Coghlan & Brannick, 2007). Several quotes from the CIG are included and add to the research's authenticity (Guba & Lincoln, 1994; Zuber-Skerritt & Fletcher, 2007) but is also considered as good practice in writing PAR studies as it conveys the co-researchers' voice (Smith et al., 2010).

5.3.1 Facilitators to implementing an RPC approach

This section outlines what the CIG considered the facilitators to integrating a rehabilitative approach were and the interpretations made by me based on the thematic analysis of the CIG meetings.

The way the CIG conducted itself was referenced specifically and in detail as a facilitator by three CIG members on the evaluation form, as follows:

> O6: “The group were productive and focused during meetings to maximise the time available; meetings always ran to time and there was well directed discussion”.
>
> A3: “Communication, teamwork and the overall enthusiasm for the project. The group was determined to think again and overcome the issues that arose”.
>
> S7: *“*Determination and motivation of the CIG group, collaboration*”.*

The characteristics of the CIG and the degree to which it influenced change were described in Inquiry One (Chapter 4). As part of the evaluation form, the CIG was asked what helped to drive the project forward. I have summarised their feedback into three key areas: engagement, subject matter and teamwork.

5.3.1.1 Engagement

Engagement was considered a critical success factor by all CIG members but there were differing views about which stakeholders had made the most difference. O6 and S7 said that it was the engagement of management that had been the facilitator and at the end of the study L8 said that senior staff seemed more aware and supportive of the concept which would help influence managerial change. A3, L8, D5 and O6 said that my involvement and the engagement of all CIG members had enabled progress to be made. This aligns with the characteristics of a co-operative inquiry and communicative space explained in Chapters Three and Four. I was also identified as a change facilitator by five CIG members for different reasons. Some felt that it was my knowledge and experience that had been the key (L8, S7), whereas others felt it was my commitment, proactivity, and hard work (A3, O6, D5).

As an enabler of change, engagement was the theme that appeared most frequently in the thematic analysis with over 100 references to it across eight out of the 11 meetings indicating that it was a theme throughout the study. The analysis from the meetings suggested that the CIG felt it was important to engage with the entire organisation including volunteers:

> "it would be helpful to have both staff and volunteers there as it could break down barriers and give out the message that we are all one team" (A3: CIG, 12/11/15), "it's really encouraging that the volunteers are so keen to support this and that this will have a positive impact on the nurses in terms of embracing the approach"(L8: CIG, 12/11/15), "it's clear that you need to get everyone on board ..with mixed groups to provide an added richness" (S7: CIG, 01/10/15).

One mechanism for doing this was to share patient stories because it enabled people to see the approach in practice or could validate existing practice: "there has been a useful case study in the IPU recently which has enabled us to demonstrate a RPC approach in practice" (A1: CIG, 12/11/15). I also found evidence of the CIG specifically wanting to engage others in certain action cycles, e.g. in planning how to integrate the approach (see 5.3.1.4)

5.3.1.2 Subject matter

Being able to explain the concept of RPC was identified by all CIG members as the key to overcoming any barriers the group faced in implementing this approach. As a concept, RPC was mentioned by three out of five CIG members as being a change facilitator. A3 felt that it had been successful because the CIG had a shared interest in the topic, which was a current, validated new approach, endorsed by two prominent hospices which gave it credibility. It was also expressed that there was already some existing good practice in place.

Evidence from the thematic analysis supported the fact that RPC as a concept, and as a model of care, was felt to be a contributory factor in bringing about change. The CIG was keen to make the connections between this approach and current practice and to ensure that existing good practice was highlighted and celebrated. Taking the time to explain what RPC was and using evidence to support its use was also mentioned as a positive feature and this was done via using patient stories. CIG members referenced how patient stories engaged staff and volunteers either because it enabled people to see the approach in practice or would validate existing practice: "'case stories' … help people to see this approach working in practice. This will be important in the training as patient stories really help to get the message across" (A3: CIG, 09/12/15).

5.3.1.3 Working together

The manner in which the CIG conducted itself and the way it considered the wider organisation was identified as one of the key factors in making change happen. In the evaluation form, the CIG members described the group as: *supportive* (L8, S7), *enthusiastic* (L8, D5), *collaborative* (L8, A3), *motivating* (L8), *responsible* (A3, O6) and *participative* (A3, O6). The thematic analysis of the notes from the CIG meetings supports this with discussions reflecting a joint problem-solving approach and collaborative working. There was some evidence that the support the CIG gained from each other enabled them to feel empowered to make change happen.

5.3.1.4 Empowerment

Empowerment was a facilitator apparent in the thematic analysis both in terms of empowering each other and others. Empowering others outside the CIG manifested itself when the CIG was:

a. planning how to integrate the approach: “It would be great to get the volunteers and the IPU staff working together to figure out how they could do this” (L8: CIG, 12/11/15), “.. we should explain that members of the CIG … want to find out the views of their colleagues” (A1: CIG, 01/10/15), and
b. discussing the training: “the groups themselves could come up with the ideas because then they’d be invested in it” (A1: CIG, 12/11/15).

Whilst the factors above were considered facilitators, when they were not present they became barriers. These and other factors that were considered as inhibitors to change will now be examined.

5.3.2 Barriers to implementing an RPC approach

In a similar vein to identifying the facilitators, CIG members were asked what they considered to be the barriers to change. Combined with the thematic analysis, the themes that I identified were: lack of engagement, infrastructure, alignment with the current model of care and roles, terminology and attitudes to change.

5.3.2.1 Lack of engagement

Despite the positive feedback about engagement, according to their evaluations, two members of the CIG felt that a lack of engagement by senior management had been a barrier to achieving change, or at least to making as much progress as they would have liked. In the thematic analysis I found that a lack of engagement was something that caused concern for other group members too: "both times the concept had been presented at the Clinical Leaders Forum (CLF)…the key people hadn't been there. It feels like this is where the block is rather than the staff who are keen to move it forward" (E2: CIG,11/02/16). At one CLF meeting a director asked, "*have we signed up for this*?" which was interpreted as a criticism by CIG members and they became concerned that the nursing team felt that the approach was being imposed upon them. This perception of a lack of engagement by senior managers was fuelled when a communication produced by CIG members for the internal Hospice newsletter was discarded on the basis that it was premature and that more awareness raising was needed first (see 4.2.4).

Two CIG members reported a sense of apathy about the approach from some clinical staff: "I don't get a sense of any real enthusiasm about it" (E2: CIG, 12/11/15) and A3 stated in the evaluation that a barrier was a "lack of engagement from some people (clinical)".

5.3.2.2 Infrastructure

'Infrastructure' refers to issues that the CIG raised relating to the practical, organisational difficulties it encountered when trying to implement this approach. Two members of the CIG highlighted insufficient time and resources either for themselves to progress the work of the CIG, or for the broader team to be available to attend training:

> "there are staffing issues on IPU and from my reading of organisational change, you only have one chance to get it right and this will fail if no-one can attend*"* (L8: CIG, 01/10/15),

> “if it (the training) is not within protected time it will be a real challenge to get nurses off the ward to attend training” (O6: CIG, 12/11/15).

Staff vacancies were also raised as a concern: “I’m concerned about who will deliver them (training sessions) given the planned absence of the occupational therapy team and the vacancy in the physio team” (E2: CIG, 13/04/16). There were also concerns about the volume of people who needed to undertake training and the financial implications of doing this (L8).

The CIG felt that the process for approving the adoption of RPC was unclear: “this is a seminal piece of work and yet there is no forum to take it forward. How can organisational change be effected when there was no opportunity to discuss such things?” (S7: CIG, 02/09/15).

This was compounded by the concerns raised earlier about a lack of engagement from senior staff. Another member said that the in-patient unit had several competing priorities which meant that RPC would not be seen as a priority and that the perceived additional workload could also be a barrier: “we need to make sure we don’t make it sound like too big a deal because then staff might begin to think: ‘oh no, not another thing!’” (O6: CIG, 01/10/15). There was also a view that the Hospice had already been through so much change and therefore may be unable to cope with more: “Have we reached a point of fatigue within the organisation at the moment, do we have the energy to add something new when there’s so much else to do” (L8: CIG, 01/10/15).

5.3.2.3 Alignment with the current model of care and roles

RPC as a subject was recognised as a facilitator but also as a barrier to achieving change. In their evaluations two CIG members said that a lack of understanding about RPC, or an inaccurate perception of it was a barrier. One of those expanded on this by saying that the difficulty was aligning it with the current model of care. This was reflected in the thematic analysis where there was also some evidence that staff and volunteers might find adopting and adapting to RPC challenging and perceive it as a change or threat to existing practice. There was also the potential for the nursing staff to feel their skills were undervalued. S7 alluded to this by saying, “I think we have to be careful about not deskilling people, they are nurses and I think we have to be careful about the sensitivities around this” (CIG, 09/12/15). A1 expressed concern about staff becoming defensive because of a lack of knowledge and L8 said that she’d noted that “some of the staff have identified how difficult this was going to be for them” (CIG, 09/12/15). E2 recounted the following conversation when feeding back from a meeting with Wellbeing staff:

> E2 (CIG,09/12/15): “.. it was suggested that one of the things the Wellbeing staff could consider was whether they needed to make drinks for patients and.. could patients be encouraged to make their own tea. In response, the staff said that they enjoyed making tea for patients”.

L8 acknowledged how challenging this approach may be for some staff because, *“*they are so used to doing things for patients that it will take some effort to stop doing that” (CIG, 09/12/15). There seemed to be a perception that providing good care was associated with ‘doing’ things for patients which was exemplified by A3 who recounted his experience with volunteers who supported the Cookery Group: “it wasn’t enough for them [volunteers] to simply be there. They wanted to be actively involved and I had to keep explaining that it was ok for them [patients] to make a mistake or to make a mess" (CIG, 13/04/16).

5.3.2.4 Terminology

There were also issues with the terminology. When the CIG first met it spent a considerable amount of time grappling with what palliative rehabilitation and rehabilitative palliative care meant, and this was mirrored with the PAG. Given the difficulties faced by the CIG in understanding the concept, we presumed that the wider organisation would also struggle. In one CIG discussion, A1 said, "people think it's what physios and OTs do; it's the word rehabilitation" (CIG, 30/07/15). A1 was also keen to see what alternatives there were to the words 'palliative' and 'rehabilitation' to address this issue. The CIG acknowledged that to gain understanding and consensus staff and volunteers needed the opportunity to discuss the concept of RPC fully and agreed that this would be a crucial aspect of the training programme and one of its primary aims.

5.3.2.5 Attitudes to change

The final factor identified as a barrier by the CIG, and evident in some of the comments made above, was attitude to change. Although only referenced specifically by two CIG members in their evaluations, 'change' was identified as a theme in the analysis. One CIG member said that "general resistance to change" (S7: evaluation form) was a barrier whereas the other stated that she felt that there was a "fear of change for change sake in an organisation that had gone through recent changes" (D5: evaluation form). The thematic analysis offered more insight into this issue with factors such as a fear of something new, a lack of understanding of the need for change, the potential for poor execution of the change if not properly planned and change fatigue (as referenced in 5.3.2.2) being voiced.

5.3.3 Factors enabling barriers to be overcome

Despite the barriers that the CIG identified and those that I identified in the analysis, progress was made. Retrospectively, the CIG was asked, in general terms, how any obstacles were overcome. The factors they identified are described in Table 12.

Table 12: Factors enabling barriers to be overcome

Factors	**Detail**	**Referenced by**				
Good communication	Explaining RPC	O6	D5	S7	A3	L8
	Repeated communication to various audiences			S7		
Carefully considered training plan	Pro-active approach to training	O6	D5	S7		
Positive behaviour of the CIG	Productive and focused	O6				
	Determined and motivated			S7	A3	
	Good use of time	O6				
	Well- directed discussions	O6				
	Collaboration			S7		
	Teamwork				A3	
Engagement of key people	Involving all staff and volunteers		D5			
	Encouraging teams to talk about RPC and its benefits			S7		
	Senior management buy-in					L8
Research focus	There was a research project looking at the topic			S7		

Articulately explaining what RPC was about was identified as key to facilitating this approach.

5.4 Discussion

To assess whether this study was unique in terms of facilitators and barriers I compared my findings to the work of Meyer et al. (2000) who undertook a systematic review of action research with the aim of identifying those factors that inhibit and facilitate change in healthcare practice. In this review ten facilitators and 13 inhibitors were identified. Only two out of the 13 barriers identified by them were evident in our study: poor infrastructure/lack of resources and resistance to change. Four other inhibitors I identified were related to the topic of rehabilitation and were therefore subject specific, and the remaining barrier was lack of engagement.

In terms of the facilitators, seven out of 10 of those identified were evident in our study. Many of them were attributable to the CIG and identified as part of their evaluation, as described in Chapter Four: commitment, talking/supportive culture, multidisciplinary teamwork, enthusiastic leadership, appreciation that change is difficult, management support and ‘insider’ researcher.

The fact that I could identify only two out of 13 of the barriers to change but seven out of ten facilitators could imply that the environment for our study was conducive to enabling change and perhaps this supports my proposition, in Chapter Four, that the CIG created a ‘communicative space’ which enabled barriers to be overcome and the facilitators identified and augmented. In making this assertion I am aware of my own bias (this was my research and I wanted it to be successful and I was in a position within the organisation to drive it forward). However, these findings do contrast with Hockley (2006) who identified at least seven out of the thirteen inhibitors in her action research study, and she suggests that establishing a 'communicative space' could have addressed these.

The other factor to consider was my dual role of insider researcher and senior manager and in Chapter Three I outlined briefly the factors related to being an insider researcher. In reviewing the inhibitors and facilitators of change in action research, the insider researcher was identified as a facilitator (Meyer et al., 2000) and in undertaking this research, I would agree. The feedback from the CIG concurs that my presence within the group and vested interest in the outcome of the research probably was an enabler but this dual role did demand a significant degree of reflection. The following extracts from my journal illustrate this and demonstrate reflexivity in practice. Two areas are considered: control and role conflict, which illustrate the tensions of being both a facilitator and potential barrier to change happening.

Control

My journal entry states:

> "*The meeting started to discuss engaging people outside the Hospice when this is irrelevant to the study. Why didn't I curtail the conversation and pull it back to the topic needed? I can often see merit in what's being said and so felt reluctant to end a conversation that might have offered something*." (Journal entry 29/06/15).

In this example I was reflecting on the impact of my actions on the research – methodological reflection (Johnson & Duberley, 2000). I felt an urge to intervene and control the meeting but to have done so would have felt like a breach the principles of PAR. Had I not been 'chairing' it may have felt different and I may have felt less concerned about intervening. Following this meeting I talked to the group about strategies we should employ if we felt that the group were becoming distracted. We subsequently agreed that there was a mutual responsibility to be aware of and address this, but that in the early stages the group felt the onus was on me to ensure we remained focussed. This was helpful as it enabled me to realise that I did have a role in guiding the process to develop confidence and the capacity to engage in the research process (Andrews et al., 2013). There was feedback that suggested that by the end of the study this had been handled well:

> "The researcher has allowed the group to develop, while being aware of the need to ensure the research stays within reasonable parameters, which has been done through open and honest discussion*"* (S7: power survey);
>
> "The lead researcher has facilitated the team extremely well and when there have been times she has had to interject or 'steer' individuals away from particular thought patterns or conversations it has been done in an incredibly skilled way" (L8: power survey).

Role conflict

My journal entry states:

> *"I'm anxious about the sole nurse in the group, does she feel overwhelmed or outnumbered by the therapists? Should I do something or is that me stepping*

> *into management mode rather than a co-researcher? I don't want to lose her; her perspective is too important." (*Journal entry 06/08/15*).*

There was nothing I did specifically to address this other than to observe the individual's behaviour in the group, ensure she was gently encouraged to participate and overtly show that I valued her contribution. One CIG member said that this individual's presence was the most powerful in the group because it brought the voice of nursing to a field that tended to be dominated by therapists. The individual in her analysis said that she had enjoyed taking part in the project and developing her research skills and has subsequently completed a Master's degree dissertation on this topic.

I support Hockley's (2006) view who states how her "feelings and responses to what was being said and done … were just as important as other data" and that "reflexivity helped [me] to clarify what I was learning" (p.93). I would add that the reflexive nature of the research and my attention to it was a key factor in enabling the research to remain focused and for change to happen. Hockley (2006) suggests that reflection is needed for change to happen; I would argue that change can happen without reflection, but *sustainable* cultural change will only occur as a result of reflection by all those involved: "unless people can integrate change on a personal level, they cannot sustain it organisationally" (Moran & Brightman, 2001, p.112).

5.5 Conclusion

From these findings there were two factors that, if addressed, enabled change to happen but if not became obstacles: understanding and acceptance of the subject (RPC) and engagement of key people. Key facilitators included having an effective and empowered team, undertaking insider research and using patient stories as exemplars of RPC in practice. However, there were several issues that needed to be overcome to make change happen: improved organisational systems to enable new models of care to be identified, discussed and implemented; greater understanding of roles within the Hospice, particularly therapists; and an awareness that new models of care can challenge the status quo which can make people change averse.

Chapter Six: Inquiry Three: Literature review

6.1 Introduction

This literature review was intended to provide more data about what enabled or prevented a rehabilitative approach from being integrated with palliative care, by understanding what healthcare professionals (HCPs) perceived the facilitators and barriers to be. This enhances the primary research by identifying whether the enabling and inhibiting factors in my study are reflected in the literature and will also provide greater insights into the concept of rehabilitation in palliative care by explaining how this has been integrated in other settings.

6.2 Method

The literature from multiple qualitative studies involving rehabilitation in the healthcare setting was systematically collated and integrated using thematic synthesis (J. Thomas & Harden, 2008). Based on the original work of Noblit and Hare (1988), this approach aims to not just simply combine the results of qualitative data but to also search for new interpretations of the data, and includes all types of qualitative research (Aveyard, Payne, & Preston, 2016). This method has been developed and applied to several systematic reviews that address questions about people's perspectives and experiences and therefore aligns with the purpose of this review. In addition to being developed and used by Thomas and Harden (2008) and Harden (2009) collectively and independently, this approach was utilised by Joseph-Williams et al. (2014) in identifying patient-reported facilitators and barriers to shared decision making. Thematic synthesis is undertaken using the following stages:

a. Identifying a research question
b. Purposive searching with the aim of conceptual saturation rather that a comprehensive inclusion of all literature
c. Quality appraisal
d. Identifying key concepts in individual studies
e. Developing codes and themes from the key concepts
f. Checking consistency of coding/themes between different studies
g. Generating themes; third order interpretation (J. Thomas & Harden, 2008).

a. Identifying a research question

The question to be answered by the literature review was: “What are the facilitators and barriers to integrating a rehabilitative approach with palliative care according to healthcare professionals?” A preliminary literature review had been undertaken at the start of this research before the term rehabilitative palliative care had been introduced. At that stage the literature being examined related to “palliative rehabilitation”. Having only been introduced in July 2015, the term RPC is still not widely recognised within the literature and therefore the following factors defined the literature research question:

- if used in isolation “RPC” was unlikely to generate sufficient results and so a broader term - “rehabilitative approach” - was adopted
- examining a “rehabilitative approach” enabled the search to include studies where rehabilitation, as a model of care or service, had been introduced
- a “rehabilitative approach” includes therapeutic interventions by physiotherapists and occupational therapists that may not always be described as rehabilitation and also enables a rehabilitative approach adopted by nurses or other HCPs to be captured

- the words “palliative” and “rehabilitation” and variations of them were used to ensure the search was as inclusive as possible.

b. Purposive searching

A multiple and iterative search strategy was adopted using: purposive, snowball and ‘berry-picking’. A purposive approach to the literature search process is used because the purpose of the syntheses is interpretive explanation rather than predictive (Glenton et al., 2013; J. Thomas & Harden, 2008) and it focuses on concepts.

Given the limited amount of research on RPC, the search had to be broad enough to capture barriers and facilitators according to those clinicians associated with rehabilitation rather than simply relying on rehabilitation as a search term. Therefore, the words “physiotherapist” and “occupational therapist”, and variations of them, were included as search terms. Setting was not included in the search strategy on the basis that a rehabilitative approach could be combined with palliative care in any setting. *How* it worked from the HCP’s perspective was the important feature, not *where* it took place.

The search was undertaken in September 2017 and repeated in April 2018. A search using CINAHL is shown at Appendix 19 and the search terms used are shown in Table 13. These terms were searched individually and then combined using the Boolean operator AND. This search was then adapted for use in MEDLINE, PUBMED, PsycINFO, and Web of Science. A record of all database searches can be found at Appendix 20. The search was supplemented by following up references from retrieved articles and citation tracking.

Table 13: CINAHL search terms

Topic	**Search terms: CINAHL**
Hospice or palliative care	Hospice OR "palliative care" OR "terminal care" OR "hospice care" OR "end of life" OR "life threatening illness" OR “hospice and palliative nursing”.
Rehabilitation	rehabilit* (using truncation to pick up words such as rehabilitate, rehabilitative and rehabilitation) OR "goal setting" OR “goal achievement” OR "goal planning" OR “goal attainment”.
Healthcare practitioner	practitioner* (using truncation to include practitioners) OR nurs* (using truncation to include nurse, nurses or nursing) OR clinician* (clinicians) OR staff OR employee OR physiotherap* (to pick up physiotherapist(s) and physiotherapy) OR "occupational therap*” (using truncation to pick up therapy, therapies and therapist) OR “allied health”.

To determine whether the studies should be retained, the title and abstract were examined to see if they related to end of life or palliative care, referred to rehabilitation or a rehabilitative approach and included perceptions of HCPs. Although the literature search question was to understand the facilitators and barriers, these were not always immediately obvious and so studies were not excluded if these were not referred to in the title or the abstract. The inclusion and exclusion criteria shown in Table 14 were also applied.

Table 14: Inclusion and exclusion criteria

Inclusion	**Exclusion**
Feedback from any type of healthcare practitioner.	Studies focused on older people's care, stroke, spinal cord, acquired brain injury and mental health were excluded because other factors, unrelated to end of life care, may facilitate or hinder a rehabilitative approach in these contexts.
Studies based in any setting.	Paediatric palliative care.
English language texts.	Studies that focused solely on the patient experience.
All studies will be included including systematic reviews. Systematic reviews were used to identify references rather than analysed as part of the thematic synthesis and care was taken to ensure studies were not recorded twice.	Book reviews, editorial reviews, commentaries and letters.
Studies from 1970 onwards as palliative care had only been established within healthcare since then (Boa et al. 2014).	Studies prior to 1970.

After this initial screening the studies were transferred to an Excel spreadsheet so that duplicates could be removed.

c. Quality appraisal

The studies retrieved were not quality appraised on the basis that there is little inter-reliability in quality appraisal (Dixon-Woods et al., 2006) and no empirically tested methods for excluding qualitative studies based on quality (J. Thomas & Harden, 2008). Furthermore, there was such a limited number of studies available, there was a risk that after being quality appraised there would be insufficient numbers of studies to be meaningful.

d. Identifying key concepts

Using the same approach adopted by Thomas and Harden (2008), all text labelled as ‘results’ or ‘findings’ was treated as the findings from the study, and the themes were identified from those sections. This meant that any interpretation by the author in the discussion section was avoided and prevented data being duplicated because it was referenced in both the ‘findings/results’ and the ‘discussion’ sections.

e. Developing codes and themes

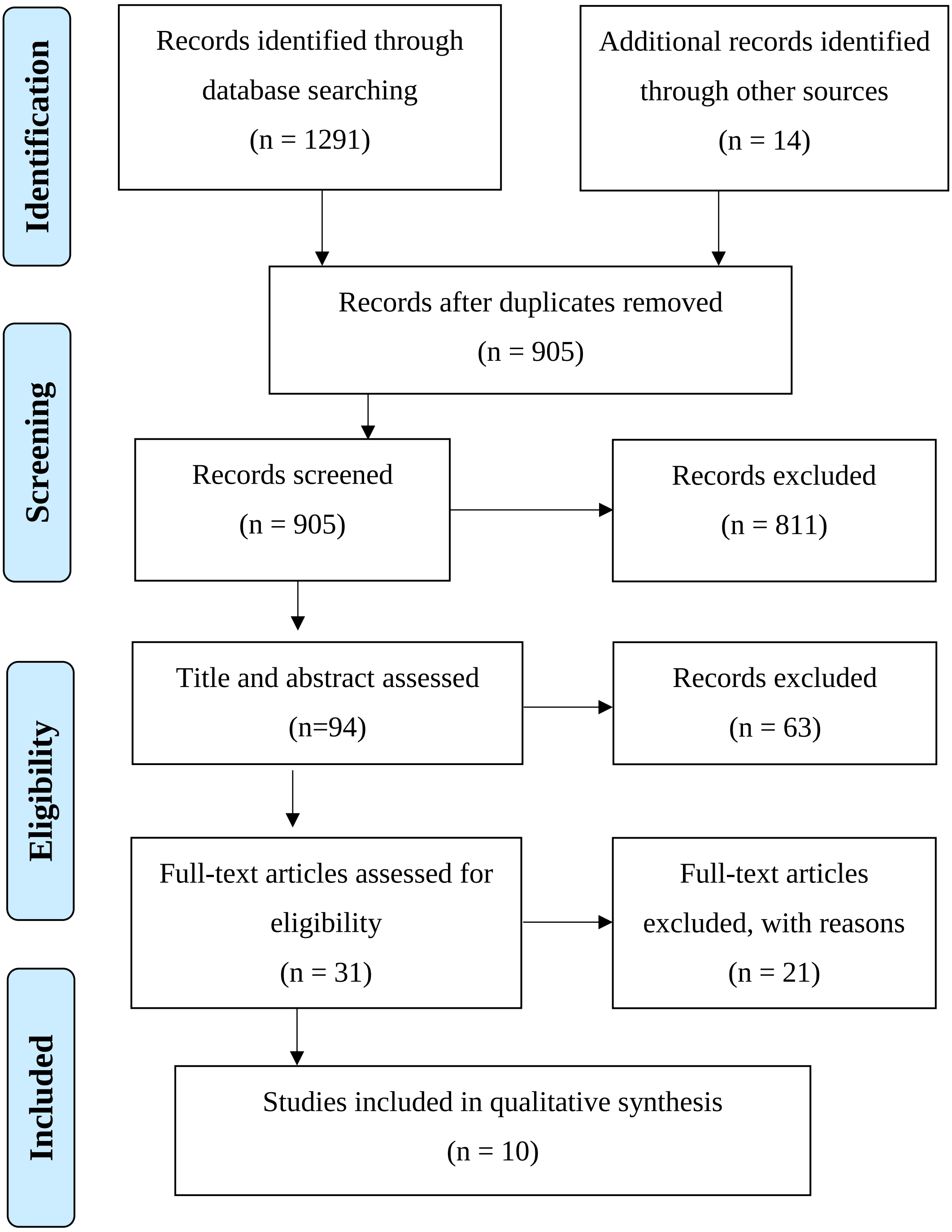
NVivo was used again to thematically code the literature. The themes that had evolved from the primary research could have been used as an a priori framework but in doing so facilitators and barriers that did not arise in my study could have been overlooked, or the focus for the synthesis be too narrow. An inductive approach was instead taken with the codes being created according to the meaning and content of each sentence in the findings of the study and this felt congruent with the inductive approach to the research that had been adopted so far.

f. Checking consistency and generating themes

Once the text had been coded I reviewed it to ensure that consistent interpretations had been applied. These developed into descriptive themes aligned with the original findings of the studies which then evolved into analytical themes.

6.3 Findings

A total of 31 full text articles were reviewed in full and 21 excluded. Figure 8 illustrates the sifting process using a PRISMA flow chart.



(Moher, Liberati, Tetzlaff, Altman, & Grp, 2009).

Figure 8: PRISMA flow diagram illustrating the literature search process

A summary of the papers retrieved via the literature review is shown in Table 15. Ten studies were identified: seven from the UK, including three from Northern Ireland, and three from Australia. Nine studies had taken place between 2010 and 2018 and one study was undertaken in 1995. The participants were: multidisciplinary (n=4), district nurses only (n=2), allied healthcare professionals (n=1), occupational therapists only (n=1), physiotherapists only (n=1) and doctors only (n=1). The predominant method used to conduct the research was qualitative individual semi-structured interviews (n=5), case study (n=2), focus groups (n=1), qualitative questionnaire (n=1), and a combination of individual interviews and focus groups (n=1). Qualitative studies have limited generalisability but their value is in exploring experience and gaining understanding (Holloway, Wheeler, & Holloway, 2010).

The study sample sizes ranged between 5 – 20 and one study, Nwosu et al (2012), had 59 participants. Small samples such as these allow for in-depth data analysis (Crouch & McKenzie, 2006) but can also mean that the findings are not representative of the entire population unless good purposive or theoretical sampling has taken place (Ritchie & Lewis, 2003).

Most studies reflected the perspective of the HCP but Ashworth (2014) comprised of three case studies, described by the author who was an occupational therapist. There are certain limitations to this study: the methodology is not described; case studies are not generalisable and the objectivity of the author is questionable. None of these limitations are acknowledged in the paper.

Table 15: Summary of papers from the literature search

Author (year)	**Aim**	**Method**	**Participants/ Setting/ Organisation**	**Setting and country**
Ashworth (2014)	Extend and increase education about the role of occupational therapy and goal-setting tools.	Qualitative - Case study	Author – occupational therapist (OT)	Palliative care unit, Hospital, Melbourne, Australia
Boa et al. (2018)	Investigate health-care practitioners' understanding and practice of patient-centred goal setting in a hospice.	Qualitative - Comparative case study	10 participants: two doctors, five nurses, one physiotherapist, one OT and one social worker.	Hospice, Scotland, UK
Carson and McIlfatrick (2013)	Explore the perceptions of physiotherapists working within palliative care and the barriers and enablers they face.	Qualitative -semi-structured interviews	11 physiotherapists based in the community	Community based Health and Social Care Trust. Northern Ireland, UK
Halkett et al. (2010)	Explore barriers to occupational therapy in palliative care as perceived by OT and other healthcare professionals.	Qualitative – semi-structured interviews	10 OT, six nurses, two medical registrars, one social worker and a physiotherapist	Hospital and Community,

				Western Australia
Leedham (1995)	Investigate the beliefs of district nurses in relation to rehabilitation in palliative care.	Qualitative – semi-structured interviews	10 district nurses (DNs)	Community, Manchester, UK
Nelson et al. (2012)	Explore district nurses' beliefs regarding referral of a patient receiving palliative care for physiotherapy.	Qualitative – focus groups	16 DNs	Community, Northern Ireland, UK
Nwosu et al. (2012)	Explore the perceptions of palliative care and respiratory MDT members about the role of rehabilitation for lung cancer patients, examine patterns of referral to and highlight the barriers preventing referrals to rehabilitation services.	Qualitative – Questionnaire	59 healthcare professionals: 22 nurses, 20 doctors, four discharge planners, four physiotherapists, three social workers, two OT, two pastoral carers, an MDT coordinator and one Other	Hospital, specialist palliative care in-patient units and community, Merseyside and Cheshire, UK
Runacres et al. (2017)	Explore palliative medicine physicians' attitudes and perceptions towards rehabilitation delivered within in-patient palliative care units.	Qualitative – interviews (telephone or face to face)	20 palliative care physicians	In-patient palliative care units,

				Australia and Tasmania
Waldron et al. (2011)	Explore the views of allied health professionals in delivering rehabilitation in palliative care to people with Parkinson's disease.	Qualitative – individual interviews and focus groups.	12 allied health professionals: physiotherapists, OT and speech and language therapists.	Community - NHS, private & voluntary specialist palliative care, N. Ireland, UK
Wosahlo (2014)	Identify the factors facilitating change in hospice culture and structure that might be required for a successful initiative to optimise the provision of rehabilitation.	Qualitative –semi-structured interviews	Three physiotherapists, an OT and a nurse	Five hospices, UK

Boa et al. (2018) was a mixed methods study which meant that in addition to the HCP’s perspective the literature review included some patient perceptions and observations made by the author on behalf of the HCP. The single site and small sample size of this study means that these findings may not transfer to other palliative care settings. However, a representative range of HCPs took part in the study, multiple data sources were used, and the data were transparently analysed and reported. With the exception of this study, several authors (Carson & McIlfatrick, 2013; Halkett et al., 2010; Nwosu et al., 2012) recognised that patients’ views were not considered as part of their studies and that this would be worthy of future research.

It is important to acknowledge that many of the studies were community-based: (Carson & McIlfatrick, 2013; Leedham, 1995; Nelson et al., 2012; Waldron et al., 2011) and Halkett (2010) and Nwosu (2012) were hospital and community. Only two studies Boa et al. (2018) and Wosahlo (2014) involved HCPs working in hospices suggesting that this setting is under-researched.

None of the studies included health care or nursing assistants in their samples and yet as a multidisciplinary approach, their involvement in delivering RPC is significant. They often spend long periods of time with patients providing personal care and are therefore ideally placed to understand what is important to them (Tiberini & Richardson, 2015).

A final consideration when comparing these findings is that models of palliative rehabilitation are likely to vary in regional or rural settings and internationally.

Furthermore, models and perceptions of the role of rehabilitation in palliative care may also be disease specific.

6.4 Data synthesis and discussion

The following section synthesises the findings to explain what the facilitators and barriers to implementing a rehabilitative approach are according to the literature. In the literature, the aim of the study influenced whether the author described the issues as facilitators or barriers, e.g. one study may describe training as a key enabler and another report that a lack of it was a barrier. For consistency, the author's interpretation of the issue has been preserved but for these reasons it is not possible to identify the facilitators and barriers separately because, depending on the author's emphasis, some factors appear as both. The factors have been summarised into four key areas: the concept of a rehabilitative approach to palliative care, different models of care, resources and infrastructure and teamworking.

6.4.1 The concept of a rehabilitative approach to palliative care

In the literature, the concept of a rehabilitative approach was identified as a facilitator and a barrier to change and referenced in five studies. There was evidence that a rehabilitative approach had an important part to play in palliative care, was an important component of holistic care and beneficial to patients (Boa et al., 2018; Leedham, 1995; Nwosu et al., 2012; Runacres et al., 2017). Wosahlo (2014) highlighted its efficacy in supporting those who wished to die at home and/or with non-malignant disease. There was mutual interest and enthusiasm for rehabilitation in palliative care and its contribution to patient care.

However, it was also evident that there was a lack of understanding about the contribution a rehabilitative approach could make to palliative care (Nwosu et al., 2012), inaccurate perceptions of it (Boa et al., 2018; Nwosu et al., 2012; Runacres et al., 2017); and stereotypical views about the roles of those who were considered the experts, i.e. physiotherapists and occupational therapists. This resulted in opportunities to offer rehabilitation being missed (Ashworth, 2014; Boa et al., 2018; Halkett et al., 2010; Nelson et al., 2012). This issue was compounded by a perceived lack of evidence about rehabilitation, or goal setting, for palliative patients (Ashworth, 2014; Boa et al., 2018; Carson & McIlfatrick, 2013; Halkett et al., 2010; Runacres et al., 2017)which led to scepticism and a lack of confidence in the approach (Halkett et al., 2010; Nelson et al., 2012; Runacres et al., 2017). Combined with a lack of understanding of the concept there was also some evidence that because it was different to the current model of hospice care, some people were unwilling to engage with a rehabilitative approach. However, neither the evidence base nor policy recommendations were mentioned by participants in Wosahlo (2014) when considering what factors facilitated the provision of rehabilitation in five hospices but these findings should be viewed with caution due to the small sample size (n=5).

6.4.2 Different models of care

One of the challenges in adopting a rehabilitative approach, described in the literature, was the difficulty in aligning it with the historic and traditional model of hospice care (Runacres et al., 2017; Wosahlo, 2014) and that stereotyping of palliative care patients influenced staff to prioritise giving comfort and care over enablement and promoting independence, possibly to the patients' detriment (Runacres et al., 2017). Some authors suggested that staff may find RPC a threat to existing practice and therefore become defensive, and that this conflict resulted in HCPs becoming protective and risk averse (Ashworth, 2014; Boa et al., 2018; Wosahlo, 2014).

Some paternalistic attitudes were evident in the respondents to the Runacres (2017) study who perceived that if patients were admitted for rehabilitation there would be difficulties in discharging them, the patient might have unrealistic expectations and that referring them for rehabilitation might create false hope. These attitudes meant that patients were not referred for rehabilitative support. These findings may be specific to the participants of this study who were palliative care physicians, but some of this was mirrored in Nelson et al.'s (2012) examination of district nurses' reluctance to refer palliative care patients for physiotherapy. In their view physiotherapists did not have the necessary knowledge and skills to provide good palliative care and their introduction could foster false hope among carers and patients. There was also a perception that physiotherapists were task-focused and therefore unable to accommodate the psychosocial and spiritual needs of patients. There are some limitations to Nelson et al.'s (2012) study: the use of focus groups does not allow individual views or experiences to be examined in detail (Braun & Clarke, 2013) and dominant personalities can inhibit the expression of a conflicting perspective (Ritchie & Lewis, 2003). Also, using the Theory of Planned Behaviour to examine the data may have restricted the scope of the analysis.

In much the same way as it was reported from the findings in the primary research, the terms, and therefore the concepts, of palliative care and rehabilitation were reported as an issue in the literature with HCPs avoiding using certain terms such as 'goals', 'rehabilitation' and 'palliative care' for fear that they would create unrealistic expectations or be upsetting for patients (Boa et al., 2018; Runacres et al., 2017; Waldron et al., 2011). This implies that more training is required to ensure that people understand the concepts fully. Having the appropriate training for themselves and others, or personal experience of the approach in practice, were identified as facilitators (Carson & McIlfatrick, 2013; Leedham, 1995) and in Wosahlo (2014) it was suggested that education was an important for developing legitimacy for rehabilitation in palliative care. However, in many studies this was lacking (Carson & McIlfatrick, 2013; Halkett et al., 2010; Runacres et al., 2017). In their investigation into the beliefs of district nurses in relation to rehabilitation, Leedham (1995) found that 20% of respondents said that education for themselves would help them to provide rehabilitation to palliative care patients and 40% said that education of other members of the team would enable them to do this. Leedham's (1995) study is now over 20 years old and so understanding of rehabilitation for palliative patients may well have developed during that time. However, a lack of knowledge sharing amongst team members can lead to a lack in continuity of care (Carson & McIlfatrick, 2013; Nelson et al., 2012) which highlights the importance of teamworking in introducing this approach and in enabling change.

Difficulties in aligning rehabilitation with palliative care did not feature in the Nwosu (2012) and Waldron (2011) studies which is noteworthy as they were the only two studies which were disease specific: Nwosu – lung cancer and Waldron – Parkinson's disease. This could suggest that some of the findings described here relate more to aligning rehabilitation with palliative care in general and are not as prevalent when it is an approach used for specific diseases.

6.4.3 Resources and infrastructure

Aside from its perceived patient benefit another facilitator to integrating rehabilitation and palliative care reported in the literature was its cost-effectiveness and its sustainability (Wosahlo, 2014). Studies referenced access to resources, either in terms of expertise for clinicians and patients, equipment or time as enablers in integrating a rehabilitative approach (Carson & McIlfatrick, 2013; Leedham, 1995; Runacres et al., 2017). Those who had access to resources in the form of palliative rehabilitation services recognised the rehabilitative needs of their patients whereas those who did not have that access did not identify those needs in their patients (Runacres et al., 2017). Respondents attributed this to a lack of confidence in their own ability to support rehabilitation needs if they had not got expertise to turn to.

Although studies recognised how important resources were, they were often lacking. Seven studies referenced a lack resources and/or funding as a barrier (Ashworth, 2014; Carson & McIlfatrick, 2013; Halkett et al., 2010; Nelson et al., 2012; Nwosu et al., 2012; Runacres et al., 2017; Waldron et al., 2011). In one study, a misperception that palliative care patients did not have rehabilitation needs had led to funding restrictions for allied health professionals in palliative care (Runacres et al., 2017).

Aligned with a lack of resources was a lack of infrastructure to support a rehabilitative approach or ineffective systems to enable it (Ashworth, 2014; Nelson et al., 2012; Nwosu et al., 2012; Waldron et al., 2011).

6.4.4 Teamworking

The benefit of effective teamworking between and amongst the internal and external multidisciplinary team and its positive impact on patients was cited in two studies as being an enabler to integrating a rehabilitative approach (Carson & McIlfatrick, 2013; Wosahlo, 2014). However, most studies suggested that poor teamworking was a barrier to providing rehabilitation to palliative care patients (Leedham, 1995; Waldron et al., 2011) and Wosahlo (2014) specified the challenge in engaging the entire team in adopting an enablement focused approach.

6.5 Conclusion

In terms of the literature, a rehabilitative approach for palliative patients was considered beneficial but several factors hindered it application: a perceived conflict in models of care, negative perceptions about the terminology, a lack of awareness of the breadth of the therapists' role, limited resources, an insufficient evidence base and a failure to prioritise training in both palliative care and rehabilitation.

Many of the barriers to implementing a rehabilitative approach identified in this and the previous chapter are common to change initiatives generally. These include: poor communication (Chartered Institute of Personnel and Development, 2018); lack of engagement and teamworking (Iles & Sutherland, 2001; Meyer et al., 2000; Moran & Brightman, 2001; Salmela et al., 2013); inadequate resources (Hoag et al., 2002; Meyer et al., 2000); and insufficient training (Meyer et al., 2000; Vakola & Nikolaou, 2005). Other barriers, however, are unique to this topic: a lack of understanding of the concept, terminology and roles within it and a potential conflict between models of care - one perceived to be focused on caring (palliative) and one based on enabling (rehabilitation). Despite these issues there was consensus that a rehabilitative approach was an important component of holistic care and could benefit palliative patients and that it is possible, from the findings of this study, to integrate a rehabilitative approach into a hospice in-patient setting. Whether it offers an opportunity to integrate a health promoting approach to a hospice in-patient setting will be considered in the next chapter.

Chapter Seven: Rehabilitative palliative care and health promoting palliative care

7.1 Introduction

Health promoting palliative care (HPPC) is to "enhance a sense of control and support for those living with a serious life-limiting illness" (Kellehear, 1999, p.31). It recognises that professional resources are finite and unable to meet the future demands on palliative care, but also argues that dying and death are a social phenomenon and that communities have an integral role to play in supporting those at the end of life. However, a paradigmatic transition from palliative care to HPPC is unachievable unless palliative care organisations work alongside communities to achieve it (Rosenberg & Yates, 2010). The purpose of this chapter is to explore whether RPC care offers an opportunity to integrate a health promoting approach to a hospice in-patient setting.

The findings from the primary study have demonstrated that it is possible to integrate RPC in one hospice setting and there was also some evidence of rehabilitation and palliative care being integrated in the literature (Wosahlo, 2014). The challenges to integrating RPC into an in-patient setting in this study included gaining conceptual understanding and adapting to a model that was perceived to conflict with the current model of care. The focus now will be on taking what has been learned from those inquiries and applying it to the context of HPPC. There are a limited number of empirical studies involving health promoting palliative care. In 2.2, it was mentioned that in 2017, there had been 18 studies worldwide relating to public health approaches to palliative care (Dempers & Gott, 2017b). This means that there is a reliance on a relatively small number of sources. However, the issue under discussion is the *principles* of HPPC, where there does seem be consistency in the literature, and its relationship with RPC.

This chapter will first consider RPC in relation to the key action areas of the Ottawa Charter (WHO, 1986). It will then discuss where there are common themes between RPC and HPPC before examining areas of discord to assess whether RPC and HPPC are complementary approaches.

7.2 Rehabilitative palliative care in the context of health promotion

To understand RPC in the context of health promotion, Rosenberg and Yates' (2010) model will be considered. The model aligns each of the core health promotion components of the Ottawa Charter (WHO, 1986) with descriptions of their application to palliative care organisations. I have expanded Rosenberg and Yates' model to illustrate how the components of the Charter are also applicable to RPC (Table 16). Of the five pillars of health promotion that accord to the Ottawa Charter (WHO, 1986) (noted in the left-hand column of Table 16), three of these are of particular note in relation to RPC and this study: create supportive environments, develop personal skills, and reorient health services.

7.2.1 Create supportive environments

When implementing a health promoting approach in this Hospice, the principles of creating a supportive environment mirrored the experience reported by Rosenberg and Yates (2011) in that they were "immediately understood by hospice staff and volunteers as core business in palliative care and were viewed as already in place to varying levels

Table 16: Applying health promotion to palliative care organisations and RPC

Action areas to support health	**Health promotion description**	**In palliative care organisations**	**In rehabilitative palliative care**
Building public policies that support health	Health is on the agenda of all policy makers, who must consider the health consequences of policy decisions. Obstacles to the adoption of healthy public policies need to be identified and removed.	Concerned with the participation of organisations in the development and/or uptake of public policy relating to palliative care and the support of dying people.	Hospice UK (the national membership body for UK hospices) has adopted RPC as a model for hospice care and is linking it to other new developments such as Age-Attuned Hospice Care (Nicholson & Richardson, 2018).
Creating supportive environments	Health cannot be separated from other societal goals. A sociological basis for health embraces the links between people and their environment.	Concerned with the ways in which organisations contribute to the creation of supportive environments to enhance well-being for consumers and employees of the palliative care service.	RPC works collaboratively with patients, families and carers to develop strategies and to supply equipment to create a supportive environment. It also values and respects all members of the multidisciplinary team who enable patients to adapt to their changing condition whilst retaining as much control as possible.

Strengthening community action	Communities set their own health priorities, make decisions, and plan and implement strategies to promote their empowerment. Community development enhances participation in, and direction of health matters.	Related to the nature of the engagement of organisations with the wider community, beyond the recipients of palliative care services, to promote community action towards improved support of people at the end of life.	The in-patient team are the patient's community while they are at the Hospice. Volunteers bring the community into the work of the Hospice and work in partnership with the patient and clinical colleagues in delivering RPC.
Developing personal skills	The enhancement of life skills through personal and social development promotes people exercising control over their health throughout life.	Concerned with organisations' participation in the development of personal skills to assist individuals to deal with issues around death and dying. Includes both healthcare professionals and primary caregivers.	RPC empowers people to adapt to a new state of living and provides mechanisms to help them anticipate and cope constructively with losses resulting from deteriorating health (Tiberini & Richardson, 2015). These strategies extend to the patient's support network who not only develop skills to support the patient but also to care for themselves.
Reorienting health services	Responsibility for health promotion within the healthcare system rests with all participants. Health services must move beyond clinical and curative services to	Related to the activities of organisations in reorienting their members to a health promoting approach and has a	RPC requires a shift in hospice culture from one focused on care alone to one that incorporates enablement within care to enable people greater choice and

	support individuals and communities for a healthier life. Health research, professional education and training are necessary strategies for refocusing health services towards the needs of the whole person.	particular focus on the holistic needs of its client population, and changes in organisational attitudes.	dignity in advancing illness and to ensure their wellbeing and social needs are given the same prominence as their physical needs.

Source: Adapted from Rosenberg and Yates (2010, p.207).

(Rosenberg & Yates, 2011, p.103). Similarly, there was some evidence from the workshop feedback (Inquiry One) that participants in this study quickly grasped the concept of RPC and considered that aspects of it were already evident in the in-patient unit. This was supported by examples of patient stories provided by the CIG. Workshop participants also recognised that the Hospice had the facilities to create a supportive environment e.g. gym and shared dining area, but that these were under-utilised (Table 9).

RPC introduces the concept of an enabling environment where there are a range of activities and equipment to support patients' independence and to enable them to engage in normal routines such as making a hot drink or preparing vegetables. In the Hospice where this study took place, patients and families are encouraged to bring with them into the in-patient unit any items that will support them to continue to participate in the activities they would do at home. As part of the assessment process the multidisciplinary team works with the patient to understand their daily routine and develops strategies to enable them to continue to do this or to adapt their activities to take account of their changed abilities because of their illness. Although this was one of the weaknesses identified in this study (Inquiry One, 4.4) when the "How rehabilitative is your hospice?" checklist was first undertaken, when re-assessed, improvements were highlighted.

7.2.2 Develop personal skills

In working with HCPs to enable them to continue to do activities they enjoy or to adapt their activities to take account of their changed abilities because of their illness, patients are learning new skills about how to adapt and cope with their deteriorating health status. This in turn increases the options for people to exercise more control and make choices conducive to their health. In Appendix 18 there is an extract from a CIG meeting where A1 describes how learning how to use a commode independently gave one patient more confidence in her ability to cope when returning home. An important aspect of RPC is preparing for death and dying (Bye, 1998) and additionally, a RPC approach works collaboratively with patients' relatives and carers and in doing so informs, educates and supports them to have the skills and confidence to continue to provide assistance.

7.2.3 Reorient health services

A health promoting approach asks health services to be responsive to and to work alongside patients rather than doing things to them which renders them passive recipients of care (McLoughlin, 2012; Rumbold, 2011). Richardson (2002) describes this as a humanistic approach which focuses on the individual, not the disease and regards people as active participants in their own health (Sallnow et al., 2015). However, this requires a paradigm shift in the way patients are supported. In the primary research and the literature, one of the issues was that a rehabilitative approach was a different model of care that challenged the traditional ways of doing things, Wosahlo describes this as the "caring versus the enabling challenge" (2014). There was some evidence from the literature that HCPs in palliative care assumed that caring for patients involved doing things for them (Boa et al., 2018; Runacres et al., 2017); and this was borne out in the example given by E2 of her discussion with Wellbeing staff who said that they enjoyed making tea for patients.

7.3 Alignment between rehabilitative and health promoting palliative care

This section will take the learning from the PAR and the literature review and use it to reflect similarities between RPC and HPPC to support a proposition that there is a synergy between them. When both present, they create a stronger shift in terms of care provision for people with palliative care needs in more settings. The following four similarities will be discussed:

- Definitions, although both concepts can be difficult to grasp
- Participatory models of healthcare
- Promote independence and enablement
- Multidisciplinary in approach.

7.3.1 Definitions and conceptual clarity

The concept of RPC was considered a facilitator and a barrier to implementing it in the in-patient setting. The CIG, PAG and participants attending the training sessions all discussed the confusing and potentially contradictory terminology in relation to RPC: rehabilitation, frequently associated with recovery, is deemed to be incompatible with palliative care, often associated with dying. This was also reflected in the literature where studies cited misperceptions about what rehabilitation meant in this context (Boa et al., 2018; Nwosu et al., 2012; Runacres et al., 2017) which made implementing a rehabilitative approach challenging.

Conceptual blurring was also identified as a risk to effective implementation of HPPC when transitioning from conventional to HPPC in a hospice (Rosenberg & Yates, 2011).

The concepts of health promotion and palliative care are paradoxical with contrasting ideas (Pegg & Tan, 2002): palliative care is seen as something for those who are seriously unwell whereas health promotion is perceived to be about being well and potentially death-denying.

Whilst gaining conceptual clarity is difficult, there is conceptual congruence between HPPC and RPC. Firstly, there are similarities between the definition of health promotion and the aims of RPC discussed in sections 2.2 and 2.3 respectively. Enablement, control and independence, and optimising or realising aspirations or goals whilst coping with their situation, are evident in both (Tiberini & Richardson, 2015, p.2; WHO, 1986, p.1). Therefore, provided the concepts of RPC and HPPC are clear, it is possible to identify their common features. One such feature is their participatory approach.

7.3.2 Participatory models

Rumbold (2011) suggests that palliative care should be reformed within a participatory model of health where health is connected to all aspects of life and is a concern for all (Kellehear, 1999). In 7.2.1 the supportive environments within the Hospice where this study is located were discussed and it was argued that these spaces support RPC because they enable people to live as normal a life as possible (Bray & Cooper, 2010; Tester, 2008) but they are also conducive to social interaction. Social interaction is a key tenet of HPPC with patients’ interaction with others seen as a priority for people nearing the end of life and recognised as a key determinant in improving quality of life (D'Onofrio & Ryndes, 2003; Pegg & Tan, 2002). Quality of life is a sense of wellbeing related to subjective responses – self-esteem, life satisfaction and morale (Ferrans & Powers, 1992). Many of these issues can be addressed through participation in usual day to day activities and social interaction.

In HPPC participatory social relations include an egalitarian relationship between the patient and the HCP where the patient works with, rather than submits to the HCP (Rumbold, 2011). This is also advocated within RPC which is seen as a collaboration between the patients, relatives, carers and the multidisciplinary team including volunteers (Tiberini & Richardson, 2015). This was acknowledged in the PAR workshops (Table 9) where participants were keen to identify the role that volunteers could play in supporting patients to achieve their goals. In these sessions there was also some recognition from nurses that they needed to "step back more and empower patients" and in the literature it was noted that hospice nurses struggle in adopting an enabling approach to patients (Wosahlo, 2014).

7.3.3 Promoting independence and enablement

For clinicians "letting go" or relaxing control is difficult (Conway, 2008) and HCPs can be risk averse and paternalistic when it comes to sharing care with untrained individuals (Rosenberg et al., 2018). This type of behaviour was identified in the literature (Boa et al., 2018; Runacres et al., 2017; Wosahlo, 2014) and had the potential to damage a patient's confidence. It was also acknowledged in the PAR when E2 described how the staff "enjoyed making tea for patients" (CIG, 09/12/15, p.127) and in reference to volunteers who became too involved in supporting patients attending a cookery group (A3, CIG, 13/04/16, p.127); in effect disempowering them. However, to implement RPC and to adopt a health promoting approach empowering patients and their carers is essential.

Empowerment is referred to in the rehabilitation and health promotion literature (Buckley, 2002; Cotterell, 2008; Feldstain, Lebel, & Chasen, 2016; Malcolm et al., 2016; Silver et al., 2015) and is associated with autonomy and a person's sense of who they are. However, individuals have a choice about whether and to what degree they wish to be empowered and the enablement paradigm assumes that people choose if they want or need support (Tiberini & Richardson, 2015, p.39). However, there was evidence from the literature that stereotypes regarding palliative care patients needing care and assistance with activities of daily living, influenced staff to prioritise care provision and comfort over enablement and promoting independence (Runacres et al., 2017).

In RPC, support for patients needs to be reframed so that the two paradigms of enablement *and* care can be held in balance and are not mutually exclusive as Figure 9 illustrates. Within this diagram there is a spectrum of support from self-management through to total care with the balance of enablement and care tailored to an individual's needs and wishes. In HPPC this is referred to as self-care (Kellehear, 1999) where the individual decides what support they need and the HCP plays a facilitating role. The active involvement of people in their care, rather than them being passive recipients, is a key characteristic of HPPC (McLoughlin, 2012; Rumbold, 2011) and is based on the principles of participation and partnership.

Despite being associated with the ability to do things for oneself, both HPPC and RPC refer to 'independence' in the context of exercising control, self-reliance, self-esteem and self-determination, all of which can co-exist with high levels of physical

(Tiberini & Richardson, 2015, p.39)

Figure 9: Integration of enablement and care

dependence (Rumbold, 2011). This distinction is particularly important for implementing RPC if it is to avoid perpetuating the misconception that rehabilitation is all about improving physical function and independence.

7.3.4 Multidisciplinary approach

As a result of implementing RPC, it was noted that there was closer integration between the nursing staff and therapists (A3, Evaluation Form, 4.4.2.2). It was also highlighted that volunteers had a role to play in RPC and that this in itself would have a positive impact on the nurses embracing it (L8: CIG, 12/11/15). However, there was a concern that adopting RPC could be perceived as deskilling the nurses and devaluing their unique contribution (S8, CIG, 09/12/15). In contrast to this perspective, some argue that rehabilitation in palliative care is the role of nurses (Richardson, 2002; Rosenberg & Hammill, 2015) who, in doing so, relinquish an expert-led approach for a more egalitarian nurse-patient relationship (Richardson, 2002). Whilst their professional skills of pain and symptom relief remain important, support for psychological health and wellbeing becomes more prominent. Rosenberg and Hammill (2015) expand this view by suggesting that in adopting a rehabilitative approach nurses can also help to promote the normalisation of dying and the engagement of the community as part of a health promoting approach.

To exemplify RPC and HPPC, participation needs to extend beyond therapists and nurses to create a democratic partnership between all: HCPs, the patient, the family, volunteers and members of the wider community.

Based on the PAR findings and the literature, there is some alignment between RPC and HPPC, but there are also features of HPPC which are not evident in RPC or have not been illustrated in this study.

7.4 Potential areas of divergence

Based upon the characteristics of HPPC outlined in 2.2, the following section addresses claims that could be made which would challenge RPC as a health promoting approach. These are:

- inflexibility of the model of enablement and caring adopted in the RPC literature
- lack of community aspect of RPC
- death education is not addressed in RPC
- RPC is death denying and perpetuates a clinical model of death and dying.

7.4.1 Integration of enablement and caring

The first issue addresses the inflexibility of the integrated model of enablement and caring shown in Figure 9. Whilst Figure 9 helpfully illustrates that the paradigms of enablement and caring could be held in parallel, it does not adequately take account of the fact that the boundary between the two fluctuates. This could be according to the patients' needs, the progression of their illness, their state of wellbeing, how much support and encouragement is available in their network, personal choice and according to an individual's goals and wishes (Richardson, 2002; Tester, 2008). If RPC is to be considered as health promoting and to respond to the challenge that it is death- denying (which will be discussed later), this model needs to be more fluid, responsive and person-centred. Figure 10 suggests two evolutions of this model. In the first diagram enablement and caring are provided in equal measure up until the point of death, but this is still too rigid and does not account for the unpredictability and fluctuations of a serious life-limiting illness. In contrast, the second image shows how sometimes an enabling approach is required and at other times the emphasis will be on caring. During the early phase of someone's disease trajectory, the enabling focus may be more prominent but as their condition declines the caring approach is likely to dominate; it is unlikely to be exclusively one or the other until very near to the end of life when the caring paradigm is likely to be more prevalent. Dignity and feeling empowered to do things for oneself are essential features of personhood and important until someone dies (Pegg & Tan, 2002) and an important feature of HPPC (Kellehear, 1999; McLoughlin, 2012; Richardson, 2002; Rumbold, 2011; Sallnow et al., 2015). Whilst RPC advocates this, the model portrayed in the literature does not illustrate this effectively enough.

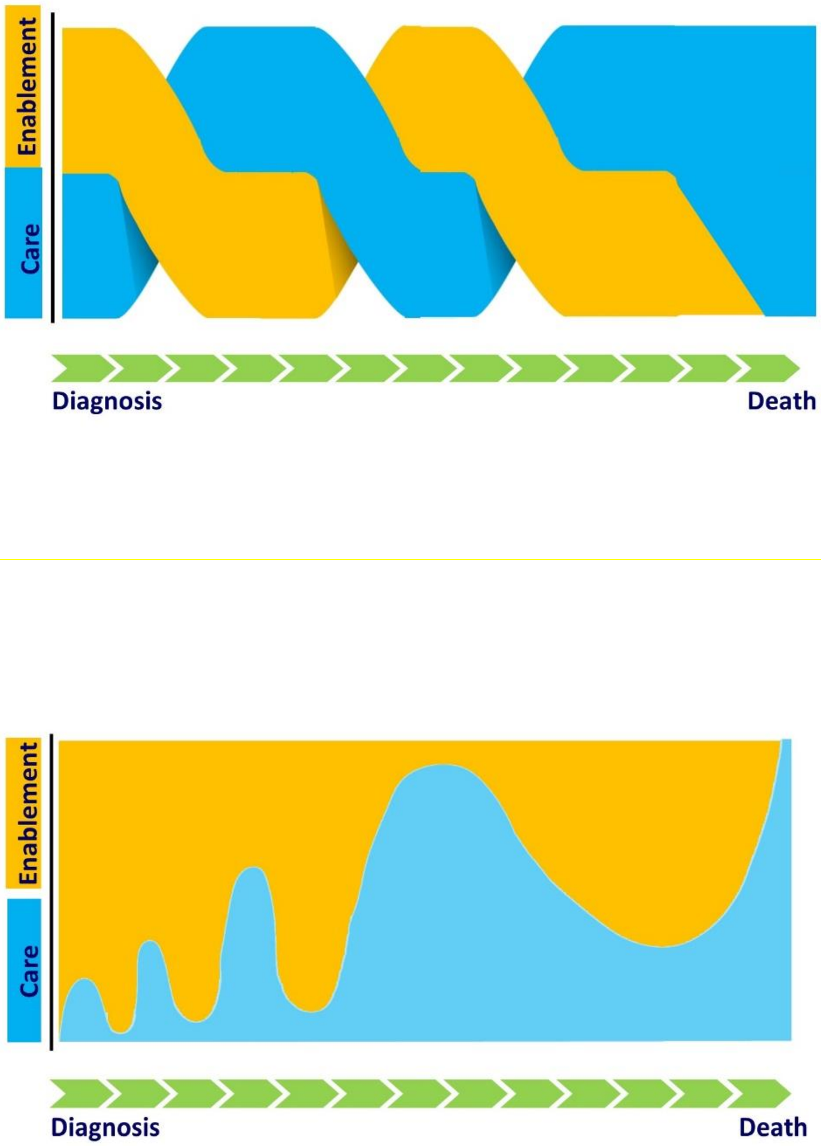


Figure 10: Evolved models of integration of enablement and care.

7.4.2 Community emphasis in health promoting palliative care

The literature demonstrates a propensity for public health and palliative care developments to be community based (Dempers & Gott, 2017b; Horsfall et al., 2013;

Rosenberg & Yates, 2010; Sallnow & Paul, 2015) and HPPC has a strong community emphasis (Kellehear, 2016). RPC as a model of care, implemented in an in-patient setting is not community-based and so it may not conform to current HPPC developments. However, there are some ways that RPC can have a relationship with the community and this was considered as part of the PAR. One CIG workstream was internal and external communications (see Figure 7), to address concerns that rehabilitation would not be part of the public perception of hospices. One initiative was to develop a ‘postcard’ about RPC that would be on display on tables in the Street Café. This would form part of a wider and more meaningful, future community engagement strategy.

When discussing RPC and its relationship with community, the role of volunteers is also relevant. As demonstrated in the RPC literature and in the Hospice setting for this research, RPC relies on the support of volunteers, drawn from the local community, to facilitate, support and enable patients, “in ways that transcend the purely clinical” (Hospice UK, 2012, p.1). Their presence provides, “an informal and symbolic ‘link’ to the local community, both in terms of their ‘normalising’ roles in the hospice and as providing a two-way flow of information with the external environment” (Morris, Payne, Ockenden, & Hill, 2017, p.1).

Despite the focus in end of life care policy to support people to die at home (Department of Health, 2008), there is likely to always be the need for palliative care in-patient facilities (Lysaght Hurley, Strumpf, Barg, & Ersek, 2014). Dying at home or in a care home may not be an option due to complex needs or a lack of infrastructure to support the individual, or a short in-patient admission may be required to enable someone to return home to die. Therefore, how people nearing the end of life are supported at home must be congruent with how care is provided in the in-patient setting. HPPC implemented only in the community means there is a dissonance with the care delivered within in-patient settings. As demonstrated by this PAR, with its aligned HPPC principles, and its empowering, democratic and participatory approach, RPC offers the ability to achieve this.

Another perspective that demonstrates a community aspect of RPC concerns the definition of the word ‘community’. In public health approaches “community” is rarely defined (Dempers & Gott, 2017b) and in their paper, Sallnow and Paul (2015) deliberately avoided defining community “leaving communities and services free to interpret the term as they see fit and to adapt it to the local context” (p.234). One public health definition is that a community is a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings (MacQueen et al., 2001). Using that definition, it could be argued that the hospice in-patient unit is a community: the people located there have a shared purpose (either as patient or a HCP) and are engaging in joint activities. Furthermore, those who are admitted to or work within the in-patient community are also members of the public and part of communities outside.

These suggestions are not intended to diminish the potential for RPC to participate in community engagement nor the importance of engaging communities in palliative care but are to illustrate that although RPC is not community-driven, that should not imply that it cannot be considered as HPPC. In implementing RPC in an in-patient setting, *that* community has successfully participated, engaged and become empowered to reorient the organisation's services according to HPPC.

7.4.3 Death education is not addressed in RPC

A key aspect of HPPC is providing education and information such that there is a change in community attitudes, values and behaviours to health, dying and death and the RPC literature does not address this. However, RPC encourages a change in attitude to death and dying by promoting and communicating rehabilitation as an approach to palliative care. Emphasising goal setting and choice, it challenges assumptions of palliative care and hospice which expands the debate and the personal knowledge of people who work or visit the hospice. Through developing the rehabilitative skills of the in-patient community health is being reframed in the context of dying and death and through working with people. Other ways that

At a more practical level, HCPs constantly share knowledge and information with patients and carers. Many studies have shown the benefit to patients and their families of HCPs providing education including in relation to pain management (B. R. Ferrell, Rhiner, & Ferrell, 1993; Betty R. Ferrell & Rivera, 1997; Oliver, Kravitz, Kaplan, & Meyers, 2001); reducing fatigue (Kealey & McIntyre, 2005; Vockins, 2004); and breathlessness (Barton, English, Nabb, Rigby, & Johnson, 2010). Whilst these examples are symptom focused they demonstrate HCPs working with patients to enable them to adapt to their changing condition as discussed in 7.2.2. In the PAR, refocusing HCPs to consider the patient's wishes rather than what might address their physical symptoms was considered a key characteristic of RPC and in the literature identifying and agreeing the patients' goals was considered an important aspect of palliative care (Boa et al., 2018).

7.4.4 RPC is death-denying

One of the criticisms of RPC is that with its focus on function and enablement it is death-denying (2.4.3) which conflicts with the intention of HPPC to combat death-denying attitudes and behaviours (Kellehear, 1999). An example from the PAR helps to illustrate how RPC can be relevant until the end of someone's life. It was important for a patient to clean their teeth twice daily, but as their condition deteriorated and they could no longer do it for themselves either their partner or a HCP did it for them. In enabling this to happen, the HCP was not only supporting the patient's wishes but allowing their partner to play a meaningful and intimate role in their care. This required the HCP to focus on assisting the person to adjust to their current and future health and functioning status, while still valuing their remaining life (Bye, 1998; Pizzi & Briggs, 2004) and aligns with one of the aims of HPPC - interpersonal reorientation (2.2.1). When this happens the HCP "with a blend of expertise, intuition, creativity and compassion can make this experience as bearable as possible both for the patient and his/her family" (Buckley, 2002, p.508). A volunteer could also play a vital role in this scenario, enabling them to engage in purposeful activity and releasing the HCP for other duties. This suggests that in contrast to being death-denying RPC supports the individual to develop resilience to cope with adapting to their illness progression, and for them and their family to approach death in a manner that is life-affirming, comforting and dignified.

7.4.5 RPC perpetuates a clinical model of dying and death

It could be argued that RPC, conceived by a therapist and a nurse perpetuates a clinical rather than social model for death and dying which conflicts with HPPC (See Chapter 2). Whilst RPC involves clinicians, at its core is a multidisciplinary approach involving all the clinical team, patients, families and volunteers; not a pharmacological or technical intervention. In the PAR the role of the volunteer was considered invaluable in supporting patients through social interaction and assisting in making drinks and preparing meals, and their engagement can enable the model to be long-term sustainable.

RPC is also person-centred and challenges a tendency by HPC towards a "professional-centred" approach that is based on what the healthcare professional can influence, or what they perceive to be important to the patient (Tiberini & Richardson, 2015). In doing this, it attempts to challenge paternalistic attitudes and a tendency to over-care identified in this study and the literature (Boa et al., 2018; Runacres et al., 2017; Wosahlo, 2014). It also seeks to ensure that patient cues to focus on simple, day to day activities are not missed (Boa et al., 2018). This person-centred approach attends to what matters to that individual and strives to continue to meet those needs until end of life.

In the same way that a strong community response augments rather than supplants the professional response (Sallnow et al., 2015), RPC integrates with clinical models and enhances social or community led approaches to death and dying. The hospice pioneers believed that to die well was to die with ease of distress across the range of domains of human existence: physical, psychological, social and spiritual (Saunders 1998). Health and social care strategies need to work collaboratively to meet the needs of people who are dying considering their wider social context (Rosenberg & Yates, 2010) and this holistic approach is an outcome of HPPC (Paul & Sallnow, 2013; Pizzi, 2015). From its inception the hospice movement reoriented health services to achieve this and RPC could be regarded as the latest iteration of those original intentions.

7.5 Conclusion

This chapter added a further dimension to a model created by Rosenberg and Yates (2010) to illustrate how components of the Ottawa Charter relate to RPC and suggested evolutions of the enablement and caring model by Tiberini and Richardson (2015). It has taken some of the findings from the PAR and the literature and used them to illustrate an alignment between RPC and HPPC.

The arguments presented in this chapter suggest that HPPC is not simply about community engagement, which is the prevalent health promoting approach currently adopted in the UK. This work offers an approach, where HPPC and RPC complement each other, and reach out into care settings beyond the community.

Chapter Eight: Conclusion

8.1 Introduction

To conclude this thesis, the objectives of the study will be reviewed to assess the degree to which the initial objectives were met. The key findings will be summarised, and the strengths and limitations of the study discussed before concluding with an explanation of what its contribution to knowledge has been.

8.2 Key findings

8.2.1 Inquiry One: Participatory Action Research

This Inquiry had three phases, and each will be discussed individually:

a. Establishing and working as a co-operative inquiry

The co-operative inquiry group was established and made good progress in a relatively short space of time (13 months) which it was suggested was due, in part, to the way that the CIG conducted itself. There was evidence presented that demonstrated the CIG's ability to work in line with the principles of co-operative inquiry (Heron & Reason, 2001) and that it created a communicative space (Kemmis & McTaggart, 2005). This produced an environment which enabled change to take place and showed an authentic approach to the research (Guba & Lincoln, 1994). When an issue arose with a newsletter article the CIG used it as an opportunity to review where power lay within the organisation and in the group. This was helpful in showing that, within the CIG, the participants felt empowered and on an equal footing with no hierarchy (Zuber-Skerritt, 1996). The impact of those who held positions of power outside the CIG was captured in the facilitators and barriers to the research.

b. Collectively develop knowledge

There were several ways the CIG collectively developed knowledge. The first objective was to understand what palliative rehabilitation was and, although there was literature available regarding this, it was important that the CIG understood it collectively. It was also able to critically assess whether the launch of RPC was aligned with its aims. In doing so the CIG demonstrated the different ways of knowing: propositional, and then as the inquiry progressed, experiential and practical knowing (Heron & Reason, 2001). The CIG acquired an understanding of organisational change by participating in individual and group learning involving both the literature and examination of a case study. This knowledge was then put into practice as part of the active phase of the study – practical knowledge (Heron & Reason, 2001).

Through completing an evaluation form at the end of the study, the CIG identified what they had learnt personally and professionally from being co-researchers in this project: working as a multidisciplinary team, an appreciation of how interesting research could be, and a greater understanding of RPC and of roles within the Hospice. By highlighting these factors, members of the CIG demonstrated that they had been able to construct and use new knowledge which is an important feature of PAR (Reason, 2006).

c. Identify, plan and implement ways to integrate rehabilitative palliative care into a hospice in-patient setting;

The CIG used several tools to identify, plan and implement ways to integrate a rehabilitative approach including using organisational documents, checklists, action planning and delivering workshops. The discussions at the CIG meetings also helped to do this, e.g. the discussions regarding the MDS and IPOS audit helped to confirm that the approach was valid in this setting, and the outcome from the checklist indicated that training was a key priority. Figure 7 offers further insights and demonstrates a repetitive process of multiple action cycles which is recognised as a key component of action research and an example of its rigour (Coghlan & Brannick, 2007).

Using the "How rehabilitative is your hospice?" checklist (Tiberini & Richardson, 2015), before and after the action research, progress was identified. This was in relation to:

- different MDT members undertaking patients' functional assessments and documentation
- more proactive, early referrals being made to allied health professionals (AHP)
- greater awareness amongst patients' families about what enablement focused support was
- increased support for patients to maintain their normal routines of daily living while at the Hospice, and
- proactive discharge planning.

In relation to the goal setting and action planning document, the CIG suggested that progress had been made with regards to discharge planning, the team's appetite for change, interest in RPC, training in RPC and engagement of senior staff.

8.2.2 Inquiry Two: Facilitators and barriers to adopting an RPC approach

The key enablers of change identified from the thematic analysis and the feedback from the CIG were: engagement, subject matter, teamwork and empowerment. The barriers were: lack of engagement, infrastructure, alignment with the current model of care, terminology and attitudes to change. Of note was that engagement and the concept of RPC arose in both, suggesting that if they were identified and addressed as part of the change initiative they facilitated change but, if not, became inhibitors. It was also suggested that in creating a communicative space the CIG had facilitated change but possibly to the detriment of building engagement with the wider organisation. The fact that this study was being initiated by an insider researcher was also discussed as being a positive influence on the study.

8.2.3 Inquiry Three: Literature review

In the literature there were more barriers identified than in this study. The terminology of RPC and underlying concepts were highlighted as a barrier to integrating the approach, but there was also evidence that a lack of understanding of the role of therapists in palliative care was a barrier to referring patients to rehabilitative services. An insufficient evidence base, ineffective teamworking and a lack of resources were also highlighted. It was acknowledged that many of the barriers identified in the literature were the generic issues normally associated with change: poor communication, lack of training etc. This implied that, to address change in this context, the key barriers that needed addressing were ensuring that the concept and the terminology was understood and acknowledging that there may be concerns about a potential conflict between different models of care: enablement versus caring. This supported what was evidenced as a facilitator, which was that rehabilitation was an important aspect of holistic care for patients nearing the end of life and not a replacement for it.

8.2.4 RPC as a health promoting approach to palliative care

In Chapter Seven, it was suggested that there was a synergy between the characteristics of RPC and health promotion, and Rosenberg and Yates's model (2010) was expanded to illustrate this. There were examples given of where there was alignment particularly in relation to the philosophical underpinnings of both concepts. Areas of discord were also discussed, and a different perspective offered through drawing on the literature and the findings from this study. Alternative models of the interface between caring and enablement were offered. The conclusion was that RPC could be considered as a means of integrating a health promoting approach within a service provider context.

8.3 Strengths and limitations of the study

8.3.1 Strengths

The strengths of this study were the establishment of the CIG, that it was insider research, the attention to ensuring rigour in the research and the alignment between the features of participatory action research, rehabilitative palliative care and health promoting palliative care, namely: participation, democracy and empowerment.

8.3.1.1 The CIG

The CIG has been identified as a strength of this study because the group created a communicative space which enabled an issue of concern to be discussed whilst allowing participants to voice divergent views in a democratic context. It then permitted the mutual understanding and the evolution of new practices which arose and were tested through authentic engagement (Carr & Kemmis, 1986). In the hospice sector there is a strong grounding in multidisciplinary working where all the HCPs work collaboratively to support patients and their families. This holistic approach to teamworking, so strongly embedded in the culture within this Hospice, was reflected within the CIG and therefore facilitated change.

8.3.1.2 Insider researcher

Being an 'insider' researcher and a senior manager were strengths of this study. Firstly, I was familiar with the organisation and its politics (Coghlan & Shani, 2008). Secondly, I had worked successfully with several members of the team on various projects and so had established my credibility and trust with them. Thirdly, my manager and other managers were supportive of my undertaking the research and allowed time for their staff to participate. Therefore, it had some senior level approval – although as explained in Chapter Four this did not mean that all the CIG's decisions were automatically approved by the senior team. These factors also meant that time was not spent at the beginning of the study forming relationships between the facilitator and the group, although the group did spend time establishing relationships, and itself as an entity. It also meant that there was an implicit belief that any changes would happen as I was a senior manager and they had my engagement and support.

The fact that I was not a clinician also helped to ensure a democratic approach to the research. My prior knowledge of organisational change, both at theoretical and practical level, was an advantage as it meant that I had some experience which I was able to share with the CIG. This may have compensated for, and complemented, my lack of clinical knowledge which other members of the group had. The different areas where people held power, i.e. knowledge or position, went some way to ensuring the power was not held by one particular individual (Andrews et al., 2013; Meyer, 2000).

A further strength is that some of the approaches used may be useful in other studies. Although the findings from action research are not usually generalisable due to their context specific nature (McNiff & Whitehead, 2002) the questionnaires and the lesson plan for the workshops could be used by others who were interested in integrating RPC in a hospice in-patient setting.

8.3.1.3 Demonstrating quality

Section 4.5 outlined how rigour could be evidenced in Inquiry One using Coghlan and Brannick's (2007) criteria. The quality criteria identified by Reason (2006) and set out in 3.9 will now be used to evidence the quality of the study.

a. Extent to which worthwhile practical purposes are addressed

The purpose of the CIG was to implement a new approach to care within the Hospice in-patient setting to better meet the needs of patients with conditions other than cancer and also enable the Hospice to support more people. Chapter Four explained how the CIG gained conceptual clarity and assessed whether RPC was appropriate for this setting, before planning and implementing actions to integrate RPC into the in-patient setting. There was evidence presented that changes in practice had taken place. A further phase of the study could have been to assess the impact on patients and this is recognised as a limitation of the study.

b. Levels of democracy and participation

The findings in Chapter Three suggested that the CIG had created a communicative space (Kemmis & McTaggart, 2005), worked democratically and willingly engaged in activities to bring about change - all key components of action research (Meyer, 2000). There was evidence presented of how different members of the CIG undertook various responsibilities, thus heightening the degree of participation in the study and demonstrating the different forms of knowing.

c. Different forms of knowing: experiential; presentational, propositional and practical knowledge

In the findings described in Inquiry One (4.2) there is evidence of the different forms of knowing as described in 3.2. Experiential and practical knowing was also employed when the CIG was reviewing the facilitators and barriers to implementing this approach. In taking on additional responsibilities the CIG engaged in different forms of knowledge. This included: O6 and A3 delivering a workshop and presenting RPC to mixed audience of staff, volunteers and managers; using the RPC knowledge gained to make changes to practice on the in-patient unit, e.g. discharge planning; taking responsibility for chairing the CIG meetings; and learning and engaging with PAR.

d. Extent to which the research has been and continues to be responsive and developmental

The results from the active phase of the study demonstrate that the CIG had started to bring about a change in practice. There is also evidence from the way that the CIG conducted itself that represents PAR in practice. Based upon the workshop created by the CIG, RPC training was incorporated into the Hospice’s mandatory training programme for the year preceding this research and the last CIG meeting concluded with agreement that a funding bid would be submitted to ensure that momentum for this work was maintained. One of the CIG members has since assessed the impact of RPC on patients as part of her Master’s degree.

8.3.1.4 Alignment between the features of PAR, RPC and HPPC

The alignment between the methodology and the topics of rehabilitative palliative care and health promoting palliative care should also be acknowledged. Participation, democracy and empowerment are key issues within participatory action research (Heimerl & Wegleitner, 2013) and were highlighted in section 2.2.1 as core characteristics of HPPC. The paragraphs below summarise this and include RPC.

a. Participation

In RPC, the concept of participation is evident with the patient and family actively engaging in identifying goals and helping to achieve them, and all members of the multidisciplinary team actively contribute to supporting an individual to achieve their goals. Health promotion mirrors this participatory intent and suggests that palliative care should be reformed within a participatory model of health (Rumbold, 2011) and that communities should work collaboratively to improve end of life care locally (Kellehear, 1999).

b. Democracy

Health promoting palliative care is based on the principle of participatory social relations which includes the relationship between the patient and the healthcare professional (Rumbold, 2011). This democratises the relationship between the two.

RPC aspires to be person-centred with HCPs focusing support to best meet an individual's goals rather than being led by their own professional agenda (Tiberini & Richardson, 2015). RPC also purports that enabling and caring are equally important in supporting patients at the end of life and are not mutually exclusive. A fundamental principle of PAR and the participatory paradigm is a democratic impulse (Meyer, 2000).

c. Empowerment

RPC is about enabling people to optimise their ability to engage in day to day activities by putting supportive mechanisms in place and not disempowering them by over-caring. It fosters choice and independence and is empowering and nurturing (Tiberini & Richardson, 2015). In the same way that Heron and Reason (2001) claim that good research is research *with* people rather than *on* people, RPC aims to enable people rather than do things for or to them. In health promoting palliative care, on a personal level, a health promoting approach advocates empowering people to enable them to remain in control.

8.3.2 Limitations

The most significant limitation to this study was a lack of evidence from patients and families about the impact of RPC on them. There was some evidence in the literature of rehabilitation being beneficial to palliative patients and the fact that it was endorsed by Hospice UK gave the CIG confidence in the approach. However, the study would have been enhanced if it could have been evidenced whether RPC was beneficial to patients and, if so, how. The PAG was established to guide the research and provide the patient perspective which offered a degree of oversight and scrutiny of the study, as well as the actions the CIG was proposing to take. Their support and enthusiasm for the project also provided some assurances that this model was appealing to patients. The outcome of an RPC approach for patients is an important area for further research.

The CIG met for 12 months and then concluded. This was an artificial end due to the work being part of a PhD and therefore time-limited. It is likely that more could have been achieved if time had allowed. The CIG was keen to continue the work and an external funding bid was submitted.

It would have been beneficial to have had more nurses in the CIG to balance the strong therapies presence. Also, a nurse less positive about rehabilitation in palliative care might have brought a different and more critical perspective to the discussion. Wider MDT involvement would have also been welcomed.

Finally, as a single site study, the conclusions drawn here regarding the relationship between RPC and HPPC need further exploration and 'testing' in other settings.

8.4 Contribution to knowledge

This is the first participatory action research project, based within a UK hospice in-patient unit, that has considered rehabilitative palliative care in this context. It therefore contributes to knowledge on several levels including: action research and participatory action research in the hospice setting and in relation to RPC; rehabilitation and in particular RPC in a hospice in-patient setting; and co-operative inquiry within a hospice. It also contributes to knowledge in relation to creating culture change in a hospice through co-operative inquiry, with opportunities to further explore the factors that enable and inhibit change in this context.

It has contributed to the evidence base of rehabilitation in palliative care, identified as lacking in the literature (Chapter Six). It has also suggested an evolution of the model of enabling and caring developed by (Tiberini & Richardson, 2015) to one that reflects the fluctuating emphasis on each paradigm depending on the needs, circumstances and wishes of patients and their families. This was illustrated by Figure 10 section 7.4.1.

The final contribution to knowledge is in relation to considering RPC as an opportunity for hospice in-patient units to adopt a health promoting approach. It may prompt palliative care service providers to review their models of care to more closely align with a health-promoting approach. If nothing else, it may encourage a dialogue on this topic.

8.5 Final conclusions

Palliative and end of life care do not preclude interventions that optimise health, well-being and functional independence, and this is aligned with the principles and practice of health promotion (Rosenberg & Hammill, 2015). Rehabilitation is a valid intervention in advanced disease focused on promoting optimal function, enabling daily living, well-being and quality of life. It is therefore aligned with health promotion, and critical in supporting someone at the end of life. If this is the case, it follows that rehabilitative palliative care is a model of health promoting palliative care and one that can be adopted in a hospice in-patient setting. In doing so hospices can offer "*conventional end of life care, e.g. excellent symptom control, but also demonstrate the integration of health promoting palliative care*" (Rosenberg & Yates, 2011, p.106).

This study has demonstrated that rehabilitative palliative care can be adopted in the in-patient setting and, when comparing its principles with health promoting palliative care, there is an alignment. Therefore, health promoting palliative care, which has already been embraced as a way to engage communities in caring for the dying, can now be integrated into an in-patient setting. This suggests that there can be a common philosophical approach to supporting those at the end of life, across palliative care organisations and communities, based upon the principles of participation, democracy and empowerment.

9. References

Andrews, S., McInerney, F., & Robinson, A. (Eds.). (2013). *Chapter 11: Power relations: enhancing the delivery of a palliative approach in an aged care setting*. Oxford: Oxford University Press.

Ashworth, E. (2014). Utilizing participation in meaningful occupation as an intervention approach to support the acute model of inpatient palliative care. *Palliat Support Care, 12*(5), 409-412. doi:10.1017/s1478951513000734

Aveyard, H., Payne, S. A., & Preston, N. J. (2016). *A post-graduate's guide to doing a literature review in health and social care*: Oxford University Press.

Badger, T. G. (2000). Action research, change and methodological rigour. *Journal of Nursing Management, 8*(4), 201-207. doi:10.1046/j.1365-2834.2000.00174.x

Barton, R., English, A., Nabb, S., Rigby, A. S., & Johnson, M. J. (2010). A randomised trial of high vs low intensity training in breathing techniques for breathless patients with malignant lung disease: a feasibility study. *Lung Cancer, 70*(3), 313-319. doi:10.1016/j.lungcan.2010.03.007

Benzein, E. G., & Saveman, B. I. (2008). Health-promoting conversations about hope and suffering with couples in palliative care. *Int J Palliat Nurs, 14*(9), 439-445. doi:10.12968/ijpn.2008.14.9.31124

Boa, S., Duncan, E., Haraldsdottir, E., & Wyke, S. (2018). Patient-centred goal setting in a hospice: a comparative case study of how health practitioners understand and use goal setting in practice. *International Journal of Palliative Nursing, 24*(3), 115-122.

Brannick, T., & Coghlan, D. (2007). In Defense of Being “Native”: The Case for Insider Academic Research. *Organizational Research Methods, 10*(1), 59-74. doi:10.1177/1094428106289253

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research : A Practical Guide for Beginners*.

Bray, J., & Cooper, J. (2010). The Contribution of Occupational Therapy to Palliative Medicine. In G. Hanks, N. Cherny, N. Christakis, M. Fallon, S. Kassa, & R. Portenoy (Eds.), *Oxford Textbook of Palliative Medicine*. New York: Oxford University Press.

British Geriatric Society. (2014). *Fit for Frailty - consensus best practice guidance for the care of older people living in community and outpatient settings*. London: British Geriatric Society

Brydon-Miller, M. (2008). Ethics and Action Research: Deepening our Commitment to Principles of Social Justice and Redefining Systems of Democratic Practice. In P. Reason & H. Bradbury (Eds.), *The SAGE Handbook of Action Research Participatory Inquiry and Practice* (2nd ed.). doi:10.4135/9781848607934

Bryman, A. (2012). *Social research methods* (4th ed. ed.): Oxford : Oxford University Press.

Buckley, J. (2002). Holism and a health-promoting approach to palliative care. *Int J Palliat Nurs, 8*(10), 505-508. doi:10.12968/ijpn.2002.8.10.10697

Burnes, B. (2003). Managing change and changing managers from ABC to XYZ. *Journal of Management Development, 22*(7), 627-642.

Bye, R. A. (1998). When clients are dying: Occupational therapists' perspectives. *Occupational Therapy Journal of Research, 18*(1), 3-24.

Calanzani, N., Higginson, I. J., & Gomes, B. (2013). Current and future needs for hospice care: an evidence-based report. *London: Commission into the Future of Hospice care*.

Care Quality Commission. (2015). *Inspection Report*. Retrieved from London:

Carr, W., & Kemmis, S. (1986). *Becoming critical : education, knowledge, and action research*. London ; Philadelphia: Falmer Press.

Carson, K., & McIlfatrick, S. (2013). More than Physical Function? Exploring physiotherapists' experiences in delivering rehabilitation to patients requiring palliative care in the community setting. *Journal of Palliative Care, 29*(1), 36-44.

Carter, H., MacLeod, R., Brander, P., & McPherson, K. (2004). Living with a terminal illness: patients' priorities. *Journal of advanced nursing, 45*(6), 611-620.

Chartered Institute of Personnel and Development. (2018). Change Management. Retrieved from https://www.cipd.co.uk/knowledge/strategy/change/management-factsheet

Cheville, A. (2001). Rehabilitation of patients with advanced cancer. *Cancer, 92*(4 Suppl), 1039-1048.

Clark, D. (2002). Between hope and acceptance: the medicalisation of dying. *British Medical Journal, 324*(7342), 905-907. doi:10.1136/bmj.324.7342.905

Clark, D. (2015a). Hospice care of the dying. In J. M. Stillion & T. Attig (Eds.), *Death, dying, and bereavement: Contemporary perspectives, institutions, and practices*. (pp. 135-149). New York, NY, US: Springer Publishing Co.

Clark, D. (2015b). The question of 'public health' - thoughts from the EAPC Congress in Copenhagen. *http://endoflifestudies.academicblogs.co.uk/the-question-of-public-health-thoughts-from-the-eapc-congress-in-copenhagen*. Retrieved from http://endoflifestudies.academicblogs.co.uk/the-question-of-public-health-thoughts-from-the-eapc-congress-in-copenhagen

Coghlan, D., & Brannick, T. (2005). *Doing action research in your own organization* (2nd ed. ed.). London: Sage.

Coghlan, D., & Brannick, T. (2007). *Doing Action Research In Your Own Organisation* (2nd ed.). London: Sage.

Coghlan, D., & Shani, A. (2008). Insider Action Researcher: The Dynamics of Developing New Capabilities. In P. Reason & H. Bradbury (Eds.), *The Sage Handbook of Action Research Participatory Inquiry and Practice* (2nd ed.). London: Sage.

Cohen, J., & Deliens, L. (2012). *A public health perspective on end of life care*: Oxford University Press.

Conway, S. (2008). Public health and palliative care: principles into practice? *Critical Public Health, 18*(3), 405-415.

Costello, P. J. M. (2003). *Action research*: A&C Black.

Cotterell, P. (2008). Striving for independence: experiences and needs of service users with life limiting conditions. *J Adv Nurs, 62*(6), 665-673. doi:10.1111/j.1365-2648.2008.04638.x

Creswell, J. W. (2014). *Research design : qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, Calif. ; London: SAGE Publications, Inc.

Crocker, T., Forster, A., Young, J., Brown, L., Ozer, S., Smith, J., . . . Greenwood, D. (2013). Physical rehabilitation for older people in long-term care. *Cochrane Database of Systematic Reviews*(2). doi:10.1002/14651858.CD004294.pub3

Crouch, M., & McKenzie, H. (2006). The logic of small samples in interview-based qualitative research. *Social Science Information Sur Les Sciences Sociales, 45*(4), 483-499. doi:10.1177/0539018406069584

D'Onofrio, C., & Ryndes, T. (2003). The Relevance of Public Health in Improving Access to End of Life Care. *The Hastings Center Report, 33*, S30-S32.

Dempers, C., & Gott, M. (2017a). The status of a public health approach to palliative care at New Zealand hospices. *Progress in Palliative Care, 25*(2), 75-81. doi:10.1080/09699260.2016.1261530

Dempers, C., & Gott, M. (2017b). Which public health approach to palliative care? An integrative literature review. *Progress in Palliative Care, 25*(1), 1-10. doi:10.1080/09699260.2016.1189483

Department of Health. (2008). *End of Life Care Strategy – promoting high quality care for all adults at the end of life*. London: Department of Health

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., . . . Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology, 6*(1), 35. doi:10.1186/1471-2288-6-35

Dzingina, M. D., & Higginson, I. J. (2015). Public health and palliative care in 2015. (1879-8853 (Electronic)).

Ellershaw, J. E., Peat Sj Fau - Boys, L. C., & Boys, L. C. (1995). Assessing the effectiveness of a hospital palliative care team. (0269-2163 (Print)).

Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine, 15*(1), 102. doi:10.1186/s12916-017-0860-2

European Association for Palliative Care. (2019). What is Palliative Care? Retrieved from https://www.eapcnet.eu/about-us/what-we-do

European Association of Palliative Care. (2019). EAPC invites comments from members re proposed new global consensus definition for palliative care. Retrieved from https://www.eapcnet.eu/publications/eapc-invites-comments-re-proposed-new-global-consensus-definition-for-palliative-care

Eva, G., & Payne, C. (2014). Developing research capital in palliative rehabilitation: a ten point manifesto. *Progress in Palliative Care, 22*(6), 311-312.

Fallon, M., & Smyth, J. (2008). Terminology: the historical perspective, evolution and current usage – room for confusion? *European Journal of Cancer, 44*(8), 1069-1071. doi:https://doi.org/10.1016/j.ejca.2008.02.034

Feldstain, A., Lebel, S., & Chasen, M. (2016). An interdisciplinary palliative rehabilitation intervention bolstering general self-efficacy to attenuate symptoms of depression in patients living with advanced cancer. *Support Care Cancer, 24*(1), 109-117. doi:10.1007/s00520-015-2751-4

Ferrans, C. E., & Powers, M. J. (1992). Psychometric assessment of the Quality of Life Index. *Res Nurs Health, 15*(1), 29-38.

Ferrell, B. R., Rhiner, M., & Ferrell, B. A. (1993). Development and implementation of a pain education program. *Cancer, 72*(11 Suppl), 3426-3432.

Ferrell, B. R., & Rivera, L. M. (1997). Cancer pain education for patients. *Seminars in Oncology Nursing, 13*(1), 42-48. doi:https://doi.org/10.1016/S0749-2081(97)80049-6

Flick, U. (2009). *An introduction to qualitative research* (4th ed. ed.): Los Angeles, Calif. : SAGE.

Froggatt, K. (2013). Demonstrating quality and rigour in action research: peer education for end of life issues. In J. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Participatory Research in Palliative Care*. Oxford: Oxford University Press.

Froggatt, K., Heimerl, K., & Hockley, J. (2013). Challenges for collaboration. In J. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Palliative research in palliative care : action and research*. Oxford: Oxford University Press.

Georghiou, T., & Bardsley, M. (2014). Exploring the cost of care at the end of life. *London: Nuffield Trust Research Report*.

Gillies, M. (2016). *Palliative and end of life care in Scotland: The rationale for a public health approach*. Scotland: Scottish Public Health Network

Glenton, C., Colvin, C. J., Carlsen, B., Swartz, A., Lewin, S., Noyes, J., & Rashidian, A. (2013). Barriers and facilitators to the implementation of lay health worker programmes to improve access to maternal and child health: qualitative evidence synthesis. *Cochrane Database Syst Rev, 10*(10).

Gomes, B., & Higginson, I. J. (2008). Where people die (1974--2030): past trends, future projections and implications for care. *Palliat Med, 22*(1), 33-41. doi:10.1177/0269216307084606

Graetz, F. (2006). *Managing organisational change* (2nd Australasian ed. ed.). Milton, Qld.: John Wiley & Sons Australia.

Greenwood, D. J., & Levin, M. (2006). *Introduction to action research: Social research for social change*: SAGE publications.

Guba, E. G., & Lincoln, Y. S. (1994). Competing Paradigms in Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Handbook of Qualitative Research* (pp. 105-117). Thousand Oaks: Sage.

Habermas, J. (1996). *Between Facts and Norms* (W. Rehg, Trans.). Cambridge, Massachusetts: MIT Press.

Halkett, G. K., Ciccarelli, M., Keesing, S., & Aoun, S. (2010). Occupational therapy in palliative care: is it under-utilised in Western Australia? *Aust Occup Ther J, 57*(5), 301-309. doi:10.1111/j.1440-1630.2009.00843.x

Hall, S., Petkova, H., Tsouros, A., Costantini, M., & Higginson, I. (2011). Palliative care for older people: better practices. In. Denmark: World Health Organisation.

Harden, A. (2009). Teenage pregnancy and social disadvantage: systematic review integrating controlled trials and qualitative studies. *BMJ :, 339*.

Hart, E. (1995). *Action research for health and social care : a guide to practice*: Buckingham ; Philadelphia : Open University Press.

Hart, E. (1996). Action research as a professionalizing strategy: issues and dilemmas. *Journal of advanced nursing, 23*(3), 454-461.

Hazra, N. C. A.-O. h. o. o., Rudisill, C., & Gulliford, M. C. (2017). Determinants of health care costs in the senior elderly: age, comorbidity, impairment, or proximity to death? LID - 10.1007/s10198-017-0926-2 [doi]. (1618-7601 (Electronic)).

Heimerl, K., & Wegleitner, K. (2013). Organizational and health system change through participatory research. In J. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Participatory research in palliative care. Actions and reflections* (pp. 27-29).

Heron, J. (1996). *Co-operative inquiry: Research into the human condition*: Sage.

Heron, J., & Reason, P. (1997). A Participatory Inquiry Paradigm. *Qualitative Inquiry, 3*(3), 274-294. doi:10.1177/107780049700300302

Heron, J., & Reason, P. (2001). The Practice of Co-operative Inquiry: Research with rather than one people. In P. Reason & H. Bradbury (Eds.), *Handbook of Action Research: Participative Inquiry and Practice* (pp. 179-188). London: Sage.

Heron, J., & Reason, P. (2006). The practice of co-operative inquiry: Research 'with'rather than 'on'people. *Handbook of action research, 2*, 144-154.

Heron, J., & Reason, P. (2008). Chapter 24: Extending Epistemology within a Co-operative Inquiry. In R. P & B. H (Eds.), *The SAGE Handbook of Action Research* (2nd ed., pp. 366 - 380). doi:10.4135/9781848607934

Hoag, B. G., Ritschard, H. V., & Cooper, C. L. (2002). Obstacles to effective organizational change: The underlying reasons. *Leadership & Organization Development Journal, 23*(1), 6-15.

Hockley, J. (2006). *Developing High Quality End of Life Care in Nursing Care Homes: An Action Research Study.* (PhD). University of Edinburgh,

Hockley, J. (2013). Critical Theory in Action Research. In J. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Participatory Action Research in Palliative Care*. Oxford: Oxford University Press.

Hockley, J., & Froggatt, K. (2006). The development of palliative care knowledge in care homes for older people: the place of action research. *Palliat. Med., 20*(8), 835-843. doi:10.1177/0269216306073111

Hockley, J., Froggatt, K., & Heimerl, K. (2013). Action research: An overview. In J. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Participatory research in palliative care : actions and reflections*. Oxford: Oxford University Press.

Holloway, I., Wheeler, S., & Holloway, I. Q. r. i. n. (2010). *Qualitative research in nursing and healthcare* (3rd ed. ed.). Oxford: Wiley-Blackwell.

Horsfall, D., Leonard, R., Noonan, K., & Rosenberg, J. (2013). Working together–apart: Exploring the relationships between formal and informal care networks for people dying at home. *Progress in Palliative Care, 21*(6), 331-336.

Hospice UK. (2012). *Volunteers Vital to the Future of Hospice Care*. London: Hospice UK

Hospice UK. (2015). *Hospice Enabled Dementia Care*. London: Hospice UK

Hui, D., De La Cruz, M., Mori, M., Parsons, H. A., Kwon, J. H., Torres-Vigil, I., . . . Bruera, E. (2013). Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Supportive Care in Cancer, 21*(3), 659-685. doi:10.1007/s00520-012-1564-y

Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., De La Cruz, M., Kim, S. H., . . . Bruera, E. (2014). Concepts and Definitions for "Actively Dying," "End of Life," "Terminally Ill," "Terminal Care," and "Transition of Care": A Systematic Review. *Journal of Pain and Symptom Management, 47*(1), 77-89. doi:10.1016/j.jpainsymman.2013.02.021

Hynes, G. (2013). First, Second and Third Person Inquiry. In J. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Participatory Research in Palliative Care*. Oxford: Oxford University Press.

Iles, V., & Sutherland, K. (2001). *Managing change in the NHS : organisational change; a review for health care managers, professionals and researchers*: Service Delivery and Organisation Research and Development Programme.

Ingleton, C., & Davies, S. (2007). Mixed methods for evaluation research. In J. M. Addington-Hall, E. Bruera, I. J. Higginson, & S. Payne (Eds.), *Research methods in palliative care*: Oxford University Press.

Javier, N. S., & Montagnini, M. L. (2011). Rehabilitation of the hospice and palliative care patient. *J Palliat Med, 14*(5), 638-648. doi:10.1089/jpm.2010.0125

Jennings, R. (2012). A rehabilitative approach to palliative care. In. London: Hospice Information Bulletin.

Johnson, P., & Duberley, J. (2000). *Understanding management research: An introduction to epistemology*: Sage.

Johnston, B., Rogerson, L., Macijauskiene, J., Blaževičienė, A., & Cholewka, P. (2014). An exploration of self-management support in the context of palliative nursing: a modified concept analysis. *BMC Nurs, 13*, 21. doi:10.1186/1472-6955-13-21

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling, 94*(3), 291-309. doi:10.1016/j.pec.2013.10.031

Karsoho, H., Fishman, J. R., Wright, D. K., & Macdonald, M. E. (2016). Suffering and medicalization at the end of life: The case of physician-assisted dying. *Social Science & Medicine, 170*, 188-196. doi:10.1016/j.socscimed.2016.10.010

Kealey, P., & McIntyre, I. (2005). An evaluation of the domiciliary occupational therapy service in palliative cancer care in a community trust: a patient and carers perspective. *Eur J Cancer Care (Engl), 14*(3), 232-243. doi:10.1111/j.1365-2354.2005.00559.x

Kearney, M. (1992). Palliative medicine-just another specialty? *Palliative Medicine, 6*(1), 39-46.

Kellehear, A. (1984). Are we a death-denying society - A Sociological Review. *Social Science & Medicine, 18*(9), 713-721. doi:10.1016/0277-9536(84)90094-7

Kellehear, A. (1999). *Health promoting palliative care*. UK: Oxford University Press.

Kellehear, A. (2016). Commentary: public health approaches to palliative care–the progress so far. *Progress in Palliative Care, 24*(1), 36-38.

Kelley, A., Ettner, S., Morrison, R. S., Du, Q., & Sarkisian, C. (2012). Disability and Decline in Physical Function Associated with Hospital Use at End of Life. *Journal of General Internal Medicine, 27*(7), 794-800. doi:10.1007/s11606-012-2013-9

Kelley, M., & McKee, M. (2012). Capacity development in participatory action research. In J. Hockley, K. Froggatt, & K. Heimerl (Eds.), *Participatory Research in Palliative Care*. Oxford: Oxford University Press.

Kemmis, S., & McTaggart, R. (2005). Participatory Action Research: Communicative Action and the Public Sphere. In *The Sage handbook of qualitative research, 3rd ed.* (pp. 559-603). Thousand Oaks, CA: Sage Publications Ltd.

Kemmis, S., & Wilkinson, M. (1998). Participatory Action Research and the Study of Practice. In B. Atweh, S. Kemmis, & P. Weeks (Eds.), *Action research in practice : Partnerships for social justice in education* (pp. 21-36). London: Routledge.

Khan, S. A., Gomes, B., & Higginson, I. J. (2013). End-of-life care—what do cancer patients want? *Nature Reviews Clinical Oncology, 11*, 100. doi:10.1038/nrclinonc.2013.217

Koshy, E., Waterman, H., & Koshy, V. (2011). *Action research in healthcare*. Los Angeles: SAGE.

Kotter, J., & Schlesinger, L. (2008). Choosing strategies for change. *Harvard Business Review, 86*(7-8), 130-+.

Lather, P. (1992). Getting smart: feminist research and pedagogy with/in the postmodern. *Journal of Leisure Research, 24*(4), 394.

Lawton, J. (1998). Contemporary hospice care: the sequestration of the unbounded body and 'dirty dying'. *Sociology of Health & Illness, 20*(2), 121-143. doi:10.1111/1467-9566.00094

Leedham, K. (1995). District nurses' views on the role of rehabilitation in palliative care. *International Journal Of Palliative Nursing, 1*(3), 141-144. doi:10.12968/ijpn.1995.1.3.141

Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues, 2*(4), 34-46.

Lewin, K. (1948). *Resolving Social Conflicts*. New York: Harper.

Lewin, K. (1951). Field theory in social science.

Lincoln, Y. S., Lynham, S. A., & Guba, E. (2011). Chapter 6: Paradigmatic Controversies, Contradictions and Emerging Confluences, Revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research*. Thousand Oaks: Sage.

Lupu, D., Deneszczuk, C., Leystra, T., McKinnon, R., & Seng, V. (2013). Few U.S. public health schools offer courses on palliative and end-of-life care policy. *Journal of palliative medicine, 16*(12), 1582-1587. doi:10.1089/jpm.2013.0161

Lynn, J., & Adamson, D. M. (2003). *Living well at the end of life. Adapting health care to serious chronic illness in old age*. Retrieved from

Lysaght Hurley, S., Strumpf, N., Barg, F. K., & Ersek, M. (2014). Not quite seamless: transitions between home and inpatient hospice. *Journal of palliative medicine, 17*(4), 428-434.

MacQueen, K. M., McLellan, E., Metzger, D. S., Kegeles, S., Strauss, R. P., Scotti, R., . . . Trotter, R. T. (2001). What is community? An evidence-based definition for participatory public health. *American journal of public health, 91*(12), 1929-1938.

Maddocks, M., Kon, S. S. C., Canavan, J. L., Jones, S. E., Nolan, C. M., Labey, A., . . . Man, W. D. C. (2016). Physical frailty and pulmonary rehabilitation in COPD: a prospective cohort study. *Thorax, 71*(11), 988.

Maddocks, M., Mockett S Fau - Wilcock, A., & Wilcock, A. (2009). Is exercise an acceptable and practical therapy for people with or cured of cancer? A systematic review. *Cancer Treatment Review, 35*(4), 383-390.

Mahler, A., & Verney, S. (2016). The palliative advanced practice registered nurse in the rehabilitation setting. In C. Dahlin, P. J. Coyne, & B. R. Ferrell (Eds.), *Advanced practice palliative nursing.* (pp. 197-205). New York, NY, US: Oxford University Press.

Malcolm, L., Mein, G., Jones, A., Talbot-Rice, H., Maddocks, M., & Bristowe, K. (2016). Strength in numbers: patient experiences of group exercise within hospice palliative care. *BMC Palliative Care, 15*(1), 97-97.

McCarthy, B., Casey, D., Devane, D., Murphy, K., Murphy, E., & Lacasse, Y. (2015). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*(2). doi:10.1002/14651858.CD003793.pub3

McIlfatrick, S., Hasson F Fau - McLaughlin, D., McLaughlin D Fau - Johnston, G., Johnston G Fau - Roulston, A., Roulston A Fau - Rutherford, L., Rutherford L Fau - Noble, H., . . . Kernohan, W. G. (2013). Public awareness and attitudes toward palliative care in Northern Ireland. (1472-684X (Print)).

McIntosh, P. (2010). *Action research and reflective practice: Creative and visual methods to facilitate reflection and learning*: Routledge.

McLoughlin, K. E. (2012). *Identifying and changing attitudes toward palliative care: an exploratory study*. National University of Ireland Maynooth,

McNiff, J. (2013). *Action research: Principles and practice*: Routledge.

McNiff, J., & Whitehead, J. (2002). *Action research : principles and practice* (2nd ed. ed.). London: RoutledgeFalmer.

McNiff, J., & Whitehead, J. (2006). *All you need to know about action research*. London: Sage.

McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007). Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative medicine, 21*(2), 115.

Mertens, D. M. (2007). Transformative Paradigm: Mixed Methods and Social Justice. *Journal of Mixed Methods Research, 1*(3), 212-225. doi:10.1177/1558689807302811

Meyer, J. (1993). New paradigm research in practice: the trials and tribulations of action research. *Journal of advanced nursing, 18*(7), 1066-1072.

Meyer, J. (2000). Qualitative research in health care. Using qualitative methods in health related action research. *BMJ, 320*(7228), 178-181.

Meyer, J. (2006). Action research. In C. Pope & N. Mays (Eds.), *Qualitative research in health care* (Third edition ed.). Oxford, UK: Blackwell Publishing Limited.

Meyer, J., Spilsbury, K., & Prieto, J. (2000). Comparison of findings from a single case on relation to those from a systematic review of action research. *Nurse Researcher, 7*(2), 37-60.

Mitchell, R., Agle, B., & Wood, D. (1997). Toward a theory of stakeholder identification and salience: Defining the principle of who and what really counts. *Academy of Management Review, 22*(4), 853-886. doi:10.2307/259247

Moher, D., Liberati, A., Tetzlaff, J., Altman, D., & Grp, P. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Plos Medicine, 6*(7). doi:10.7326/0003-4819-151-4-200908180-00135|10.1371/journal.pmed.1000097

Moran, J. W., & Brightman, B. K. (2001). Leading organizational change. *Career development international, 6*(2), 111-119.

Morris, S. M., Payne, S., Ockenden, N., & Hill, M. (2017). Hospice volunteers: bridging the gap to the community? *Health & social care in the community, 25*(6), 1704-1713.

Morrison, B., & Lilford, R. (2001). How can action research apply to health services? *Qual Health Res, 11*(4), 436-449.

Murray, S. A., Kendall, M., Mitchell, G., Moine, S., Amblàs-Novellas, J., & Boyd, K. (2017). Palliative care from diagnosis to death. *BMJ, 356*, j878. doi:10.1136/bmj.j878

Murray, S. A., & McLoughlin, P. (2012). Illness Trajectories and Palliative Care. In L. Sallnow, S. Kumar, & A. Kellehear (Eds.), *International Perspectives on Public Health and Palliative Care*. Oxford: Routledge.

National Institute for Clinical Excellence, N. (2007). *Improving Supportive and Palliative Care for Adults with Cancer*. London: NICE

National Institute for Health and Care Excellence. (2017). Quality Statement 10: End of Life Care. Retrieved from https://www.nice.org.uk/guidance/qs13/chapter/quality-statement-10-specialist-palliative-care

National Partnership for Palliative and End of Life Care, N. (2015). *Ambitions for palliative and end of life care : a national framework for local action 2015-2020*. London.

NCPC, N. C. f. P. C. (2011a). *Commissioning End of Life Care*. London: National Council for Palliative Care

NCPC, N. C. f. P. C. (2011b). *Specialist Palliative Care Longitudinal Survey of English Cancer Networks*. Surrey: Mouchel

Nelson, L. A., Hasson, F., & Kernohan, W. G. (2012). Exploring district nurses' reluctance to refer palliative care patients for physiotherapy. *International Journal of Palliative Nursing, 18*(4), 163-170.

Nicholson, C., & Richardson, H. (2018). Age Attuned Hospice Care - An opportunity to better end of life care for older people. In. London: St Christopher's Hospice.

Noblit, G. W., & Hare, R. (1988). *Meta-Ethnography: Synthesizing qualitative studies*. Newbury Park: Sage.

Nwosu, A. C., Bayly, J. L., Gaunt, K. E., & Mayland, C. R. (2012). Lung cancer and rehabilitation-what are the barriers? Results of a questionnaire survey and the development of regional lung cancer rehabilitation standards and guidelines. *Supportive Care in Cancer, 20*(12), 3247-3254. doi:10.1007/s00520-012-1472-1

Oldervoll, L. M., Loge Jh Fau - Lydersen, S., Lydersen S Fau - Paltiel, H., Paltiel H Fau - Asp, M. B., Asp Mb Fau - Nygaard, U. V., Nygaard Uv Fau - Oredalen, E., . . . Kaasa, S. (2011). Physical exercise for cancer patients with advanced disease: a randomized controlled trial. *The Oncologist, 16*(1549-490X (Electronic)), 1649-1657.

Oliver, J. W., Kravitz, R. L., Kaplan, S. H., & Meyers, F. J. (2001). Individualized patient education and coaching to improve pain control among cancer outpatients. *J Clin Oncol, 19*(8), 2206-2212. doi:10.1200/JCO.2001.19.8.2206

Paul, S., & Sallnow, L. (2013). Public health approaches to end-of-life care in the UK: an online survey of palliative care services. *BMJ Support Palliat Care, 3*(2), 196-199. doi:10.1136/bmjspcare-2012-000334

Payne, S. (2010). EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 2. *European Journal of Palliative Care, 17*(6), 286-290.

Pegg, B., & Tan, L. (2002). Reducing suffering to improve quality of life through health promotion. *Contemp Nurse, 12*(1), 22-30.

Pizzi, M. A. (2015). Promoting health and well-being at the end of life through client-centered care. *Scandinavian Journal of Occupational Therapy, 22*(6), 442-449. doi:10.3109/11038128.2015.1025834

Pizzi, M. A., & Briggs, R. (2004). Occupational and physical therapy in hospice - The facilitation of meaning, quality of life, and well-being. *Topics in Geriatric Rehabilitation, 20*(2), 120-130.

Portegijs, E., Buurman, B. M., Essink-Bot, M. L., Zwinderman, A. H., & de Rooij, S. E. (2012). Failure to regain function at 3 months after acute hospital admission predicts institutionalization within 12 months in older patients. *J Am Med Dir Assoc, 13*(6), 569.e561-567. doi:10.1016/j.jamda.2012.04.003

Proot, I. M., Abu-Saad, H. H., Crebolder, H. F. J. M., Goldsteen, M., Luker, K. A., & Widdershoven, G. A. M. (2003). Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scandinavian*

Journal of Caring Sciences, 17(2), 113-121. doi:10.1046/j.1471-6712.2003.00220.x

Randall, F., & Downie, R. S. (2006). *The philosophy of palliative care: Critique and reconstruction*: Oxford University Press.

Rao, J. K., Anderson, L. A., & Smith, S. M. (2002). End of life is a public health issue. *American Journal of Preventive Medicine, 23*(3), 215-220. doi:https://doi.org/10.1016/S0749-3797(02)00500-7

Reason, P. (1991). Power and Conflict in Multidisciplinary Collaboration. *Complementary Medical Research, 3*(3), 144-150.

Reason, P. (1998). Political, epistemological, ecological and spiritual dimensions of participation. *Studies in cultures, organizations and societies, 4*(2), 147-167.

Reason, P. (2002). The Practice of Co-operative Inquiry. In (Vol. 15, pp. 169-176). Systematic Practice and Action Research: Plenum Publishing Corporation.

Reason, P. (2004). A Representation of Competing Worldviews. Retrieved from http://www.peterreason.eu/Papers/Worldviews_table.pdf

Reason, P. (2006). Choice and Quality in Action Research. *Journal of Management Inquiry, 15*(2), 187-203.

Reason, P., & Bradbury, H. (2013). *The Sage Handbook of Action Research: Participative Inquiry and Practice* (3rd ed.). London: Sage.

Reeve, J., Lloyd-Williams, M., Payne, S., & Dowrick, C. (2010). Revisiting biographical disruption: exploring individual embodied illness experience in people with terminal cancer. *Health (London), 14*(2), 178-195. doi:10.1177/1363459309353298

Resqueti, V. R., Gorostiza, A., Gladis, J. B., de Santa María, E. L., Clarà, P. C., & Rous, R. G. (2007). Benefits of a home-based pulmonary rehabilitation program for patients with severe chronic obstructive pulmonary disease. *Archivos de Bronconeumología ((English Edition)), 43*(11), 599-604.

Richardson, J. (2002). Health promotion in palliative care: the patients' perception of therapeutic interaction with the palliative nurse in the primary care setting. *J Adv Nurs, 40*(4), 432-440.

Riel, M. (2010, September 2013). Understanding Action Research. Retrieved from http://cadres.pepperdine.edu/ccar/define.html

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice : a guide for social science students and researchers* (J. R. a. J. Lewis Ed.): London : SAGE.

Robson, C. (2002). *Real World Research*. Oxford: Blackwell.

Rosenberg, J. P., & Hammill, K. (2015). Health promotion and rehabilitation in palliative care. In M. Matzo & D. W. Sherman (Eds.), *Palliative care nursing: Quality care to the end of life, 4th ed.* (pp. 189-204). New York, NY, US: Springer Publishing Co.

Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2018). Informal care networks’ views of palliative care services: Help or hindrance? *Death Studies, 42*(6), 362-370. doi:10.1080/07481187.2017.1350216

Rosenberg, J. P., Mills, J., & Rumbold, B. (2016). Putting the ‘public’into public health: community engagement in palliative and end of life care. *Progress in Palliative Care, 24*(1), 1-3.

Rosenberg, J. P., & Yates, P. (Eds.). (2011). *Transition from conventional to health promoting palliative care: an Australian case study*: Oxford University Press Oxford, England.

Rosenberg, J. P., & Yates, P. M. (2010). Health promotion in palliative care: the case for conceptual congruence. *Critical Public Health, 20*(2), 201-210. doi:10.1080/09581590902897394

Round, J., Leurent, B., & Jones, L. (2014). A cost-utility analysis of a rehabilitation service for people living with and beyond cancer. *BMC Health Services Research, 14,* 558-558. doi:10.1186/s12913-014-0558-5

Rumbold, B. (2011). Health promoting palliative care and dying in old age. In M. Gott & C. Ingleton (Eds.), *Living with ageing and dying: palliative and end of life care for older people* (pp. 75-89). Oxford: Oxford University Press.

Rumbold, B., & Aoun, S. (2014). Bereavement and palliative care: A public health perspective. *Progress in Palliative Care, 22*(3), 131-135. doi:10.1179/1743291X13Y.0000000079

Runacres, F., Gregory, H., & Ugalde, A. (2017). "The horse has bolted I suspect': A qualitative study of clinicians' attitudes and perceptions regarding palliative rehabilitation. *Palliative Medicine, 31*(7), 642-650. doi:10.1177/0269216316670288

Sallnow, L., & Paul, S. (2015). Understanding community engagement in end-of-life care: developing conceptual clarity. *Critical Public Health, 25*(2), 231-238.

Sallnow, L., Richardson, H., Murray, S. A., & Kellehear, A. (2015). The impact of a new public health approach to end-of-life care: A systematic review. *Palliative Medicine, 30*(3), 200-211. doi:10.1177/0269216315599869

Salmela, S., Eriksson, K., & Fagerström, L. (2013). Nurse leaders' perceptions of an approaching organizational change. *Qualitative health research, 23*(5), 689-699.

Santiago-Palma, J., & Payne, R. (2001). Palliative care and rehabilitation. *Cancer: Interdisciplinary International Journal of the American Cancer Society, 92*(S4), 1049-1052.

Saunders, C. (1987). What's in a name? *Palliative Medicine, 1*(1), 57-61. doi:10.1177/026921638700100108

Saunders, C. (2004). Foreward. In D. Doyle, G. Hanks, N. Cherny, & K. Calman (Eds.), *Oxford Textbook of Palliative Medicine* (3rd Edition ed.). Oxford: Oxford University Press.

Scialla, S., Cole, R., Scialla, T., Bednarz, L., & Scheerer, J. (2000). Rehabilitation for elderly patients with cancer asthenia: making a transition to palliative care. *Palliative Medicine, 14*(2), 121-127.

Shanley, C. (2007). Management of change for nurses: lessons from the discipline of organizational studies. *Journal of nursing management, 15*(5), 538-546.

Silver, J. K., Raj, V. S., Fu, J. B., Wisotzky, E. M., Smith, S. R., & Kirch, R. A. (2015). Cancer rehabilitation and palliative care: critical components in the delivery of high-quality oncology services. *Support Care Cancer, 23*(12), 3633-3643. doi:10.1007/s00520-015-2916-1

Smith, L., Rosenzweig, L., & Schmidt, M. (2010). Best Practices in the Reporting of Participatory Action Research: Embracing Both the Forest and the Trees 1Ψ7. *The Counseling Psychologist, 38*(8), 1115-1138. doi:10.1177/0011000010376416

Stjernswärd, J., Foley, K. M., & Ferris, F. D. (2007). The Public Health Strategy for Palliative Care. *Journal of Pain and Symptom Management, 33*(5), 486-493. doi:10.1016/j.jpainsymman.2007.02.016

Talbot Rice, H., Malcolm, L., Norman, K., Jones, A., Lee, K., Preston, G., . . . Maddocks, M. (2014). An evaluation of the St Christopher's Hospice rehabilitation gym circuits classes: Patient uptake, outcomes, and feedback. *Prog Palliat Care*, *22*(6), 319-325. doi:10.1179/1743291x14y.0000000083

Taylor, C., & White, S. (2000). *Practising reflexivity in health and welfare*: Open University Press Buckingham.

Taylor, R., Sagar, V. A., Davies, E. J., Briscoe, S., Coats, A. J. S., Dalal, H., . . . Mordi, I. R. (2014). Exercise-based rehabilitation for heart failure. *Cochrane Database of Systematic Reviews*(4). doi:10.1002/14651858.CD003331.pub4

Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., . . . Lynch, T. J. (2010). Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. *New England Journal of Medicine, 363*(8), 733-742. doi:10.1056/NEJMoa1000678

Tester, C. (2008). Palliative Rehabilitation. In K. Boog & C. Tester (Eds.), *A Pratcical Guide to Working in Palliative Care: Finding Meaning and Purpose in Life and Death*. USA: Elsevier.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology, 8*(1), 45.

Thomas, R., & Hardy, C. (2011). Reframing resistance to organisational change. *Scandinavian Journal of Management, 27*, 322-331.

Tiberini, R., & Richardson, H. (2015). Rehabilitative Palliative Care - Enabling people to live fully until they die: A challenge for the 21st Century. In. London: Hospice UK.

Titchen, A. (1995). Issues of Validity in Action Research. *Nurse Researcher, 2*(3), 38-48.

Titchen, A. (2000). Professional Craft Knowledge in Patient-centred Nursing and the Facilitation of its Development. In. Ashdale Press, Tackley, Kidlington, Eng.

Vakola, M., & Nikolaou, I. (2005). Attitudes towards organizational change: What is the role of employees’ stress and commitment? *Employee relations, 27*(2), 160-174.

Vockins, H. (2004). Occupational therapy intervention with patients with breast cancer: a survey. *European journal of cancer care, 13*(1), 45-52.

von Post, H., & Wagman, P. (2017). What is important to patients in palliative care? a scoping review of the patient’s perspective. *Scandinavian journal of occupational therapy*, 1-8.

Waldron, M., Kernohan, W. G., Hasson, F., Foster, S., Cochrane, B., Payne, C., . . . Johnson, C. (2011). Allied health professional's views on palliative care for people with advanced Parkinson's disease. *International Journal of Therapy & Rehabilitation, 18*(1), 48-58.

Waterman, H., Tillen, D., Dickson, R., & de Koning, K. (2001). Action research: a systematic review and guidance for assessment. *Health Technology Assessment, 5*(23).

WHO, W. H. O. (1986). *The Ottawa Charter for Health Promotion*. Geneva: World Health Organisation

WHO, W. H. O. (2018). Palliative Care: Key Facts. Retrieved from https://www.who.int/en/news-room/fact-sheets/detail/palliative-care

Wicks, P. G., & Reason, P. (2009). Initiating action research: Challenges and paradoxes of opening communicative space. In: Sage Publications Sage UK: London, England.

Williamson, G. R., Bellman, L., & Webster, J. (2012). *Action research in nursing and healthcare*. London: SAGE.

Williamson, G. R., & Prosser, S. (2002). Action research: politics, ethics and participation. *Journal of advanced nursing, 40*(5), 587-593.

Wosahlo, P. (2014). An analysis of the implementation of palliative rehabilitation in five UK hospices using the Stakeholder Salience Model. *Progress in Palliative Care, 22*(6), 342-346. doi:10.1179/1743291X14Y.0000000103

Wosahlo, P., & Maddocks, M. (2015). Benchmarking the provision of palliative rehabilitation within the hospice setting. *Palliative Medicine, 29*(5), 477-478. doi:10.1177/0269216314564240

Yoshioka, H. (1994). Rehabilitation for the terminal cancer patient. *American journal of physical medicine & rehabilitation, 73*(3), 199-206.

Zuber-Skerritt, O. (1996). *New directions in action research*: London, Falmer.

Zuber-Skerritt, O. (2001). Action Learning and Action Research: Paradigm, Praxis and Programs. In S. Sankara, B. Dick, & R. Passfield (Eds.), *Effective Change Management through Action Research and Action Learning: Concepts, Perspectives, Processes and Applications* (pp. 1-20). Lismore, Australia: Southern Cross University Press.

Zuber-Skerritt, O., & Fletcher, M. (2007). The quality of an action research thesis in the social sciences *Quality Assurance in Education, 15*(4), 413-436.

10. Appendices

Appendix 1: Invitation to participate in the research

Lancaster University

28 April 2015

Dear Colleagues

Re: Integrating rehabilitation into palliative care

I am writing to invite you to attend a meeting to discuss a piece of research that I am about to undertake. You have received this letter because you are either a nurse or healthcare assistant who works on the in-patient unit or a therapist, and representation from these groups of staff is considered to be very important in getting a balanced view about the approach to be taken for the research.

As you may be aware, there is a growing body of literature that suggests that the palliative care provided in hospices, although intended to be supportive, may disable patients and reduce their ability to do things for themselves and therefore there needs to be a greater emphasis on supporting the patient to remain as independent as possible. One way to do this is by developing a rehabilitative approach to palliative care.

The research I will undertake intends to engage clinical staff and volunteers in considering what a rehabilitative approach means for patient care in an in-patient setting and how this could be integrated. A research method called 'participatory action research' will be used which means that participants are actively involved in all stages of the research process – from understanding the issue more fully, to planning what action to take, reviewing the progress made, suggesting further action and, at the end, assessing how effective the study has been.

If you are interested in taking part, and/or would like to find out more about this research, there will be meetings in the Education Suite on:

- Tuesday 19 May at 9.30am
- Wednesday 27 May at 12.30pm
- Thursday 28 May at 2.30pm.

Refreshments will be provided.

Participation in this research is entirely voluntary and a decision not to become involved will not have any consequences for your employment with the Hospice.

Thank you for your time and consideration. Should you have any questions please don't hesitate to contact me via email: k.clarke1@lancaster.ac.uk or telephone: 01323 434205.

Yours sincerely

K. L. Clarke.

Karen Clarke

Appendix 2: Participant Information Sheet

Participant Information Sheet

Integrating rehabilitation into palliative care

My name is Karen Clarke and I am conducting this research as a student in the PhD Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to develop ways that clinical staff and volunteers can integrate a rehabilitative approach to palliative care for Hospice in-patients. In this context a rehabilitative approach is one that enables patients to do as much as they can for themselves and supports them in adapting to changes in function as a result of their condition. This is particularly important in the context of a hospice in-patient unit where prolonged periods spent in bed can reduce patients' functional independence.

A research method called 'participatory action research' will be used which means that participants are actively involved in all stages of the research process – from understanding the issue more fully, to planning what action to take, reviewing the progress made, suggesting further action and at the end assessing how effective the study has been.

Why have I been approached?

Participatory action research recognises the importance of engaging individuals in generating knowledge and involving them in decisions that affect them. This research will involve those who work (staff and volunteers) in the Hospice's in-patient unit and as you are part of that team you, and your colleagues, have been invited to participate in this research.

Do I have to take part?

No. It is completely up to you to decide whether or not you take part. If you decide you do not wish to be part of the co-operative inquiry group (CIG) who will undertake the research it will not have any consequences for your volunteering or employment with the Hospice

If you do decide to take part but subsequently change your mind you are free to withdraw at any time without giving a reason and without your employment or volunteering relationship with the Hospice being affected. However, if the group has meet at least once after the initial set up meeting, it will not be possible to withdraw your contribution to the discussions.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be invited to become a member of the 'co-operative inquiry group' (CIG) who will undertake the research with me. As mentioned above because this is participatory action research you will not only be participating in the research but also be part of the team who will shape, guide and review it. You will be asked to sign a consent form agreeing to be part of this group.

The participatory nature of this research means that I cannot be specific about what else you will be asked to do as part of the research as this will be decided by those who participate. If you decide to take part, you will be part of this decision-making group and will shape what activities you and your colleagues will undertake. The kinds of activities you are likely to be involved in include: consulting colleagues about their views in relation to rehabilitation, active participation in the CIG meetings and reflecting on your practice. Your consent to participate in other activities will be sought throughout the study.

Will my data be confidential?

The information you provide is confidential but because this is participatory action research your fellow researchers will hear the discussions that take place at the CIG meetings and any contributions you make. The following safeguards will be in place in relation to data:

- Audio recordings from CIG meetings will transcribed by me and then deleted from the digital recording device. The transcripts and copies of recordings stored on computer will be destroyed and/or deleted after the research project has been examined
- Other notes from meetings will be typed and stored on a computer.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- Any written documentation that you have been involved in will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from any interviews or meetings may be used in the reports or publications from the study, so your name will not be attached to them.

There are some limits to confidentiality: if what is said in the meetings makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my research supervisor about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis to gain my PhD and may be submitted for publication in an academic or professional journal. It may also be used in presentations at conferences, seminars and workshop.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress either as a result of taking part, or in the future you are encouraged to contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participation interesting, there are no direct benefits in taking part. However, action research is about the generation of knowledge and therefore you may find that participation may support your ongoing professional development.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact me: Karen Clarke, PhD Research Student, k.clarke1@lancaster.ac.uk, 01323 434205.

Supervisors:

Katherine Froggatt
Professor of Ageing and Palliative Care
International Observatory on End of Life Care
Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster LA1 4YG
00 44 (0) 1524 593308
k.froggatt@lancaster.ac.uk

Dr Sarah G Brearley
Lecturer
International Observatory on End of Life Care
Faculty of Health and Medicine
C049 Furness College
Lancaster University
Lancaster LA1 4YG
Tel. 01524 592574
Sarah.brearley@lancaster.ac.uk

Resources in the event of distress

Should you feel distressed either as a result of taking part in this research or in the future please contact a member of the Hospice's counselling team or a member of the HR Department. Please phone 01323 434200 and ask to be put through to the relevant department. Alternatively, you may wish to seek support outside the organisation, the British Association for Counselling and Psychotherapy (BACP) has a register of approved counsellors who can be accessed through their website: http://www.bacp.co.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to me, you can contact the following:
Professor Steven Jones
Title: Director of Spectrum Centre for Mental Health Research, Lancaster University
Telephone: 01524 593382 Email: s.jones7@lancaster.ac.uk

Or, if you wish to speak to someone outside the Division of Health Research, you may also contact:
Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine (Division of Biomedical and Life Sciences)
Lancaster University
Lancaster LA1 4YG

Thank you for taking the time to read this information sheet.

Appendix 3: Consent form

Consent Form

Study Title: Integrating rehabilitation into palliative care

I am asking if you would like to take part in a research project which aims to develop ways that clinical staff and volunteers can integrate a rehabilitative approach to palliative care for Hospice in-patients. It will use participatory action research methodology which means that participants are actively involved in all stages of the research process.

Before you consent to participating in the study I ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the Consent Form please speak to me, Karen Clarke.

Please initial box after each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study at this stage.	☐
2. I understand that this study involves participatory action research (PAR) and therefore the full details of what will be expected of me will only become clear during the research itself. However, I understand that participation will involve attending meetings of the co-operative inquiry group and participating in decisions about the research.	☐
3. I confirm that I have had the opportunity to ask any questions and to have them answered.	☐

4. I understand that my participation in any meetings will be audio recorded and then made into an anonymised written transcript.	☐
5. I understand that audio recordings will be transferred to an encrypted, password protected laptop for transcription and then deleted from the digital recording device. The recording stored on the laptop will be destroyed once the thesis has been completed and assessed.	☐
6. I confirm that my decision to participate is entirely voluntary.	☐
7. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my employment or volunteering status being affected.	
8. I understand that once my data have been anonymised and incorporated into themes it will not be possible for it to be withdrawn.	☐
9. I understand that any information I provide will be pooled with other participants' responses, anonymised and may be published	☐
10. I consent to information and quotations from any interviews and meetings being used in reports, conferences and training events and in producing the researcher's PhD thesis.	☐
11. I understand that because this is participatory action research, I will be part of a research team, as will other individuals, which means that the information I share as part of the co-operative inquiry group (CIG) will be available to those the CIG members.	☐
12. I understand that any information I give will remain strictly confidential and anonymous outside of the CIG unless it is thought that there is a risk of harm to myself or others, in which case the researcher will/may need to share this information with her research supervisors and take action in line with the Hospice's "Ensuring Good Practice (Whistleblowing) Policy".	☐
13. I consent to Lancaster University keeping written transcriptions of the meetings and interview for 10 years after the study has finished.	☐
14. I agree to maintain confidentiality regarding discussions and data collected through the CIG.	☐

15. I consent to take part in the above study.	☐

Name of Participant__________________ Signature____________________ Date ___________

Name of Researcher ____________________Signature _________________Date _________

Appendix 4: Overview of data collection

Types of data	Purpose	How was it collected and by whom?	Quantity	Dates of collection	Action research phase	Method of analysis
Questionnaire	Descriptive data about members of the CIG, e.g. length of service, occupational group.	Word document, self-completed, by hand, by the CIG and returned to me for analysis	8 issued, 8 returned	29 June 2015	Situational analysis	Descriptive statistics
	Power survey to understand perspectives about power within the CIG and the organisation.	Electronic Word document, self-completed by the CIG. Returned me for analysis via email, collated and stored on a personal computer	6 issued, 6 returned	11 February 2016	Review	Descriptive statistics and thematic analysis
	Evaluation form for participants to evaluate the research project	Electronic Word document, self-completed by the CIG. Returned me for analysis via email, collated and stored on a personal computer	6 issued, 5 returned (one member on maternity leave)	01 June 2016	Review	Thematic analysis
Record of meetings - systematic observation	To record the date, time, content, attendance at CIG meetings.	Handwritten by me at each CIG meeting then input onto an excel spreadsheet and stored on personal computer.	11	29 June 2015 - 7 June 2016	Review	Descriptive statistics

Notes	To record the discussions at the CIG meetings.	Audio recorded at the meeting by me and then transcribed and stored on a personal computer.	11 meetings	30 June 2015 - 7 June 2016	Plan, Act and Review	Concurrent analysis and thematic, retrospective analysis
	To record the discussions at the PAG meetings to ensure the patient voice was captured.	Audio recorded at the meeting by me and then transcribed and stored on a personal computer.	5 meetings	June 2015 - April 2016	Plan, Act and Review	Concurrent analysis
	To record the discussions at the Discharge Planning Working Group (DPWG) meetings which developed from the CIG and was evidence of the RPC approach in practice	CIG members took handwritten notes the DPWG meetings and then transcribed and stored onto personal computer.	2 meetings	29 October 2015 and 9 December 2015	Plan, Act and Review	Concurrent analysis
Journal	Collect a personal database of events, reflections and commentary; Maintain the momentum of thought processes; Provide a useful prompt for the final thesis.	Hand-written in a journal completed by me after meetings, whilst reflecting on actions, when considering next steps, after a significant event.	53 entries	Throughout the project	Plan, Act and Review	Concurrent analysis and thematic, retrospective analysis

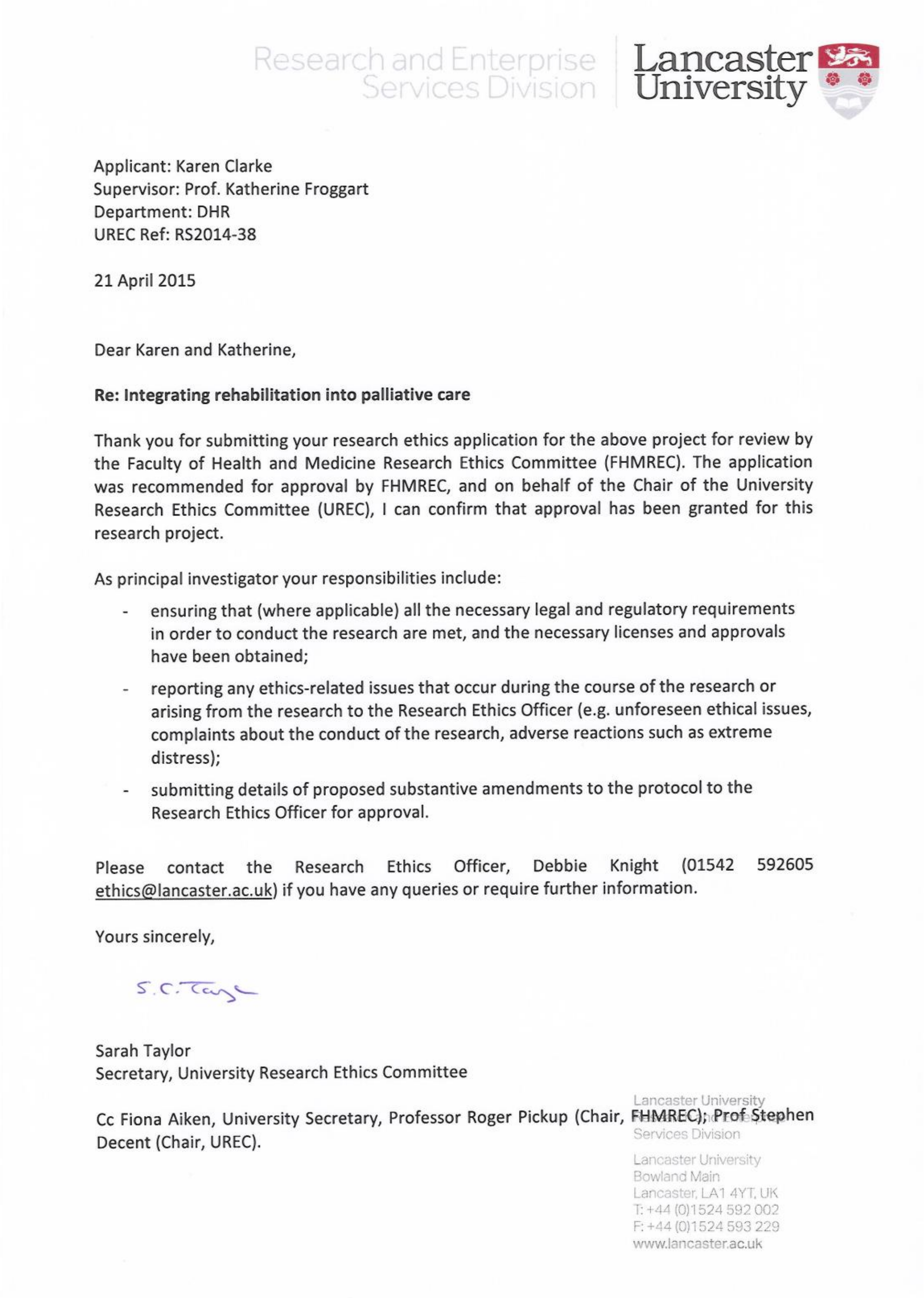
Organisational documents	In-patient unit (IPU) Minimum Data Set (MDS) - to understand the profile of patients being admitted to the in-patient unit in a year, e.g. age, diagnosis, length of stay, outcome from admission; no. of deaths etc. This would inform whether a rehabilitative approach was appropriate in this setting.	I collected hard copies of the MDS from the Hospice records and photocopied them for the CIG.	Two years' data: 2013/14 and 2014/15	30 July 2015	Plan	Concurrent analysis
	Integrated Palliative Outcome Score (IPOS) audit - to understand what gave patients, admitted to the in-patient unit, the greatest cause for concern on and during their admission and upon discharge. This would inform whether a rehabilitative approach was appropriate in this setting.	IPOS scores completed by patients on admission, repeated 3-5 days later and if relevant on discharge. Collected by IPU nurses, collated by doctor, presented at Audit feedback meeting. Clinical CIG members collected hard copies of the audit presentation and photocopied it for the CIG.	One audit of 30 patients	30 July 2015	Plan	Concurrent analysis
Flipcharts	To develop a shared understanding of the terminology relating to	Completed, by hand, by the CIG and then completed by me at the PAG meeting. These were then	4 at the CIG meeting and one at the	29/06/2015 (CIG) and 07/08/15 (PAG)	Plan	Concurrent analysis

	rehabilitation in the context of palliative care.	transcribed and stored on a personal computer.	PAG meeting			
Tools developed by Tiberini and Richardson (2015) to support hospices in introducing a rehabilitative approach	Action planning & goal setting document: Used by the CIG to describe their understanding of the Hospice's current position in relation to RPC and identify the goals for the research.	Completed independently by members of the CIG and then reviewed collectively and one handwritten version produced. This was then transcribed and stored on a personal computer	1	Completed October 2015 and reviewed in June 2016	Plan	Concurrent and retrospective analysis
	"How rehabilitative is your hospice checklist?": Used by the CIG to measure how rehabilitative the Hospice's approach was prior and post activities developed by the CIG.	Completed by CIG members in consultation with the wider multidisciplinary team and then reviewed collectively at the meeting and collated. This was then transcribed and stored on a personal computer.	2	Assessed in September 2015 and repeated in June 2016	Plan and Act	Concurrent and retrospective analysis
Organisational change literature and case study	Develop and share knowledge in relation to organisational change	Articles were identified by me and allocated to the CIG who reviewed the article and fed back to the group.	7 articles	Articles circulated after 2 September. Discussed 1 October 2015.	Plan and Act	Concurrent analysis

		I presented a case study of an organisational change project.	1	1 October 2015	Plan	Concurrent and retrospective analysis
Session plan for the workshops	It was important that the workshops were carefully planned and prepared to ensure they were engaging, informative, empowering and successful	Ideas collected on a whiteboard, formulated into a lesson plan by a sub group of the CIG, shared with the broader group for refinement and approval. It was then stored onto personal computer	1	Reviewed by the CIG 9 December 2015 and agreed on 14 January 2016	Plan and Act	Concurrent analysis
Presentations	Raising awareness of and creating engagement in a rehabilitative approach with the PAG, the Clinical Leaders Forum and the Wellbeing team	Ideas collected on a whiteboard, formulated into a PowerPoint presentation by CIG members, shared with the broader group for refinement and approval. It was then stored onto personal computer	1 x PAG with 5 patients; 3 x Clinical Leaders Forum (CLF) with c12 staff at each; 1 x Wellbeing Away Day (WB) with 21 staff	PAF: 16 October 2015; CLF: October 2015, May 2016 and June 2016; WB: June 2016.	Act	Concurrent analysis

Summary of workshop evaluations	The feedback from the workshops was used to inform further action and to assess how receptive the organisation might be to adopting this approach.	Participants attending the workshops were asked to provide feedback on how useful and relevant the workshops had been by completing an evaluation form, by hand, at the end of the workshop. These were collated by A3 and O6 who delivered the workshop and shared with the CIG. They were then stored on personal computer.	18 attendees	Jan 2016 and March 2016	Plan and Review	Concurrent analysis
Postcards	Raising awareness of and creating engagement in a rehabilitative approach	Produced by a CIG sub group. Consultation with the PAG and further refined. Shared with the entire group for approval. Electronic copy produced and stored on personal computer	1	08 April 2016	Act	Concurrent analysis

Appendix 5: Ethics Committee approval for the research



Research and Enterprise
Services Division
Lancaster University

Applicant: Karen Clarke
Supervisor: Prof. Katherine Froggart
Department: DHR
UREC Ref: RS2014-38

21 April 2015

Dear Karen and Katherine,

Re: Integrating rehabilitation into palliative care

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

S.C. Taylor

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, Professor Roger Pickup (Chair, FHMREC); Prof Stephen Decent (Chair, UREC).

Lancaster University
Research and Enterprise
Services Division

Lancaster University
Bowland Main
Lancaster, LA1 4YT, UK
T: +44 (0)1524 592 002
F: +44 (0)1524 593 229
www.lancaster.ac.uk

Appendix 6: Details of the co-operative inquiry group (CIG) meetings

	Date	Time	Content	Attendees/ Chair
1	Monday 29 June 2015	2.00pm	Clarified the purpose of the research and its focus on organisational change rather than outcomes for patients	All/ K9
			Agreed the ground rules for the CIG meetings	
			In pairs and then as a group, considered the following four questions:	
			- What does the term palliative rehabilitation mean?	
			- What is palliative rehabilitation not?	
			- What other words or phrases could we use instead of "palliative rehabilitation"?	
			- What would a patient/family member think or understand by the term palliative rehabilitation?	
2	Thursday 30 July 2015	2.30pm	Considered feedback from the Patient Advisory Group (PAG)	All/ E2
			Considered feedback from internal and external perspectives of the terminology	
			Reviewed organisational documentation: Minimum Data Set (MDS), Integrated Palliative Outcome Score (IPOS)	
			Considered feedback from the study day on Rehabilitative Palliative Care (RPC) attended by L8 and A1	
			Agreed to use the RPC checklist to assess how rehabilitative the organisation was	

3	Wednesday 2 September 2015	2.30pm	Reviewed the membership given N4's withdrawal	All except N4 who had withdrawn /A3
			Reviewed the aims of the research and progress to date	
			Considered feedback from the PAG and agreeing ongoing involvement	
			Reviewed the collated RPC checklist	
			Agreed each member would review an organisational change article to summarise at the next meeting	
4	Thursday 1 October 2015	2.30pm	Reflected on the last meeting	All except E2/ A1
			Each CIG member fed back on the organisational change literature they had read	
			KC presented an organisational change case study	
			Discussed action planning and goal setting and agreed next steps	
			Actions agreed: CIG members (Occupational therapist, physiotherapist and nurse) to participate in the Discharge Planning Working Group (DPWG), prepare presentation for the Clinical Leaders Forum (CLF), draft an education plan, raise awareness of RPC with Host Liaison Volunteers, consider other communication.	
5	Thursday 12 November 2015	2.30pm	Considered feedback from Host Liaison, PAG, DPWG and CLF meetings.	All except S7 and D5 /L8
			Discussed draft training/education plan, including the practicalities of delivering this and ensuring good attendance, and presentation at Wellbeing Away Day	
			Agreed to create two sub groups: Education and communications	
6		2.30pm	Reflected on the last meeting	All/

	Wednesday 9 December 2015		Considered feedback from the DPWG and Wellbeing Away Day	O6
			Discussed updated plans for education and plans for communication	
			Agreed plans for inviting people to attend the workshops	
			Agreed to reread the notes from all meetings in order to start to discuss emerging themes	
7	Thursday 14 January 2016	2.30pm	Reviewed updated education plan, dates for training, plan for communicating this, delegate preparation prior to the workshop	All/S7
			Reviewed communication plan - postcards were being redrafted following feedback and Hospice Voice (newsletter) article	
			Discussed what the CIG thought had emerged from the meetings and activities that had taken place between June to November 2015	
8	Thursday 11 February 2016	2.30pm	Considered feedback from the workshop in January 2016 both in terms of how the facilitators felt it had gone and the evaluation from attendees	All/D5
			Agreed to run a further workshop and invite key staff who supported the work of the in-patient unit (e.g. facilities team, complementary therapists)	
			Discussed whether a new volunteer role of Dining Companion could be linked to this project and how to facilitate this	
			Updated on Hospice Voice and Facebook communication plans	
			Discussed what the CIG thought had emerged from the meetings and activities that had taken place between June to November 2015	

			Agreed to consider ‘power’ within the group by completing a questionnaire	
9	Wednesday 13 April 2016 (postponed from March to allow the second workshop to have taken place).	2.30pm	Considered feedback from the second workshop	All/ K9
			E2 reported back on bespoke RPC training to volunteers she had been asked to deliver	
			Discussed the organisational plans for volunteer training and the importance of having joint volunteer and staff training to embed the approach	
			Discussed what the CIG thought had emerged from the meetings and activities that had taken place between December 2015 and February 2016	
			KC presented a summary of the responses to the Power survey	
			Discussed plans for raising awareness of RPC with key groups (CLF) and other ways of communicating	
			Agreed to present the work done to date and a proposal for how this work could continue after the research had been concluded to the CLF.	
10	Wednesday 18 May 2016	2.30pm	CIG members fed back from the CLF meeting	All/ K9
			S8 updated on the organisation volunteer training plan and how RPC featured in this	
			Agreed to complete the "How rehabilitative is your hospice?" checklist following the CIG activities	
			Discussed and agreed an evaluation form for the project	
			Agreed to meet finally in June to conclude the research phase.	
11		2.30pm	Reviewed the scores for the checklist and compared this to the scores achieved last year	

	Tuesday 7 June 2016		Reviewed the action plan and goal setting document completed in October 2015 to assess what had been achieved.	All except O6/K9
			Discussed the bid that was being submitted to St James' Place to progress this work	
			Agreed that RPC training would become part of mandatory training	
			Agreed that the Rehabilitation Assistant would undertake a People with Personal Experience (PPE) initiative with patients to gather some patient feedback on RPC.	
			The group agreed to meet again in September to maintain contact and momentum for the work.	

Appendix 7: Power survey

February 2016

Dear CIG members,

At our meeting in February we started to discuss the concept of ‘power’ and how it had played out within the co-operative inquiry group. To explore this further we agreed that I would circulate a questionnaire for you to complete and return to me.

The following questions are intended to gather your perceptions of several things that we, as a group have observed, but also from what I have read around the concept of power in action research. Although I will be able to identify who responded and how, the questionnaires will remain anonymous to other members of the group and only collated responses will be shared.

The information that you provide will be used in the PhD research. Thanks for taking the time to complete this survey.

A	**POWER EXTERNAL TO THE CIG**
1.	**On a number of occasions, members of the CIG questioned whether senior managers had signed up to the action it was planning to take. What does this say about the where power lies within the organisation?**

2.	**Consider where the power sits within the Hospice. What impact will this have on the integration of this approach and why?**					
3.	**Do you feel as though the CIG has the power to challenge this status quo in order to enable this approach to flourish? Yes/No** **What evidence is there to substantiate this?**					
B	**POWER WITHIN THE CIG**					
4.	**Who, if anyone, exercised the most influence in the group? (Please tick all that apply, you may choose more than one)**					
	Nurses	**Therapists**	**Volunteers**	**Managers**	**Researcher**	**Equal**
5.	**Please explain the reason for your answer to question 4.**					
6.	**“Co-researchers rely on the researcher to facilitate engagement in the research”. To what degree has this happened in this project?**					
To a large degree	**To a reasonable degree**	**To a small degree**	**Never**			
7.	**Please explain the reason for your answer to question 6.**					
8.	**“Power relations between the group can impact on the egalitarian process”. To what degree has this happened in this study?**					
To a large degree	**To a reasonable degree**	**To a small degree**	**Never**			
9.	**Please explain the reason for your answer to question 8.**					
10.	**Although at the beginning, the CIG established the ground rules, do you think it took into account power relationships within the group and how this might impact on the research from the outset? Yes/No**					

<table>
<tr><td></td><td colspan="4">Please explain the reason for your answer.</td></tr>
<tr><td>11.</td><td colspan="4">The CIG acknowledged the importance of the role of volunteers in this project and committed to train volunteers alongside paid staff. What does this say: a) about the culture of the organisation and b) about traditional hierarchies within the organisation?</td></tr>
<tr><td colspan="5"></td></tr>
<tr><td>12.</td><td colspan="4">To what degree do you, as a member of the CIG feel empowered to bring about change and why?</td></tr>
<tr><td colspan="5"></td></tr>
<tr><td>13.</td><td colspan="4">It could be argued that the growing independence of CIG members as the research has progressed reflects a change in power relations between participants and the researcher. Do you agree? Yes/No

Please explain the reason for your answer.</td></tr>
<tr><td>C</td><td colspan="4">LEAD RESEARCHER</td></tr>
<tr><td>14.</td><td colspan="4">“The researcher provides leadership and guidance to negotiate power relations and build capacity for engagement with the research.” To what degree, if any, have I done this?</td></tr>
<tr><td colspan="2">To a large degree</td><td>To a reasonable degree</td><td>To a small degree</td><td>Never</td></tr>
<tr><td>15.</td><td colspan="4">Please explain the reason for your answer to question 14</td></tr>
<tr><td>16.</td><td colspan="4">What impact did the fact that I was novice researcher have on this process?</td></tr>
<tr><td colspan="5"></td></tr>
</table>

17.	**Any other comments in relation to ‘power’ within the CIG that you would like to add?**

Please return this by **9am on Thursday 31 March 2016** via email to: k.clarke1@lancaster.ac.uk

Thanks again

Karen

Appendix 8: Evaluation form

Co-operative Inquiry Group Evaluation

This questionnaire is designed to evaluate the outcome of the project from the perspective of the cop-operative inquiry group members (CIG). It is a based on an outcome evaluation tool created by (Williamson et al., 2012). In order to place the evaluation in context and as a prompt, I have restated the aims of the project below:

Aim of the project:

This research aims to explore how a rehabilitative approach can be integrated into a hospice in-patient setting using participatory action research (PAR). A CIG will:

- collectively develop their knowledge about what a rehabilitative approach means
- plan how to integrate a rehabilitative focus into hospice palliative care, for a specific group of patients, with particular attention paid to the facilitators and barriers to this approach
- lead on the actions that have been agreed as part of the plan
- meet regularly to review progress, adapt or amend plans where appropriate and to agree how the study should be evaluated.

Please be a thorough as possible in your responses. If you need additional space, please use a separate page and attach it to the questionnaire ensuring that the number of the question you are responding to is clearly stated. You are not obliged to answer all the questions but any responses or comments that you can provide would be greatly appreciated.

The information you provide will be used in my PhD thesis and you will not be identifiable from the data you provide. The data extracted from the questionnaire will be stored on an encrypted password protected laptop stored in a locked cabinet in my locked office.

1. **Please tick the box that describes your role at the Hospice:**

Physiotherapist	Occupational Therapist	Volunteer	Manager	Nurse

2. What have you learnt personally and professionally from being a co-researcher in this project?

3. What do you believe overall helped to drive the project forward?

4. What do you consider overall were the barriers to change regarding this project?

5. How were problems resolved?

6. What changes have occurred as a direct result (impact) of the project – for patients/colleagues/multidisciplinary team/the ward/yourself?

7. What could be shared with other colleagues thinking of making a similar change in practice?

8. What could be shared with other colleagues thinking of doing an action research project?

9. How would you like this initiative to continue in the future?

10. Anything else you would like to say?

Thank you for taking the time to complete this survey. Your participation is appreciated.

Please return the completed survey to k.clarke1@lancaster.ac.uk by 30 June 2016. If you have any queries or comments in relation to this questionnaire, please contact Karen Clarke via e-mail at: k.clarke1@lancaster.ac.uk

Yours faithfully
Karen Clarke

Appendix 9: Quotes from co-researchers (A3 and L8)

These quotes are taken from the evaluation form the co-researchers completed.

A3: “I have become more aware of what it takes to implement a new way of working in an organisation. The RPC approach, as we have discussed many times, is not a massive paradigm shift and is present in our day to day work across the Hospice. However, it will and has taken a lot of work to inform and educate, train and generally get people on board with this way of looking at hospice care. This has had to happen on so many levels within the organisation and cannot ever be fully successful unless everybody is on board. I think we have got there or are at least getting there, and I look at the inclusive way we tried to bring this about as a successful model for organisational change.

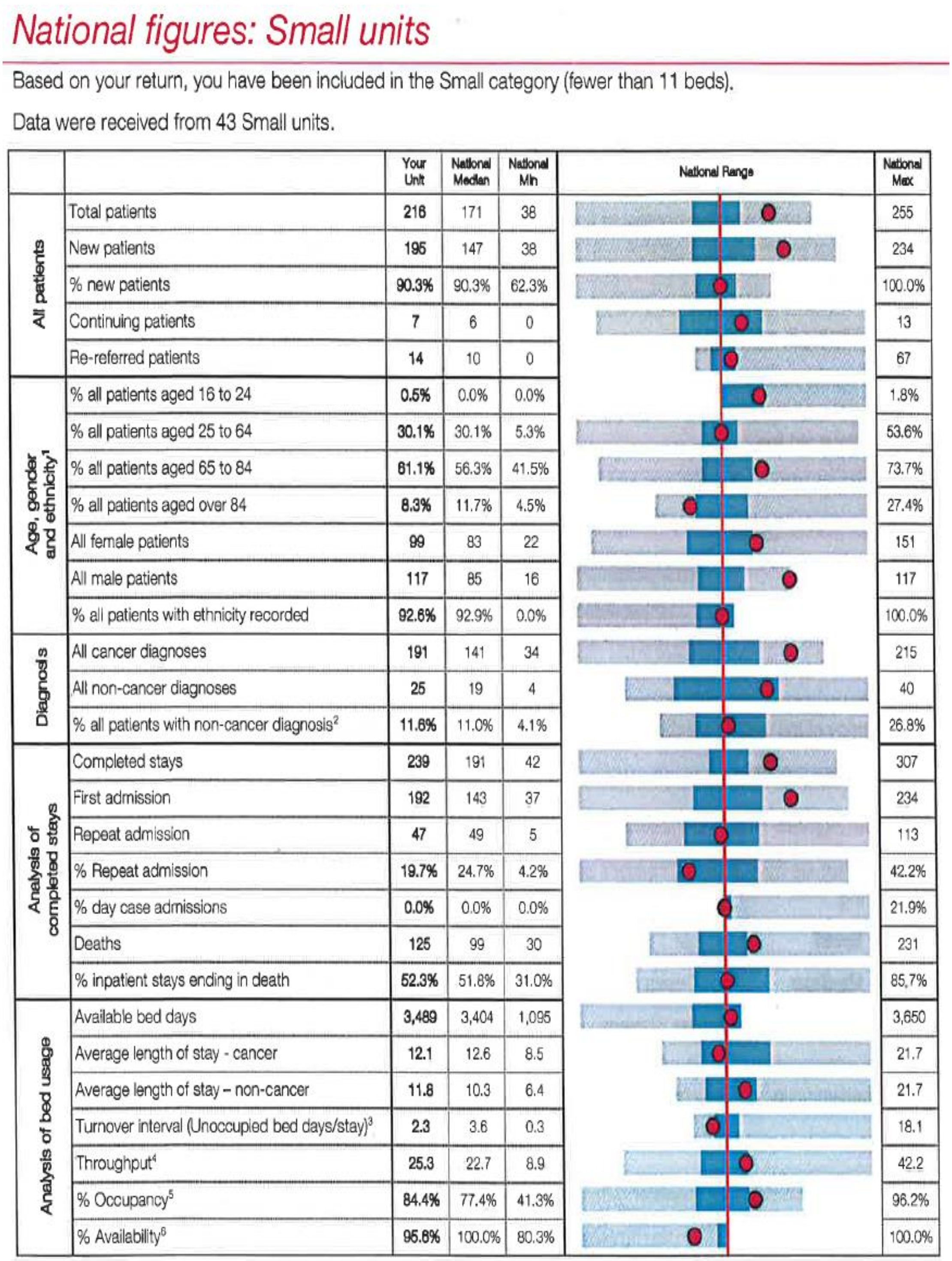
I have had to take on the responsibility of organising and delivering training … which was exciting but daunting and I gained a lot from that … and the challenges of delivering a training program to a sometimes-challenging audience. I feel I have advanced my skills in teamwork and understand more in terms of what I can offer a group such as the CIG. I have become more confident in my own abilities to contribute to a team and a project.

I have also learned a lot about my own communication style (which has benefited me both personally and professionally). The experience has also given me the chance to be a bit more confident when expressing my views, to be a bit more “out there” and visible which is not something I always feel happy doing, especially around more senior staff and especially as I am still a relative novice OT.”

L8: “Personally: I have learnt to adapt my communication skills to meet the tone of the group, I am always an individual who has much to say and it is difficult for me to step back and contain my enthusiasm. This can be often interpreted as overbearing and this group format has given me a chance to work on this characteristic. This project has also allowed me to learn patience is key in organisational development, again an element I struggle with when my passion makes me want to rush forward with ideas.

Professionally: I have learnt much about the process of change and influencing change which tied in perfectly with my recent management and leadership training. It has been really useful in helping me see how my team fit in with the rehabilitative palliative approach and where best to focus their influence. This project group has given me a designated time to explore this safely without the impact of other work load."

Appendix 10: Extract from the in-patient unit minimum data set (MDS)



National figures: Small units

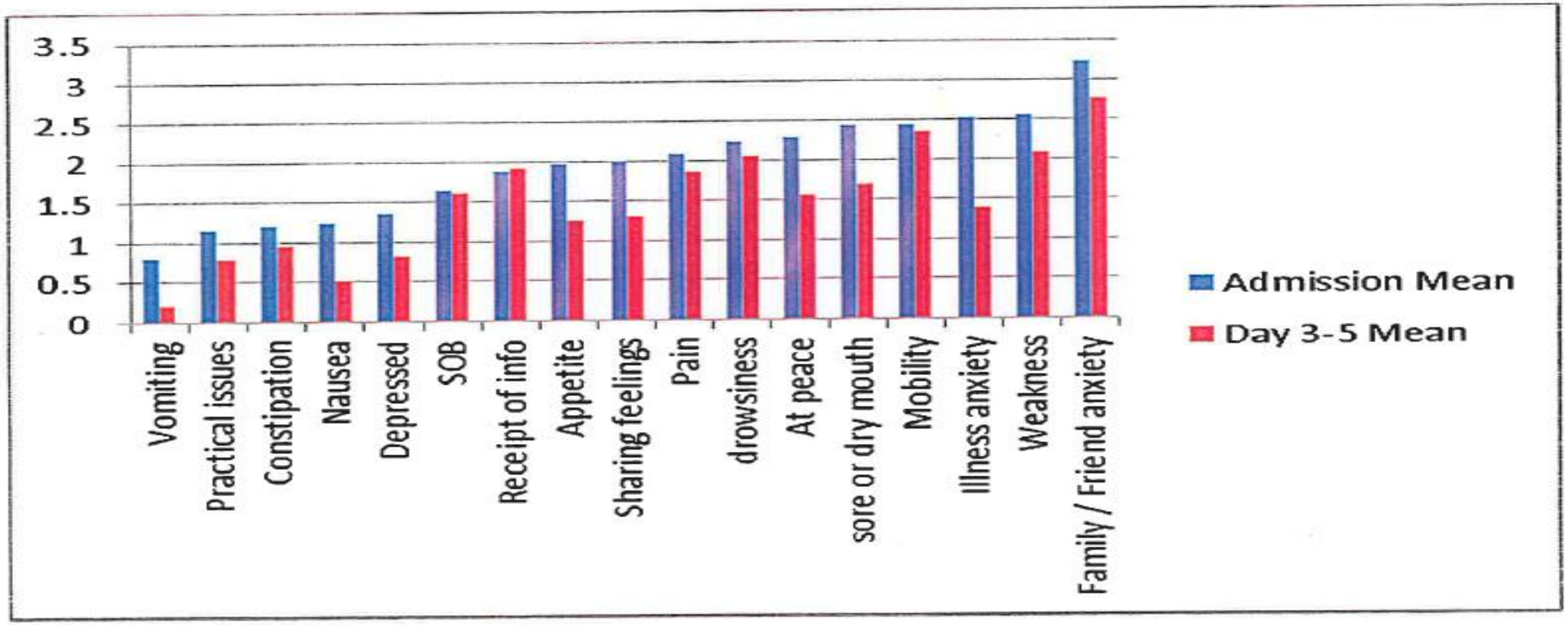
Based on your return, you have been included in the Small category (fewer than 11 beds).

Data were received from 43 Small units.

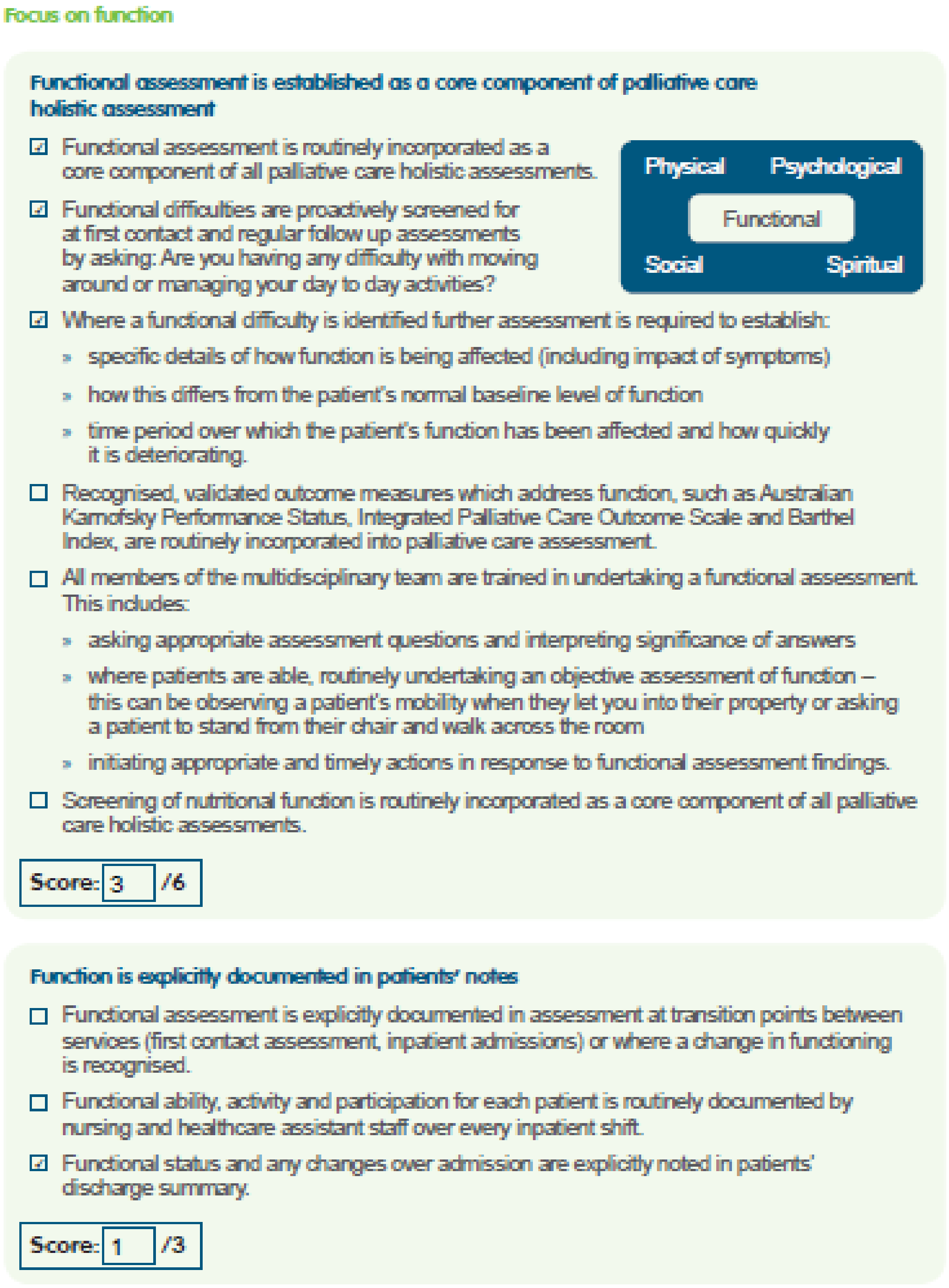
		Your Unit	National Median	National Min	National Range	National Max
All patients	Total patients	**216**	171	38		255
	New patients	**195**	147	38		234
	% new patients	**90.3%**	90.3%	62.3%		100.0%
	Continuing patients	**7**	6	0		13
	Re-referred patients	**14**	10	0		67
Age, gender and ethnicity[1]	% all patients aged 16 to 24	**0.5%**	0.0%	0.0%		1.8%
	% all patients aged 25 to 64	**30.1%**	30.1%	5.3%		53.6%
	% all patients aged 65 to 84	**61.1%**	56.3%	41.5%		73.7%
	% all patients aged over 84	**8.3%**	11.7%	4.5%		27.4%
	All female patients	**99**	83	22		151
	All male patients	**117**	85	16		117
	% all patients with ethnicity recorded	**92.6%**	92.9%	0.0%		100.0%
Diagnosis	All cancer diagnoses	**191**	141	34		215
	All non-cancer diagnoses	**25**	19	4		40
	% all patients with non-cancer diagnosis[2]	**11.6%**	11.0%	4.1%		26.8%
Analysis of completed stays	Completed stays	**239**	191	42		307
	First admission	**192**	143	37		234
	Repeat admission	**47**	49	5		113
	% Repeat admission	**19.7%**	24.7%	4.2%		42.2%
	% day case admissions	**0.0%**	0.0%	0.0%		21.9%
	Deaths	**125**	99	30		231
	% inpatient stays ending in death	**52.3%**	51.8%	31.0%		85,7%
Analysis of bed usage	Available bed days	**3,489**	3,404	1,095		3,650
	Average length of stay - cancer	**12.1**	12.6	8.5		21.7
	Average length of stay – non-cancer	**11.8**	10.3	6.4		21.7
	Turnover interval (Unoccupied bed days/stay)[3]	**2.3**	3.6	0.3		18.1
	Throughput[4]	**25.3**	22.7	8.9		42.2
	% Occupancy[5]	**84.4%**	77.4%	41.3%		96.2%
	% Availability[6]	**95.6%**	100.0%	80.3%		100.0%

Appendix 11: Integrated palliative outcome scale (IPOS) audit results

Analysis of the actual iPOS scores



Appendix 12: “How rehabilitative is your hospice?” checklist extract



Focus on function

Functional assessment is established as a core component of palliative care holistic assessment

☑ Functional assessment is routinely incorporated as a core component of all palliative care holistic assessments.

☑ Functional difficulties are proactively screened for at first contact and regular follow up assessments by asking: Are you having any difficulty with moving around or managing your day to day activities?

☑ Where a functional difficulty is identified further assessment is required to establish:
  - specific details of how function is being affected (including impact of symptoms)
  - how this differs from the patient’s normal baseline level of function
  - time period over which the patient’s function has been affected and how quickly it is deteriorating.

☐ Recognised, validated outcome measures which address function, such as Australian Karnofsky Performance Status, Integrated Palliative Care Outcome Scale and Barthel Index, are routinely incorporated into palliative care assessment.

☐ All members of the multidisciplinary team are trained in undertaking a functional assessment. This includes:
  - asking appropriate assessment questions and interpreting significance of answers
  - where patients are able, routinely undertaking an objective assessment of function – this can be observing a patient’s mobility when they let you into their property or asking a patient to stand from their chair and walk across the room
  - initiating appropriate and timely actions in response to functional assessment findings.

☐ Screening of nutritional function is routinely incorporated as a core component of all palliative care holistic assessments.

Score: 3 /6

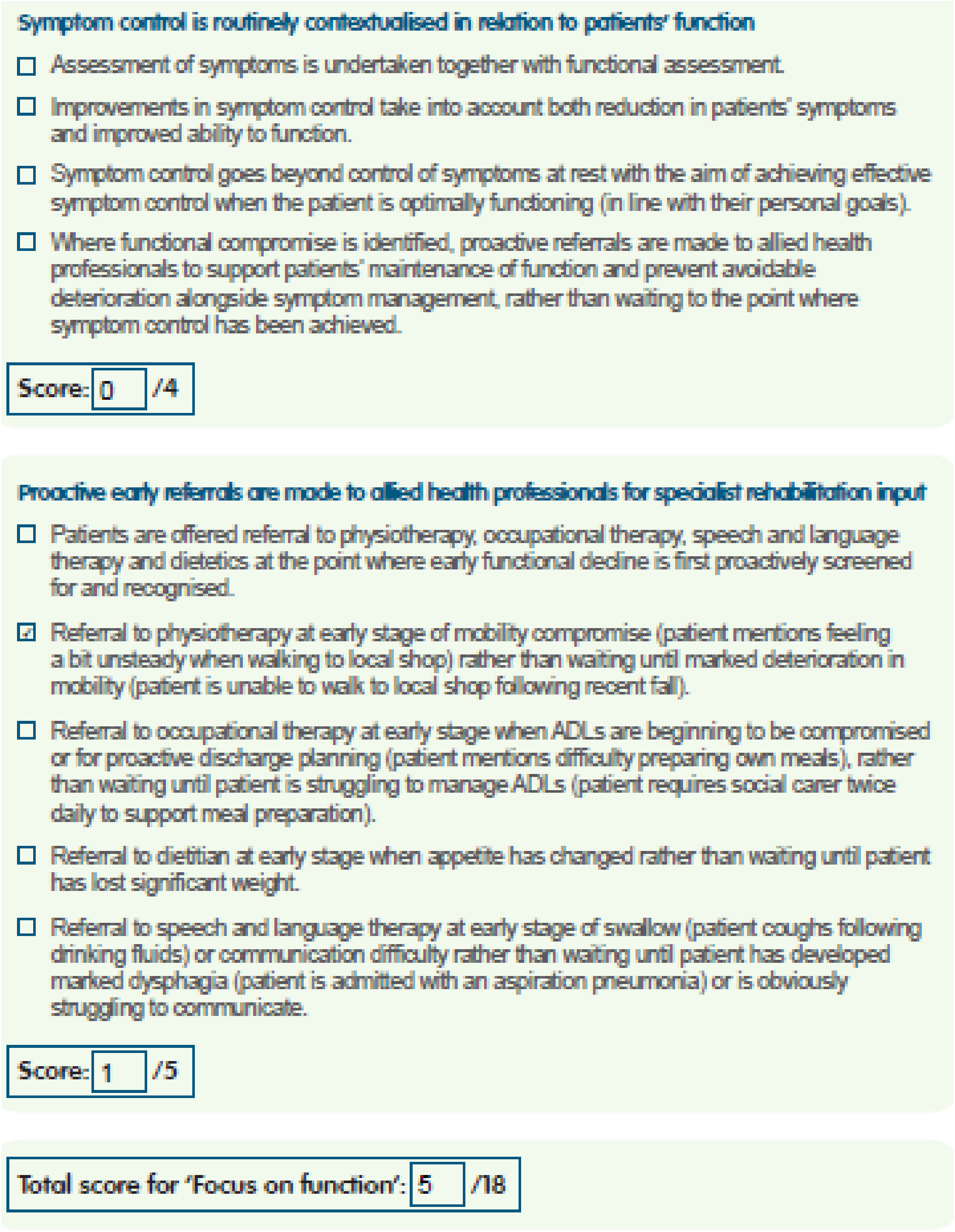
Function is explicitly documented in patients’ notes

☐ Functional assessment is explicitly documented in assessment at transition points between services (first contact assessment, inpatient admissions) or where a change in functioning is recognised.

☐ Functional ability, activity and participation for each patient is routinely documented by nursing and healthcare assistant staff over every inpatient shift.

☑ Functional status and any changes over admission are explicitly noted in patients’ discharge summary.

Score: 1 /3



Symptom control is routinely contextualised in relation to patients' function

- ☐ Assessment of symptoms is undertaken together with functional assessment.
- ☐ Improvements in symptom control take into account both reduction in patients' symptoms and improved ability to function.
- ☐ Symptom control goes beyond control of symptoms at rest with the aim of achieving effective symptom control when the patient is optimally functioning (in line with their personal goals).
- ☐ Where functional compromise is identified, proactive referrals are made to allied health professionals to support patients' maintenance of function and prevent avoidable deterioration alongside symptom management, rather than waiting to the point where symptom control has been achieved.

Score: 0 /4

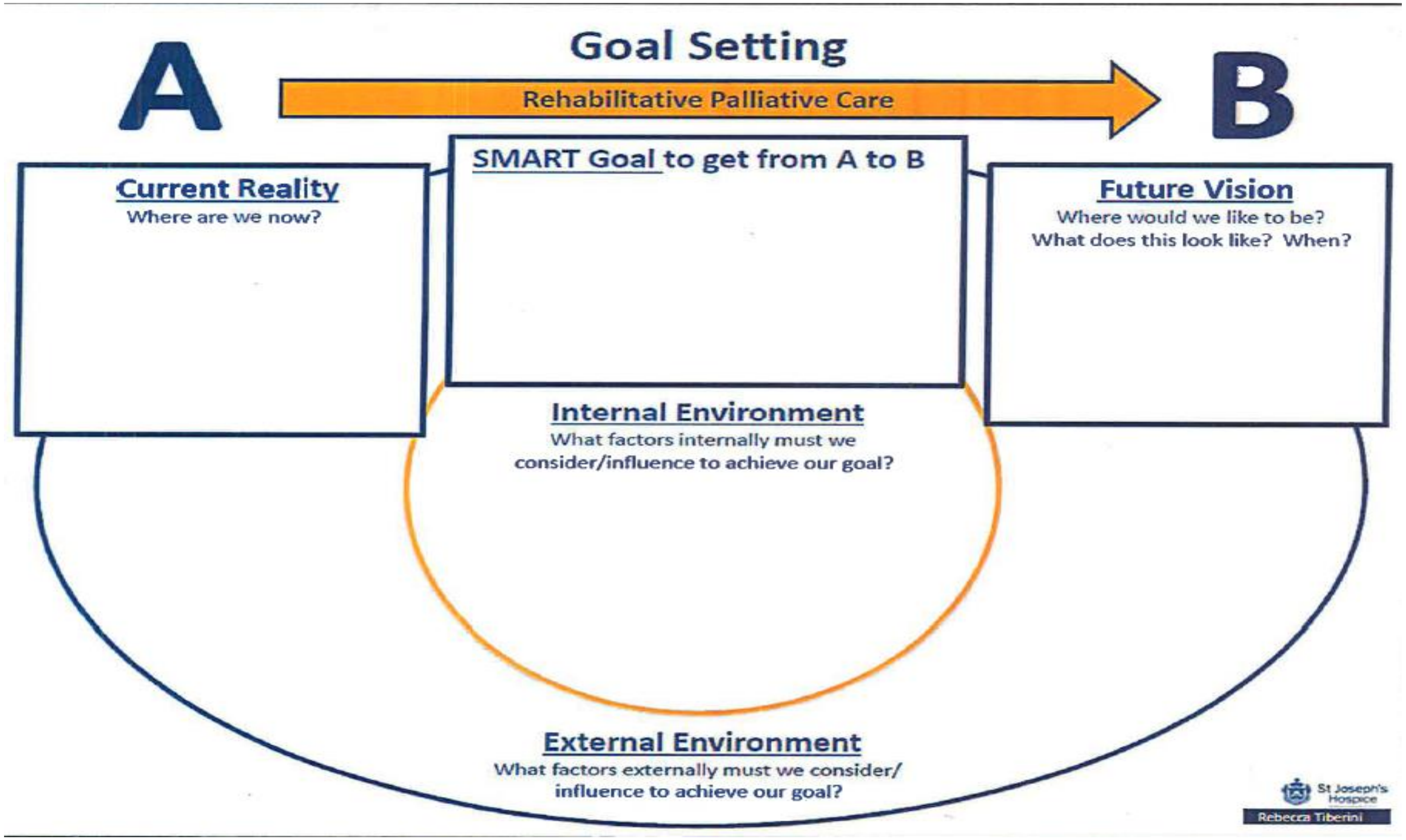
Proactive early referrals are made to allied health professionals for specialist rehabilitation input

- ☐ Patients are offered referral to physiotherapy, occupational therapy, speech and language therapy and dietetics at the point where early functional decline is first proactively screened for and recognised.
- ☑ Referral to physiotherapy at early stage of mobility compromise (patient mentions feeling a bit unsteady when walking to local shop) rather than waiting until marked deterioration in mobility (patient is unable to walk to local shop following recent fall).
- ☐ Referral to occupational therapy at early stage when ADLs are beginning to be compromised or for proactive discharge planning (patient mentions difficulty preparing own meals), rather than waiting until patient is struggling to manage ADLs (patient requires social carer twice daily to support meal preparation).
- ☐ Referral to dietitian at early stage when appetite has changed rather than waiting until patient has lost significant weight.
- ☐ Referral to speech and language therapy at early stage of swallow (patient coughs following drinking fluids) or communication difficulty rather than waiting until patient has developed marked dysphagia (patient is admitted with an aspiration pneumonia) or is obviously struggling to communicate.

Score: 1 /5

Total score for 'Focus on function': 5 /18

Appendix 13: Goal setting and action planning documents



Goal Setting

A

Rehabilitative Palliative Care

B

SMART Goal to get from A to B

Current Reality

Where are we now?

Future Vision

Where would we like to be?
What does this look like? When?

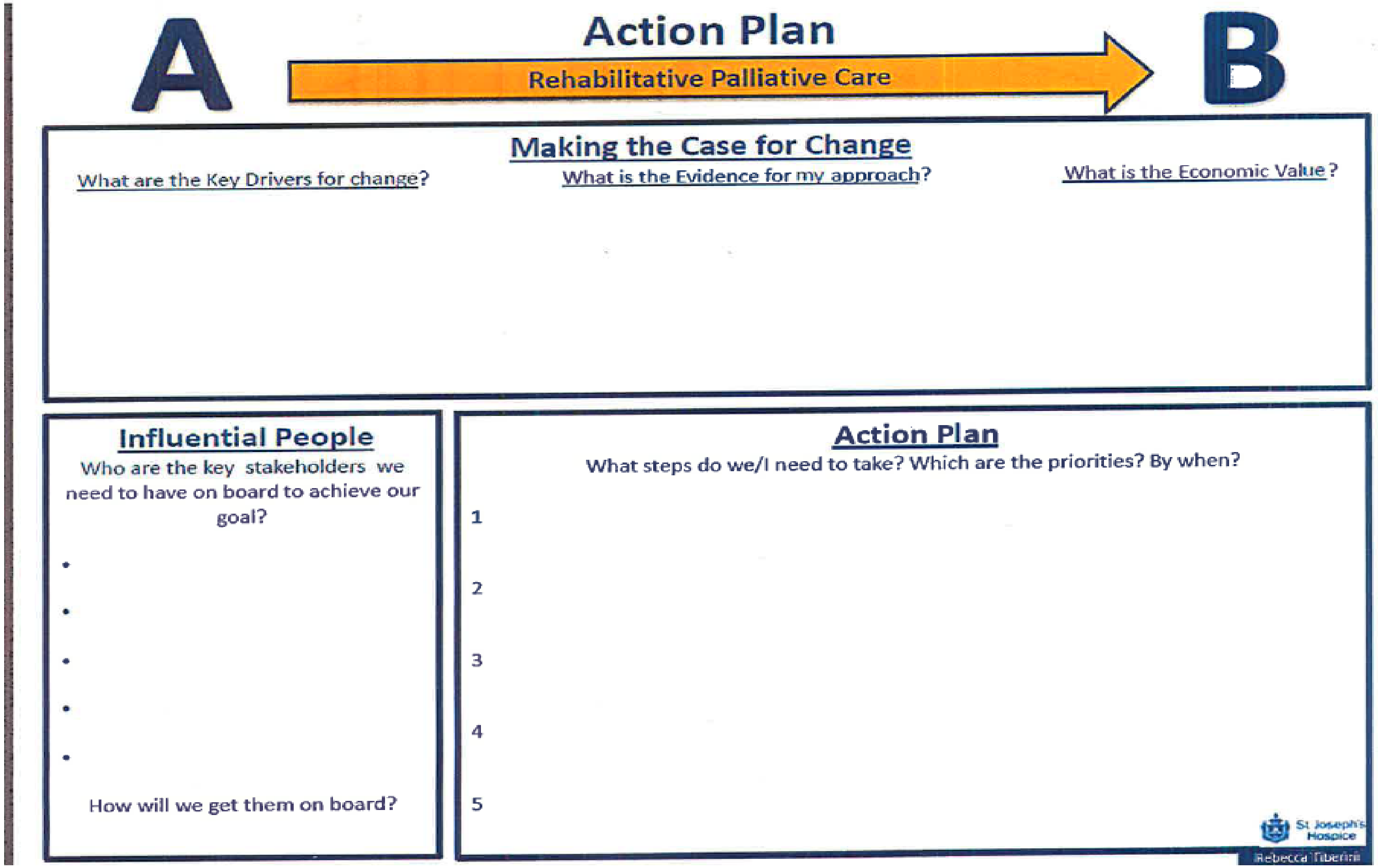
Internal Environment

What factors internally must we consider/influence to achieve our goal?

External Environment

What factors externally must we consider/ influence to achieve our goal?

St Joseph's Hospice
Rebecca Tiberini



Action Plan

Making the Case for Change

What are the Key Drivers for change?

What is the Evidence for my approach?

What is the Economic Value?

Influential People

Who are the key stakeholders we need to have on board to achieve our goal?

-
-
-
-
-

How will we get them on board?

Action Plan

What steps do we/I need to take? Which are the priorities? By when?

1

2

3

4

5

St Joseph's Hospice

Rebecca Tiberini

Appendix 14: Goal setting and action planning documents feedback

This document was completed by A1

Goal setting document: Compilation of individual goal setting sheets:

Current reality: Where are we now?

Positives:

Up to date building
Accomplished staff
AHPs on board with Rehabilitative approach to Palliative Care model and implementing elements of the approach with some success.
AHP team in place who understands rehabilitative approach and are enthused by it.
However limited diversity in AHP team (physio, OT & comp therapies only)
Protected MDT time
Organisation beginning to explore rehabilitative approach – therapies taking a rehab approach & this being embraced by a lot of wider team
Vision at management level of this approach.

Negatives:

Rehab approach & terminology around rehab & palliative care not understood outside of therapies, lack of awareness in organisation generally & in wider community. (Mentioned 3 times)
Elements of traditional medical model still present, care not truly patient centred.
Late to start discharge planning
Not good at setting patient centred goals in an MDT way.
Element of reluctance to change.
Doctor/nurse led admission with rehab completed by AHPs only.
OT referrals for discharge planning only.
IPU & wellbeing remain separate.
Patients disempowered (mentioned 3 times)

Future Vision: Where would we like to be? What does this look like? When?

Using the building as a resource
Utilising the advanced skills of staff & volunteers
Empowering & dosing
Proactive discharge planning
Self –enablement
Rehabilitative Palliative Care approach to be fully integrated into the Hospices' approach to supporting patients & their families
To educate & promote rehab approach
Full 'top down/bottom up' integration of rehab approach in 2 years? Simple elements to begin for example, white board in rooms with patient led goals
Expanded therapies team – more diversity in therapies SALT, dietetics

Internal Environment - What factors internally must we consider/influence to achieve our goal?

Are the Board on board with the approach?

Consider attitudes of current staff – can we cope with more change (staff resilience)?
Perception that this will create more work? (Mentioned 3 times)
Resources (?) to educate volunteers?
Training & resources of staff; currently lack of understanding, do we have time to train & learn?
HR/Hospice priorities for staffing – drive for nurses as main priority, so need nurses on board.
Who will champion the education/change/model of care?
Small AHP team at present
Current discharge process – needs review?
Lay out of rooms not being used to maximise patient independence/empowerment.

External Environment: What factors externally must we consider/influence to achieve our goals?

Public perception – this approach is not what the Hospice does? (Mentioned twice)
Impact of new approach/change on public support - Need to be careful about how we get our message 'out' – ensure the message is understood.
Ill-informed commissioners - this approach is not what the Hospice does (mentioned twice)
Understanding of statutory services & what they offer? Current reduction in services due to austerity
Money – financial pressures on NHS, community resources, Hospice
Evidence base for rehabilitative approach.
Approach will help avoid hospital admissions so therefore we will struggle with delayed discharges (these are contraindications of each other for our service)

Appendix 15: Workshop session plan

Draft workshop session plan – December 2015 - S7, L8, K9, A3 and O6

Guiding principles:

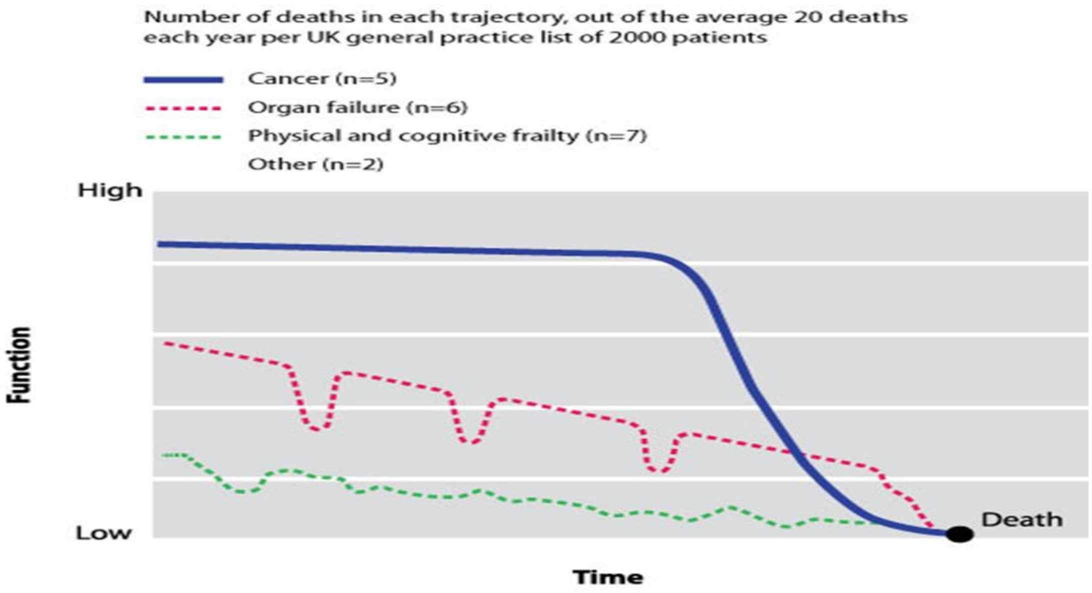
- RPC embodies multi professional teamworking – patient centred approach
- Essence of being human: what it is to be me
- Dignity and choice

Practicalities
2 hours
16 people
Café style – 4 tables of 4: 2 staff and 2 volunteers per table

Possible second session – Housekeeping staff, counselling, chaplaincy, front of house etc.

"What do you want to do in the next wee while?"

1. Understanding the patient perspective
    a. "What are the three most important things you do for yourself each day?" – Participants write their answers down on post-it notes. Stick onto wall, but remain anonymous
    b. "How would you feel if you were unable to do these things?" – Whole group, flip chart answers e.g. frustrated, unhappy, lacking in confidence, withdrawn. Aim is to illicit feels frustration, unhappy, lacking in confidence, withdrawn, lack of self-esteem.
    c. "Does this apply to patients in IPU?" Discuss as a group. These feels develop as illness progress and patients feel/believe that they can do less and less for themselves.
    d. LINK to Cicely Saunders quote: "to enable the dying person to live until he dies, at his own maximal potential performing to the limit of his physical and mental capacity with control and independence whenever possible."
    e. Discuss a scale of independence, from well (independent) to dying (supported), in turns of ADL/ functions? using examples of the post-its, to highlight that this approach can be used at all scales on the spectrum, ?with people standing up
    f. Explain a little about RPC
    g. Continuum:



Independent Some support Fully
supported
Well ↔ Dying

“How good are we at remembering this with our patients?” “ Do we see them as patients or people?” Flip chart as whole group. Highlight patient vs. person. Link quote from research ‘they wanted to do it for me’. Group task with flipchart: good vs. rubbish

Very good	Very poor
Eg	Eg
Eg	Eg

h. “Why is this? What are the barriers?” Small group work using post-it notes so the answers are anonymised. CIG to take away.

2. Solutions
    a. One case study per table: a range of cases, from quite a well patient to less well patients.

3. “TEACH”
    a. Embodies MDT approach and patient centred
    b. Essence of being human – what it is to be me
    c. Dignity in doing the small things for ourselves

4. Link to first three things people identified.

5. Conclusion, rounding up

Appendix 16: Summarised feedback from the workshops

This document was prepared by A3 and O6.

Feedback and collation of information from Rehabilitative Palliative Care training session
Jan 2016

Group information: 9 people:

- 4 volunteer hosts
- 2 health care assistance
- 2 RNs
- 2 IPU managers

Icebreaker activity, ‘What are the three most important things you do for yourself each day?’ themes emerged:

- Shower/ bath/ wash/ dress x7
- Eat x5
- Sleep/ rest x3
- Read/ music x3
- Physical activity x4
- Speak to/see family/friends x6
- Be kind x1
- Smile x1

What is Rehabilitative Palliative Care? Group discussion

- Goal setting, even if small
- Realistic planning
- Encouraging patients
- Maintaining ADLs when going home
- Parallel planning
- Adapting, learning to do things in a different way
- Not taking things/ability away from patients
- Being in control
- Common sense
- Not underestimating ability
- Removing fear
- Involving MDT and relatives
- Ongoing
- Not to be discouraged
- Lots of working/planning, starting early

What does this look like in practice? Group discussion

- Identifying needs – holistic
- Prompting tools (like a menu of functions)
- Asking patients
- Looking at base line function
- Supporting patients fearful of failure, setting realistic goals

- Looking at social and spiritual needs

Group discussion:

What are we doing well?	What not so well?	Challenges
- Elements - Getting people dressed - Encouraging bath/showers - Encouraged patients out of rooms over Christmas period	- May not always be doing - Don’t use orchard longue/ facilities as well as we could - Not using hosts - Not encouraging social interaction between patients - No program of activities for the street - Lack of consistency	- Time - Demand/ patient load - Man power - Communication

<u>March 2016</u>

<u>Icebreaker activity, ‘What are the three most important things you do for yourself each day?’ themes emerged:</u>

- Eat/ Drink/ Sustenance x6
- Washing/ Shower/ Dressing x7
- Go to the toilet x2
- Contact family x2
- Plan the day/structure x2
- Work x1
- Keeping self safe x1
- Emotions x3 (Try to be happy and positive, laughing, reminding self of how lucky I am to be healthy)
- Drive/Walk places x1

<u>Feelings if we could not do these things:</u>

- Frustration

- Loss of identity
- Angry
- Isolated
- Demeaning
- Lack of self-worth
- Guilty
- Awkward
- Loss of control
- Burden
- Lack of purpose
- Loss of dignity

What is Rehabilitative Palliative Care? Group discussion

- Enabling
- Maximising potential
- Managing our professional opinions
- Working with family
- Finding and respecting a level of independence
- Teamwork
- Respecting the individual
- Re-adjusting
- Realistic expectations
- Reinforcing things they can do
- Giving them the power
- Goal setting

What does this look like in practice? Group discussion

- Maintaining social interactions
- Volunteer involvement
- Communication
- Highlighting goals at an early stage

Case study 1 discussion

- Goal: Home
- Meet symptom control: oral tablets, create feeling of normality by removing syringe driver
- Empower
- Improve independence
- Build confidence: Physio, Complimentary therapy, gym work

Case study 2 discussion

- Symptom control – SOB, nausea
- Address physical symptoms

- Psychosocial: panic attacks, why, counselling for patient and wife, chaplain, complimentary therapy, create purpose to life – Wellbeing
- Address function, mobility, confidence and falls: physio and occupational therapy
- Address care needs at home: POC to remove pressure and support family

Appendix 17: List of nodes

Name	Sources	References	Created On	Created By
Terminology	10	60	30/11/2016 15:08	KLC
Rehabilitation	4	12	30/11/2016 15:18	KLC
Lack of understanding of rehabilitation	5	12	30/11/2016 15:20	KLC
Lack of understanding of palliative care	2	9	30/11/2016 15:08	KLC
Definitions	2	3	30/11/2016 15:09	KLC
Rehabilitative palliative care	1	3	30/11/2016 16:36	KLC
Palliative care	1	1	30/11/2016 15:10	KLC
Questionning	10	43	30/11/2016 15:38	KLC
Eachother	10	37	30/11/2016 15:39	KLC
Staff and volunteers	1	1	30/11/2016 15:39	KLC
Models of care	10	42	30/11/2016 16:01	KLC
Enhancing existing model	6	17	30/11/2016 17:19	KLC
Medical model	3	5	30/11/2016 16:19	KLC
Taking ownership	9	34	30/11/2016 15:45	KLC
Empowerment	8	33	30/11/2016 15:26	KLC
of patients	6	19	30/11/2016 15:26	KLC
Eachother	6	12	30/11/2016 15:44	KLC
Volunteers	1	1	02/12/2016 11:34	KLC
Organisational	10	29	30/11/2016 15:03	KLC
Change	9	23	30/11/2016 17:11	KLC
Facilitator	9	28	30/11/2016 17:20	KLC
Barriers	8	23	30/11/2016 17:47	KLC
Processes	2	2	30/11/2016 14:47	KLC
Fatigue	1	1	30/11/2016 17:18	KLC
Multidisciplinary team	8	29	30/11/2016 16:26	KLC
Lack of understanding of roles	5	7	30/11/2016 16:27	KLC
Whose role is rehab	5	6	30/11/2016 16:28	KLC
Action researcher	7	27	30/11/2016 15:40	KLC
Guiding the process	5	15	30/11/2016 15:40	KLC
RPC	8	25	01/12/2016 10:28	KLC
Communication	10	24	30/11/2016 15:15	KLC
with patients	4	5	30/11/2016 15:15	KLC
Consultation	4	5	30/11/2016 16:08	KLC
Reflection	8	24	30/11/2016 16:06	KLC
Problem-solving	6	22	30/11/2016 15:02	KLC
Validating	8	19	30/11/2016 17:23	KLC
Mutual respect	8	18	30/11/2016 14:59	KLC
Safety	2	6	01/12/2016 14:14	KLC
Collaboration	8	18	01/12/2016 10:37	KLC
Power	2	15	01/12/2016 14:03	KLC
Engagement	6	14	30/11/2016 17:04	KLC
MDT	8	28	01/12/2016 10:09	KLC
Volunteers	7	27	01/12/2016 12:12	KLC
Senior management buy-in	7	21	30/11/2016 17:05	KLC
Patients	5	9	01/12/2016 09:55	KLC
Hospice	4	12	30/11/2016 15:30	KLC
Perceptions of	3	9	30/11/2016 15:30	KLC
Generating knowledge	7	12	30/11/2016 16:22	KLC
Workload	8	10	30/11/2016 17:06	KLC
Patient stories	3	8	01/12/2016 12:15	KLC
Achieving consensus	4	4	30/11/2016 15:35	KLC

Appendix 18: Sample of NVivo coding against the node “patient stories”

<Internals\\CIG notes\\Notes from the CIG meeting on 09 December 2015> - § 3 references coded [1.96% Coverage]

Reference 1 - 0.60% Coverage

	A3 gave an example of where the conversation had happened early on in a patient’s admission and as a result of that they were nearing discharge now which had considerably shortened that individual’s length of stay.

Reference 2 - 0.66% Coverage

	It was acknowledged that ‘case stories’ should be captured as it helped people to see this approach working in practice. This would be important in the training as patient stories really helped to get the message across.

Reference 3 - 0.70% Coverage

	A1 suggested that we use the case studies of things that were already happening in the Hospice and then link that to teaching input. A1 said that explaining about the approach and then giving examples of how it was happening already would work well.

<Internals\\CIG notes\\Notes from the CIG meeting on 12 November 2015> - § 4 references coded [9.04% Coverage]

Reference 1 - 1.68% Coverage

	At the PAG meeting one patient described how disempowered he felt by those around him as a result of his illness. He had explained that he loved gardening and wanted to go out in the garden, but his wife wouldn’t let him because she was frightened that something might happen to him in the garden. He said he thought this approach would help to prevent this happening by ensuring that both he and his wife were involved in setting his goals.

Reference 2 - 4.54% Coverage

	A1 added that they had been a useful case study in the IPU recently which had enabled them to demonstrate a RPC approach in practice without describing it as such. The patient was worried about getting out of bed, had low mood and anxiety. She had recently had a fall which battered her confidence. She had two daughters. The plan was for her to go home but there was lots of anxiety about this. There was a round the bed meeting and the patient said she was worried about going to the toilet at night and falling and this had led them to the conclusion that they needed 24-hour care. The team suggested that a commode be put next the patient’s bed whilst they were an in-patient and that she could get used to using it whilst she was at the Hospice to see whether it was something she could continue at home. She eventually went home with one visit per day. This had a huge impact on cost and also a significant positive effect on the family. A1 suggested that this was simply as a result of someone asking, “why do you think you need someone with you overnight?” “Because I might fall” “Well let’s address that and then see whether you still feel the need to have someone with you overnight.”

Reference 3 - 1.24% Coverage

	L8 said that she had an example of a patient who was being supported by the nurses to put his shoes on, go to the toilet, put his jumper on etc. When she was in the room she encouraged him to do these things for himself which he had managed to do. L8 suggested that this was a reminder of how much we try to do for patients.

Reference 4 - 1.57% Coverage

	A3 said that patients’ stories were so powerful and that it would be helpful for members of the CIG to keep track of patients for whom this type of approach would, or had worked that could then be shared with others; it would help

	them to put it into context. O6 said that this would be helpful because it would show staff that they are also making progress and that this approach is not so different after all.

<Internals\\CIG notes\\Notes from the CIG meeting on 14 January 2016> - § 1 reference coded [1.96% Coverage]

Reference 1 - 1.96% Coverage

	Another patient explained how his wife worried about him going out alone when he was at work and so now he didn’t tell her when he had gone out and his friends were also sworn to secrecy!

Appendix 19: CINAHL literature search

Search terms (AND, OR, NOT) and truncation (wildcard characters like *)	• Hospice OR "palliative care" OR "terminal care" OR "hospice care" OR "end of life" OR "life threatening illness" OR “hospice and palliative nursing” • rehabilit* (using truncation to pick up words such as rehabilitate, rehabilitative and rehabilitation) OR "goal setting" OR “goal achievement” OR "goal planning" OR “goal attainment” • practitioner* (using truncation to include practitioners) OR nurs* (using truncation to include nurse, nurses or nursing) OR clinician* (clinicians) OR staff OR employee OR physiotherap* (to pick up physiotherapist(s) and physiotherapy) OR "occupational therap*” (using truncation to pick up therapy, therapies and therapist) OR “allied health”
Part of journals searched	Using CINAHL terminology, the parts of the journal searched were: MH Exact subject heading TI Title AB Abstract
Years of search	1970 onwards as palliative care has only been established within healthcare over the last 40 years (Boa et al 2014).
Language	English

Appendix 20: Record of all database searches.

Date	Database	No. results	No. retained
15 April 2018	CINAHL	238	16
29 April 2018	MEDLINE	425	37
30 April 2018	PsycINFO	295	13
29 April 2018	PUBMED	230	9
29 April 2018	Web of Science	103	15
Total		**1291**	**90**