Northumbria Research Link

www.northumbria.ac.uk/nrl

northumbria
UNIVERSITY NEWCASTLE

The Realist Evaluation of a Palliative Integrated Care Pathway in Primary Care: What Works, For Whom and in What Circumstances?

Sonia Michelle Dalkin

PhD

2014

The Realist Evaluation of a Palliative Integrated Care Pathway in Primary Care: What Works, For Whom and in What Circumstances?

Sonia Michelle Dalkin

A thesis submitted in partial fulfilment of the requirements of the University of Northumbria at Newcastle for the degree of Doctor of Philosophy

Research undertaken in the Faculty of Health and Life Sciences and in collaboration with the NHS North of Tyne

February 2014

Abstract

Background: Finding effective ways to care for people with palliative care needs is a national priority. A primary care locality has developed and implemented an Integrated Care Pathway (ICP) for those with life limiting illnesses. It focuses on identifying patients early, regardless of disease type, and uses proactive and patient centred interventions to plan for a good death. Although palliative care pathways present a promising practice framework, the literature does not allow for an assessment of how and when they work best. This thesis aimed to explain which parts of the ICP worked best, for whom and in what circumstances. **Design:** Realist evaluation was used to guide the analysis of multiple data strands: quantitative data from the GP practices; interviews with palliative care patients and bereaved relatives; bereaved relatives and matched health care professional questionnaires; focus groups with health care professionals; consultation recordings with palliative care patients and their GPs. **Results:** The results of this study are multifaceted, and focus on the conditions of successful implementation, such as the presence of a champion; palliative care registration decisions for all diagnoses and the importance of leadership and peer support; advance care planning, including the roles of mental capacity and time constraints; communication in consultations and the role of patient and GP traits; and using open multicomponent communication strategies to facilitate home deaths. **Discussion:** A realist approach has exposed how the ICP implementation has led to positive practice and patient level outcomes. The ICP can be construed as a translational tool, which enables the operationalisation of policy directives on shared decision making, proactivity and patient centeredness in primary care. In the context of palliative care, this study allows important reconceptualisations of shared decision making and advance care planning to be presented.

Contents

List of tables and figures

Glossary of Abbreviations

ACP – Advance Care Planning (to refer to the process of advance care planning, using all documentation described in Deciding Right)

ADRT – Advance Decision to Refuse Treatment

CCG – Clinical Commissioning Group

CMOC – Context, Mechanism, Outcome Configuration

CPR – Cardiopulmonary Resuscitation

CQI – Continuous Quality Improvement

CQUIN – Commissioning for Quality and Innovation

DNACPR – Do Not Attempt Cardio-Pulmonary Resuscitation

EHCP – Emergency Healthcare Plan

FG1 – Focus Group 1

FG2 - Focus Group 2

FG 3 - Focus Group 3

GSF – Gold Standards Framework

GSFCH – Gold Standards Framework for Care Homes

ICP – Integrated Care Pathway

LCP – Liverpool Care Pathway for the Dying Patient

LES – Locally Enhanced Services

MBSS – Miller's Behavioural Style Scale

MCA – Mental Capacity Act

MDT – Multidisciplinary Team

MIQUEST - Morbidity Information Query and Export Syntax

NPT – Normalisation Process Theory

OOH – Out of Hours

PCQV – Palliative Care Quality Visits

PCT – Primary Care Trust

PW-LPA – Personal Welfare Lasting Power of Attorney

QDDM – Quality of Dying and Death Measure

SSM – Soft Systems Methodology

Acknowledgements

I extend my sincere thanks to the participants in this research. For any person to share from their personal or practice experience can be overwhelming. Their courage and dedication to improvement in the realm of palliative care has been an inspiration and encouragement to me. I know that there is anticipation of the findings and I would sincerely like to thank them for their patience in waiting for the results.

I would also like to thank those from the locality in which the service is located. They have provided continuous support, information and learning opportunities to aid my local and practice knowledge. A great thank you is extended to the gatekeepers, without whom collection of data from patients and bereaved relatives would not have been possible and this PhD would not have been reflective of their experiences.

I also extend my boundless appreciation to my three supervisors: Dr. Monique Lhussier, Dr. Diana Jones and Dr. Bill Cunningham. Your unrelenting support has motivated me whilst your challenges have prompted my learning to go to depths I could not have foreseen. Monique's knowledge of realist evaluation and constant support in this methodological domain has been invaluable. Anna's attention to detail, academic problem solving skills and finesse in writing style is something I shall always admire. Bill's dedication to continuous quality improvement, support in my integration into the locality and development of my practice knowledge has been vital. I have been extremely fortunate to have such supportive and considerate supervisors.

I would like to thank the NHS North of Tyne and Northumbria University for giving me the opportunity and funding to embark on this journey and enhance my learning. Great thanks are also given to Joanne Atkinson for her continued emotional support and

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the School Ethics Committee and National Research Ethics Service (NRES) on 28/09/2011 and 13/12/2011, respectively.

Name: Sonia Michelle Dalkin

Signature:

Date: 31/01/2014

Introduction

"Life is pleasant. Death is peaceful. It's the transition that's troublesome."

– Isaac Asimov, American science fiction novelist and scholar (1920 - 1992).

Background

When initially facing the prospect of working within the palliative care domain I was undoubtedly nervous. My background was in psychology (Psychology BSc and Health Psychology MSc) so immigrating into health care was daunting, let alone the palliative care domain. People often asked me "won't it be depressing?" and I was not sure of the answer. But something intrigued me; the opportunity to make a difference in an area that affects every person. What I have found is that the palliative care domain is not depressing; it is actually somewhat the opposite. In the course of the three years of this PhD I have never felt upset or disheartened by the area I work in or by the people I have had the privilege to interview. They have shown me that palliative care is inspiring; it can change lives and can also aid people in their unavoidable fate. I feel as a result of this realisation I now know that previously I was affected by the death and dying taboo that western society faces and throughout this PhD that taboo has been broken down from within me. Thus, the need for death and dying to be discussed in society, I now feel, is pivotal. As the quote above from Issac Asimov demonstrates, the transition from life to death is difficult, but palliative care is a way to manage this transition. It will never be easy but it should always be attempted.

I came to this PhD, as aforementioned, from my MSc, with no formal training or expertise in primary or palliative care. I came to find that this was actually an advantage. Although learning the infrastructures, tools, and relationships within primary care, and understanding the service I have been evaluating was not easy, I have had no biases throughout this study. Instead I understood all health care professionals' roles and the difficulties that come with them. I have no allegiances to any group. This makes this thesis a very impartial and balanced account of a service implemented to improve primary care.

Having a background in the social sciences I was very drawn to realist evaluation (Pawson and Tilley 1997) for several reasons. The first was its underlying wariness of strong claims for evidence, drawing on a Popperian philosophy of science (Popper 1959). Throughout my psychology undergraduate training it became clear that all scientific data is peppered with ambiguity. The accumulation of explanation leads to an increased scientific knowledge and investigation often stops when researchers are satisfied that there is enough scientific evidence to support the claim. However, this accumulation of evidence could be falsified by new evidence in the future and thus nothing is absolute truth (Popper 1959). The second notion that drew me to realist evaluation was its embrace of the human mind and how the fate of a social programme lies in the reasoning of its stakeholders (Pawson 2013). Having a background based in psychology I was aware of individual differences and the uniqueness of individuals and their reasoning. To see this embraced and linked to context in a methodology that sought explanation of data was very attractive to me. Thirdly, I wished to pursue a methodology that explained real life issues, encompassing the difficult phenomena that can affect outcomes; realist evaluation aims to include and explain confounding

variables as opposed to eradicate them, an aspect that lends it to complex real life evaluation. Fourth and finally, one of realist evaluation's foundations is the explicit generation and testing of theory. I am a great believer in science and logical scientific principles, to see a methodology that allows the use of theory in a flexible way that does not have a sole focus on outcome was refreshing.

In summary, I faced two new challenges when I started this PhD: palliative care and realist evaluation, both of which I was drawn to and both of which I have been lucky enough to embrace and enjoy.

Formulation of the research questions

As described, my previous academic and professional life had not been in palliative or end-of-life care, thus I came to this PhD ravenous to explore the domain. Integration into the locality, the field of palliative and end-of-life care in general, and delving into realist evaluation gave me a greater understanding which prompted the formulation of the research questions. Understanding these domains made it clear that a lot is known about palliative and end-of-life care – it cannot be considered as a sparsely researched topic. However, there is little research on palliative and end-of-life care using realist methodology. This gave me a great breadth of research paths to follow in this thesis. I not only wanted to generate research that was relevant to the locality as a result of the Integrated Care Pathway (ICP), but also generate research that had a larger scope and relevance to palliative and end-of-life care across the nation. Considering this with realist evaluation I wanted to know if the ICP worked, how it worked, for whom it worked for and in what circumstances. These were the initial questions that guided the

inquiry and the formulation of the research questions, which are described within the methodology (Chapter three, pg. 72).

Protocol publication

Whilst formulating the research questions I began to write the protocol of this study (Dalkin, Jones et al. 2012). Realist evaluation is a relatively new method of inquiry and thus I found it difficult to know where to start – how do you find programme theories, what sort of data should you collect? The literature offers some exploration of this but putting this into practice is not always easy. Despite the research questions and project moving on somewhat from the publication, it provides a statement of how I started the evaluation. Realist evaluation is very difficult to 'capture' at the beginning of the project but I felt this protocol may help others when starting realist evaluations and thus felt it was important to publish.

Flow of the thesis

The thesis is divided into nine chapters. Chapters one and two introduce and use existing literature to contextualise the research in terms of palliative and end-of-life care. It also provides a description of the ICP that was implemented in the locality including commissioning aspects and specific tools used (palliative care registration, the traffic light system, the surprise question). Chapter three introduces realism and realist evaluation, provides an understanding of how the findings of the research will be presented and describes the data collection framework. The chapter also provides the reader with the research questions and programme theories that were developed from

this. The programme theories are then tested and refined in chapters four to eight through interpretation of the findings alongside existing literature. Each findings chapter begins with an initial programme theory which is refined using data from several sources; a refined programme theory is then presented at the end of each chapter. Chapter nine provides a discussion of the findings, bringing together all the programme theories to form an overall programme theory of the ICP. This chapter also includes a critical self-appraisal of the research commenting on limitations and future research.

Chapter 1: Key issues in palliative and end-of-life care

This chapter examines some of the key issues that affect palliative and end-of-life care both in the UK and internationally. A description of the history of palliative care is provided with implications for practice. Following this, preferences for end-of-life care in the UK and the societal taboo of death and dying are discussed due to their pertinence and palliative and end-of-life policies addressing these concerns will be explored. Important philosophies identified in relevant palliative care policies will be highlighted and discussed in further detail. Practicalities of using these philosophies in palliative care and primary care will then be addressed. The diffusion of innovation and Normalisation Process Theory (NPT) literature is then explored to help understand how philosophies from palliative care policy can be translated into practice.

Palliative care: historically and in practice

In the late 1950s, there was little published research focusing on care of the dying (Clark 1999); the modern hospice movement was not underway (Clark, Small et al. 2005); the term 'palliative care' was not in common use (Clark and Seymour 1999); no professional societies had formed to promote interest in palliative care (Clark 1998, Clark 2004); and there were only a few hospices which were managed by religious foundations (Humphreys 2001). In 1967 the St. Christopher's hospice opened and 'the

modern hospice movement' began (Saunders 1996). A crucial decision from the hospice was that it would only admit terminally ill cancer patients, due to limited resources and the necessity to limit who was treated and to track clinical outcomes. This pioneering work from Dame Cicely Saunders was pivotal in drawing attention to the end-of-life care needs of patients' with advanced cancer diseases (Clark 2007). Although cancer causes a large number of people globally to suffer extreme distress at the end of life, this decision meant the exclusion of patients with equally distressing and symptomatic conditions – those with non-cancer illnesses. This was despite reports in the 1950s that identified a need for improvement of services for terminally ill cancer and non-cancer patients (Bean 1961) and arguments for the UK's NHS to make terminal care, regardless of disease type, a priority (Clark 1999). Additionally, evidence of the time indicated that non-cancer patients experienced the same, if not more, distress as cancer patients (Exton Smith 1961). Despite this, the modern hospice movement was focused on cancer. This may have been because Dame Cicely Saunders' research focused on cervical or breast cancer patients aged between forty and sixty (Clark 1999). Additionally, a cancer focus reduced the strain on new services and made a clear distinction between palliative care and geriatric care (Addington-Hall and Hunt 2012). Furthermore, cancer had replaced infectious disease as the leading cause of early death (Brower 2005). Following the hospice movement, in the 1970s, palliative care began to be defined and came to be construed as the physical, social, psychological, and spiritual support of patients with life-limiting illness, delivered by a multidisciplinary team (MDT) (Clark 2007). Since the 1970s palliative care has been closely related to oncology (Clark 2007). The international need for palliative care remains much larger than the actual available provision, yet there are signs of acknowledgment by policy makers and influential bodies (referred to in the policy section of this chapter) and

interest in palliative care has never been so great (Clark 2007). In only four decades the care of cancer patients has evolved completely – patients with advanced cancer and the management of their symptoms has moved from being on the periphery of oncological care to being at the centre of modern cancer care (Clark 2007). However, patients with progressive diseases other than cancer (for example, chronic obstructive pulmonary disorder, heart failure, motor neurone disease, herein referred to as non-cancer diseases) have not been offered the same palliative services in the past, despite having similar physical and psychosocial symptoms (Eve, Smith et al. 1997, Addington-Hall 1998). Yet recent policies (described below) have stated that palliative care should be provided for all, regardless of diagnosis (Department of Health 2008). However, the historical focus on cancer has had a lasting effect on provision of health care services, resulting in inequality in the provision of services for those with a non-cancer diagnosis.

This injustice can be seen in practice, as until 2008 cancer registers were used in practice regardless of palliative or curative status. Yet there was no equivalent for patients with non-cancer diagnoses. Only recently were palliative care registers developed that are for all patients with a terminal diagnosis.

Doyle and Woodruff (2008) have reviewed barriers to providing palliative care which can relate to access issues, social factors, the patient or the health care professional. Access to palliative care can be an issue – the high cost of care, treatments and medications in developing countries, and laws and regulations restricting or prohibiting the use of opioids can have an effect on the palliative care provided (Doyle and Woodruff 2008). Social factors that prevent the delivery of palliative care include ethnic minorities and language barriers, rural communities and underprivileged communities (Doyle and Woodruff 2008). The patient can also be a barrier to providing palliative

care; they may have unrealistic expectations or believe their prognosis is better than expected by professionals. There can also be disagreements between the patient and the family about treatment options. There may also be no advance care planning (ACP) (Doyle and Woodruff 2008), delaying the onset of palliative care. This can be due to the health care professional's poor prognostication, resulting in curative care proceeding for too long or lack of communication skills to address palliative and end-of-life care issues. Alternatively, the health care professional may not believe in the use of palliative care or may not have high palliative care standards in their institution (Doyle and Woodruff 2008).

The literature identifies health care professionals' poor prognostication as a barrier to palliative care, as well as the fact that little is known about the potentially complex transition to palliative care (Gardiner, Ingleton et al. 2011). This transition can be defined as "a change of focus in the goals of a patient's care from 'active treatment,' where the focus is on cure or management of a chronic disease, to a 'palliative care' approach, where the focus is on maximising quality of life" (Gott, Ingleton et al. 2011, p.1). The boundaries between palliation and curative care are blurred and becoming increasingly so, this is due to advances in medical technology (Payne, Seymour et al. 2004). Evidence suggests that continuity of care and MDT collaboration are crucial in order to improve patient experience of the transition. Incorporating palliative care earlier in the patient's illness trajectory and implementing a stepped transition could be vital factors of high quality care (Gardiner, Ingleton et al. 2011), however this is seldom evident in UK secondary care (Gott, Ingleton et al. 2011). Adopting a stepped transition from curative to palliative care may be difficult as it requires a change in health care professionals' ethos and poses challenges for a health care system that has been created

to cure. These issues are discussed further throughout this chapter. In order to provide palliative care that is based on patient preferences the barriers to providing palliative care need to be overcome and a change in ethos needs to occur.

Preferences in end-of-life care addressed through palliative care

The North East, where the new palliative care ICP under investigation has been implemented, had the highest percentage of those who would prefer to die in their own home in 2010 (67%), with the average across government office regions being 60% (Gomes, Calanzani et al. 2011). The preference of a hospice death was second choice across the UK ranging from 26-32% across England. 89% of people would prefer to die in their own home or a hospice (Gomes, Calanzani et al. 2011). Hospital was the least preferred place of death across all government office regions apart from in the North East, where it was the second least preferred place of death for 31% of people (Gomes, Calanzani et al. 2011). A care home was the least preferred place of death (34%) in the North East in this study. However, this survey was of younger adults unlikely to be situated in care homes so might not be representative of the adult population as a whole. Data from the locality under study indicates that those asked who are current palliative care patients would prefer to die in their own care home as opposed to hospital.

It is important that patient preferences are discussed in advance of end-of-life care as patients who lack capacity and have not previously stated their preferences may receive unwanted, futile, aggressive and costly medical treatment (Detering, Hancock et al. 2010, Silveira, Kim et al. 2010). Alternatively, they may experience the withdrawal of treatments that they would have desired (Detering, Hancock et al. 2010, Silveira, Kim et al. 2010). If these decisions are not made by the individual in advance they cannot be

adhered to. This not only causes distress to the patient but also to their family and carers as they may be required to make decisions if capacity is diminished and may disagree with one another (Breen, Abernethy et al. 2001).

Across the country, there is a substantial gap between the amount of people who would prefer to die at home and those who actually do die at home. This gap is larger in the North East (46%) when compared to the government office regions as a whole (Gomes, Calanzani et al. 2011). This may be because as end-of-life approaches the use of hospital care rises very significantly, particularly via unplanned admissions (Van den Block, Deschepper et al. 2007, Pot, Portrait et al. 2009, Maddams, Utley et al. 2011, Rosenwax, McNamara et al. 2011, Bardsley, Georghiou et al. 2012). Unplanned admissions are expensive to the NHS and often not desired by patients and their families. Research has shown that ACP is effective in helping patients to achieve their preferred place of death by stating preferences and avoiding unplanned admissions (Detering, Hancock et al. 2010, Arnold, Finucane et al. 2012).

Difficulties in discussing death and dying

As discussed above, stating preferences is essential in order to achieve patient centeredness. However, in modern society people often do not wish to discuss death and dying, a fact that is often attributed to the death taboo (Lee 2008). The first publication about death was by Groer (1955); his essay 'The Pornography of Death' opened the door for others to publish on this topic. He argued that death had replaced sex as society's major taboo topic (Leming and Dickinson 2010). The 1960s sexual revolution made advances in overcoming sex as a taboo subject. However, there has been no such

revolution for death and dying. The origin of the social taboo of death and dying is complex and multifaceted, including historical, cultural and demographical considerations. Historically, priests cared for terminally ill patients at the end-of-life. This has been supplanted by medical experts who traditionally see death as failure due to the curative culture which is enforced by ever developing medical advances (Walter 1991). Adults are living longer in the UK (Caley and Sidhu 2011) and since 1945 hospitalisation of dying people has been promoted with death in the community becoming rarer (Walter 1991, Leming and Dickinson 2010), despite the curative culture that dominates hospital settings. The dying person can be seen to be banished from mainstream society with individuals seeing fewer corpses (Leming and Dickinson 2010, Meier, Isaacs et al. 2010). This change in location has made death invisible to the public (Walter 1991). Additionally, personnel in the media and medical domain who are part of institutions who have the most power in interpreting death have strong anxieties about death and dying (Walter 1991). The controversy and media storm surrounding the Liverpool Care Pathway for the Dying Patient (LCP) is a direct, recent example of this. Regardless of its origins or terminology, death is still a subject that many find difficulty in facing or discussing frankly. It is a social taboo that is present in the media and the medical domain:

> *"But whereas death was much more* of a part of everyday life for previous generations, in Britain today death is becoming a social taboo."* (BBC News 2011, p. 1)

> *"Death has become too closed off, too much behind hospital doors and altogether too sanitised."* (Yorkshire Post 2013, p. 1)

> *"We know, the physician and nurse know and the patient knows* (whether told or not) when the condition is terminal but we often exist in anything but an open awareness context. No one lets the other know

that he or she knows. Death *talk remains taboo.*" (Leming and Dickinson 2010, p. 180).

Death has been discussed as a social taboo for many years (Simpson 1987, Walter 1991), meaning that it is not a new phenomenon, yet little has been done in the past to address this. Although the social taboo of death and dying may not be as strong as it was in the 1980s, it is deeply rooted and is unlikely to be overcome in just a few years (Leming and Dickinson 2010), despite some writers considering the social taboo of death and dying to be in its twilight years (Lee 2008). The results of this are that both patients and health care professionals can feel uncomfortable discussing death and dying or caring for a person who is dying. This makes early identification and preference discussions difficult, which in turn makes planning a good, preference-based death problematic.

The political mandate

Recently the public, policy makers, hospice movement and individual case studies have been seen to attempt to break down the social taboo of death and dying, with reports of death cafes (MSN News 2013) and festivals (Cardiff University 2013), hospice care providing a greater awareness about care for the dying (Lee 2008), the Dying Matters campaign (The National Council for Palliative Care 2009), high profile end-of-life euthanasia cases such as Terri Schiavo in the USA and Tony Nicholson in the UK and publications such as the End of Life Care Strategy (Department of Health 2008) and Deciding Right (NHS North East 2012). Palliative and end-of-life care has recently become a local, regional, national and international priority (Brennan 2007, Department

of Health 2008, The National Council for Palliative Care 2009, The National Gold Standards Framework Centre 2009, NHS North East 2012). A short description of all relevant policy follows in order to frame the political context of the research and highlight important concepts in providing high quality palliative care.

The Gold Standards Framework (GSF) (2009) was originally developed in the UK from within primary care as an initiative to improve palliative care. It is a systematic approach to improving the quality and organisation of care for people approaching the end of their life. It aims to improve patient outcomes that match the patient's needs and preferences, alongside better cost-efficiency through avoiding unnecessary hospital admissions. The GSF has three essential elements:

1. Identify patients and what stage they are in their illness.
2. Assess current and future clinical needs and personal needs.
3. Plan (anticipate needs) (The National Gold Standards Framework Centre 2009).

The five goals of the GSF are to provide for patients with any final illness: consistent high quality care; alignment of patients' preferences to actual care (person centred care which can be achieved through shared decision making); pre-planning and anticipation of needs (proactive care); improved staff confidence and teamwork; more home based and less hospital based care (proactive and patient centred care) (The National Gold Standards Framework Centre 2009). The GSF is recommended as best practice by the End of Life Care Strategy published by the Department of Health (2008). This strategy identified a number of significant issues affecting dying and death in England. This included: discussions as the end-of-life approaches, assessment, care planning and review, coordination of individual patient care, delivery of high quality services in a range of settings, care in the last days of life and care after death (Department of Health

2008). All of these issues affecting death and dying can be addressed through the use of proactive and patient centred care using shared decision making. The strategy promotes high quality care for all adults at the end-of-life by providing people with more choice about where they would like to live and die. This document also defined what a 'good death' could be considered as:

- Being treated as an individual, with dignity and respect.

- Being without pain and other symptoms.

- Being in familiar surroundings.

- Being in the company of close family and/or friends.

As part of the End of Life Care Strategy (Department of Health 2008) the Dying Matters campaign (The National Council for Palliative Care 2009) was created to support the implementation of the strategy, focusing on increasing public awareness and aiming to support changing attitudes and behaviours in society towards dying, death and bereavement. Echoing this national policy is local policy, such as Deciding Right for the North East of England (NHS North East 2012). This is an integrated approach to making care decisions in advance with children, young people and adults and provides information and instruction on how to implement a proactive, integrated approach to palliative and end-of-life care that results in a good death, adhering to patient preferences. This is done through use of shared decision making, the Mental Capacity Act (Department of Health 2005), ACP, generic form use across the North of England and use of the LCP (Ellershaw and Ward 2003). Deciding Right uses The Mental Capacity Act (MCA) (Justice 2007), which is important for caring for those with palliative care needs, assuring that decisions that are made in advance, which can concern patient preferences, are valid. It states that a person lacks capacity in relation to

a matter if at that specific time he or she is unable to make a decision for her or himself in relation to the matter due to an impairment of, or a disturbance in the functioning of the mind or brain (Justice 2007). A person is not to be treated as unable to make a decision unless all feasible steps to help him or her to do so have been taken without success. Furthermore, an unwise decision should not be considered as a lack of capacity either (NHS North East 2012). Issues surrounding capacity are prominent in palliative and end-of-life care, for example, ACP should always be done with someone who has capacity for the decisions it involves.

Important concepts from palliative care policies

Patient centred care, shared decision making and proactive care are all highlighted as pivotal concepts in the recent policies related to palliative and end-of-life care that are discussed above and are explored in greater depth below.

Proactive care

The primary role of the GP is listening and offering appropriate treatment and advice, and is perceived as such by the public (Spence 1960). It is wholly attuned with high quality, contemporary primary care and encompasses the bulk of a GP's workload (Spence 1960). Thus the primary role of the GP is a reactive role. Spence (1960) defines reactive care in the following way:

> *"The essential unit of medical practice is the occasion when, in the* intimacy of the consulting room, a person who is ill, or who believes himself to be ill, seeks the advice of a doctor whom he trusts. This is a consultation, and all else *in medicine derives from it."* (Spence 1960, p. 273).

However, proactive care has become a prominent focus in the health care domain and emphasises the anticipation of needs. Gillies, Baird et al. (1995) describe proactive care as:

> "Care that attempts to prevent illness by intervention in asymptomatic individuals." (Gillies, Baird et al. 1995, p. 16).

However, in palliative care this term is refined. The patient is already ill with a condition that can only be managed. The health care professional needs to be proactive in terms of care planning. This is holistic and thus addresses physical needs (anticipating required increases in medication to alleviate pain), emotional needs (discussing end-of-life issues and fears), and practical needs (place of death). The World Health Organisation (WHO) define palliative care as:

> "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."* (World Health Organisation 2014, p. 1)

This definition highlights the inherent need for palliative care to be proactive through early identification and impeccable assessment and treatment; this means that to deliver high quality palliative care, as stated in the policies discussed above, proactive care must be central. Supporting this, the academic literature indicates that proactive care is pivotal in providing high quality palliative care (Froggatt and Hoult 2002, Norton, Hogan et al. 2007, Burns, Johnson et al. 2008). Integrating palliative care into curative care or combining palliative care with illness-oriented management earlier in the disease

trajectory resulted in increased satisfaction with care, less acute interventions, and an increased likelihood to die at home in chronically ill patients nearing the end-of-life (Brumley, Enguidanos et al. 2003, Abarshi, Onwuteaka-Philipsen et al. 2009). The first proactive action a health care professional must take to begin providing proactive palliative care is to identify patients that require it. Identifying patients early enough to work within a palliative care framework as opposed to in crises would encompass a proactive approach. The early identification of palliative care is a key concept in the UK End of Life Care Strategy (Department of Health 2008). Early identification of palliative care patients means that they can build longer term, stronger relationships with health care professionals, especially community nurses who will provide the majority of end-of-life care if a home death is the patient's preference. By building trusting relationships prior to problematic symptoms patients and their families can be offered access to timely and appropriate support (Agar, Currow et al. 2008). This is important, as often a precursor to patients needing to be cared for in a location other than their own home is linked to receiving 'unwanted' physical help from relatives, such as with incontinence (McCall and Rice 2005) or due to carer/relative fatigue in relation to providing emotional and physical support to loved ones (Grande, Todd et al. 1997). UK policy guidance on treatment and care towards the end-of-life has identified a need to better recognise patients who are likely to be in the last 12 months of life (Gardiner, Ingleton et al. 2011). This means that people with life limiting illnesses who require palliative care should be identified as early as possible (via proactive actions from health care professionals) in the course of their progressive illness.

Patient centred care

Patient centred care can be construed in different ways (Wagner, Bennett et al. 2005). Yet regardless of perspective all definitions are a reaction to the perceived inadequacies of traditional care and its focus on the biomedical model and the domination of the health care professional (Mead and Bower 2000). To many, patient centred care means focusing on the whole person and not only their health care needs (Wagner, Bennett et al. 2005, Manley, Hills et al. 2011). This includes consideration of their feelings and experience of illness and psychological and social factors in order to direct the patient's care (Wagner, Bennett et al. 2005). Thus patient centred care can also be thought of as 'the person in the patient' (Goodrich and Cornwall 2008) and is a desired feature in modern health care. The Fourth Principle of Nursing Practice, Principle D, refers to patient centred care, stating:

> *"Nurses and nursing staff provide and promote care that puts people* at the centre, involves patients, service users, their families and their carers in decisions, and helps them make informed choices about their *treatment and care"* (Manley, Hills et al. 2011, p. 35).

Patient centred care should acknowledge individual patient preferences, needs, and perspectives and ensure that patient principles guide clinical decisions (McCormack, Treiman et al. 2011).

There is a consensus that patient centred care equates with high quality care (Innes, Macpherson et al. 2006, Royal College of Nursing 2009). Chronic conditions which can be likened to palliative care indicate that high quality care of this population includes a fuller understanding of the patient's life and preferences, tailoring of management to

the patient's preferences (Wagner, Bennett et al. 2005) and the activation (Hibbard, Stockard et al. 2004) or empowerment (Anderson 1995) of patients. These are all concepts that are often associated with the term patient centred care. Achieving patient centred care consistently entails specific knowledge and abilities, a shared philosophy that is practised by the multidisciplinary health care team, a positive workplace culture, and organisational support (Manley, Hills et al. 2011). In addition, health care professionals need to be able to use different processes to develop patient centred care, including working with patients' values and beliefs, engaging patients, having a sympathetic presence, sharing decision making and accommodating patients' physical needs (McCormack and McCance 2010). Shared decision making is required to provide patient centred care and will be discussed below.

Shared decision making

Policy makers perceive shared decision making as necessary due to its potential to sustain the health care system (Coulter 2006) and promote the right of patients to be involved in decisions concerning their health (Straub, Nebling et al. 2008, Légaré, Ratté et al. 2010). It has been referred to as the crux of patient centred care (Godolphin 2009). It can be described as a middle ground between paternalism and rampant consumerism, with a medical encounter perceived as the meeting of two experts - the patient as an expert in his or her own life, values, and circumstances, and the health care professional as an expert in medicine (Tuckett, Boulton et al. 1985, Godolphin 2009). In order for shared decision making to take place the health care professional must search for and offer choices, as without choices there is no decision to be made (Godolphin 2009). The health care professional must then inform patients of the choices in order to engage

them in shared decision making. Godolphin (2009) identifies eight abilities a health care professional needs to successfully use shared decision making. These are the ability to:

1. Develop a partnership with a patient

2. Establish and review a patient's preference for the amount and format of information they receive

3. Establish and review the patient's preferences for their role in decision making (including their preferred degree of involvement)

4. Determine and act in response to patients' ideas, concerns and expectations

5. Identify relevant choices and evaluate research evidence in relation to the individual patient

6. Present or direct the patient to relevant evidence

7. Make or negotiate a decision in partnership and resolve conflict

8. Agree on an action plan and complete arrangements for follow up (Godolphin 2009)

Health care professionals should aim to relieve suffering and increase autonomy (Godolphin 2009) to allow the patient to feel more independent and self-reliant post consultation, as opposed to disempowered and dependent on the health care professional or system (Godolphin 2009). However, shared decision making is not always in isolation between the patient and the health care professional. It may also involve a team of health care professionals working collaboratively or significant others including family members and carers (Godolphin 2009).

Involving patients in care decisions makes a potentially significant and lasting difference to health care outcomes (Stewart 1995, Elwyn, Edwards et al. 2000). Despite this, the literature indicates that quality shared decision making only occurs about 10%

of the time (Braddock, Edwards et al. 1999, Godolphin 2009) and that generally shared decision making in practice is poor (Campion, Foulkes et al. 2002, Elwyn, Edwards et al. 2003, Towle, Godolphin et al. 2006, Young, Bell et al. 2008). However, it is envisaged that it will improve as the health care professional-patient relationship is changing due to a more consumerist society with greater public involvement in health care (Coulter 2002, Godolphin 2009). Furthermore, shared decision making is now an international philosophy that features in guidelines from Canada, the United States of America, Australia and the UK (Australian Council for Safety and Quality in Health Care 2005) and is incorporated into training programs and good practice (Godolphin 2009). The General Medical Council in the UK declares shared decision making as an "over riding duty or principle" and that "serious or persistent failure to follow this guidance will put your registration at risk" (General Medical Council 2008, p.5).

Difficulties in translating policy in to practice

An ageing population

The annual number of deaths in England and Wales is predicted to rise by 17% per cent from 2012 to 2030, and the average age at death is also set to substantially increase (Gomes and Higginson 2008). In 2012, cancer was the most common cause of death in England and Wales (29% of all registered deaths) but this was closely followed by circulatory diseases, such as heart disease and strokes (28% of all deaths registered) (Office for National Statistics 2013). Information was not available for other non-cancer deaths (frailty and dementia, organ failure). Since 2002, death rates for cancer have fallen by 14% for males and 10% for females (Office for National Statistics 2013); the

prevalence of non-cancer illnesses such as dementia are expected to increase, from 800,000 in 2012 to 1,000,000 in 2021 in the UK (Alzheimer's Society 2013). This evidence, alongside the knowledge that the population is ageing (Caley and Sidhu 2011) and cancer treatment is advancing (Costanzo, Ryff et al. 2009), suggests that cancer deaths will continue to decrease and non-cancer deaths will increase in the future. Due to the ageing population (Forder and Fernandez 2011, Gomes, Calanzani et al. 2011) the level of frailty, impairment and needs of people admitted to care homes is now higher than it was 10-15 years ago (Forder and Fernandez 2011). A Bupa report recently found that over 50% of care home residents were over 85 years of age in 2011 (53.9%), this figure was similar to findings from the Department of Health for 2008 for residents over 85 (55%) (Forder and Fernandez 2011). Bupa figures are largely representative of England averages in relation to age and sex. In 2011, the average length of stay in Bupa care homes was 801 days; half of residents had died by 464 days. Older adults had a shorter length of stay in care homes as they had a higher death rate (Forder and Fernandez 2011). Thus, care home residents are often elderly and frail with non-cancer diagnoses. The literature and statistics indicate that non-cancer illnesses will increase, however this poses difficulties in providing proactive care as prognosis can be difficult to determine (Murray, Boyd et al. 2005). Differences in the trajectories of cancer and non-cancer illnesses have been recognised as far back as 1968 (Glaser and Strauss 1968). Three typical illness trajectories have been defined for patients with progressive palliative illness: cancer, organ failure, and the frail elderly or dementia trajectory (Murray, Boyd et al. 2005, The National Gold Standards Framework Centre 2009). Individuals who have cancer do not have serious debilitation or restriction in activity until the final stages of the illness, when anti-cancer treatments are no longer effective (Murtagh, Preston et al. 2004). This means that for most the illness trajectory is

commonly a slow overall decline until anti-cancer treatments cease to be effective. Therefore, people with cancer diagnoses have a predictable terminal phase, similar to that described by McCusker (1984). By contrast, organ failure trajectories are erratic; they have sudden acute deteriorations followed by substantial improvement, but with an underlying downward trend in function and ability (Murtagh, Preston et al. 2004). However, not all non-cancer illnesses stemming from organ failure follow this trajectory; for example, end stage renal failure may be that of a steady decline, at a rate that varies with pathology and individual factors. However, renal disease has a high level of co-morbidity with cardiovascular and cerebrovascular disease, making this non-cancer illness also difficult to predict (Murtagh, Preston et al. 2004). Individuals who have dementia or general frailty have a much lower baseline level of functioning, with a declining but variable downward course towards death (Murtagh, Preston et al. 2004). Sudden deteriorations may lead to hospitalisation and intensive active treatment being more often associated with non-cancer (organ failure and frail elderly or dementia) than with cancer diagnoses (Murtagh, Preston et al. 2004). Thus the different trajectories make providing palliative care for those with non-cancer illnesses much more difficult and this affects health care professionals' ability to be proactive. This in turn means that health care professionals will have difficulties being patient centred and engaging in palliative care based shared decision making.

Time constraints

Over the past several decades major transformations have occurred in health care in the more developed world; this has affected the way health care professionals perform, experience, and evaluate their own clinical work (Konrad, Link et al. 2010). Health care

professionals are increasingly pressured to be proactive, deliver patient centred care, engage in shared decision making, follow guidelines and engage in evidence based practice. Thus, time is very important in designing national health care systems that operate efficiently (Konrad, Link et al. 2010). Health care professionals often struggle with how much control they have over their time in terms of hours of service and minutes of patient contact. This can affect patient centred care which requires the ability to develop good relationships, a process that can be time consuming. The relationship between the patient and front line worker is crucial to the experience of high quality, patient centred care and support (Innes, Macpherson et al. 2006). Transient experiences with patients in primary care that has high demands and time constraints may prevent health care professionals from providing patient centred care and engaging in shared decision making (Elwyn, Edwards et al. 1999). A recent systematic review identified longer health care professional visits were associated with more positive outcomes such as more attention to psychosocial problems, lower prescribing rates, lower return consultation rates and higher patient satisfaction indicators suggesting patient centeredness was higher (Wilson and Childs 2002). Furthermore, longer visits may decrease malpractice litigation risk (Levinson, Roter et al. 1997). American health care professionals reported that they scheduled more time for consultations with patients than health care professionals in the UK or Germany (Konrad, Link et al. 2010). American and German health care professionals had similar perceptions of control over their time; in comparison UK health care professionals felt that they had less control over time. Health care professionals from the UK are scheduled more tightly and appear to work more rapidly than their American colleagues (Konrad, Link et al. 2010). Thus health care professionals in the UK have shorter consultations, feel that they have less control over time and are scheduled more tightly and work faster than their associates in

America and Germany. However, with longer consultations having positive outcomes for patients and health care professionals as well as reducing risk of malpractice litigation (Levinson, Roter et al. 1997, Wilson and Childs 2002), feeling time pressured and working rapidly are not beneficial to patients or health care professionals and may compromise patient centred care and shared decision making.

Communication surrounding death and dying

The UK General Medical Council guidance on end-of-life care, which came into effect in July 2010 (General Medical Council 2010), states that health care professionals must ensure that death becomes "an explicit discussion point when patients are likely to die within 12 months, and that medical paternalism on the subject, however benignly intended, must be replaced by patient choice" (Bell 2010, p. 1). This is in line with policy initiatives to identify patients in the last twelve months of their life (Department of Health 2008). However, awkwardness, embarrassment and fear can mean that people avoid connecting with those who are dying (The National Council for Palliative Care 2009), making proactive care, patient centred care and shared decision making difficult. Both a palliative diagnosis and information about palliative care can be classed as distressing health threatening information which is difficult for the doctor to deliver and for the patient to receive (Buckman 1984, Ptacek and Eberhardt 1996, Ptacek and Ptacek 2001). The literature suggests conversations about death occur infrequently and that this may be due to professionals not feeling at ease with broaching the subject (The SUPPORT Principal Investigators 1995, Hoffman, Wenger et al. 1997, National End of Life Programme 2011). It has been proposed that in such health related risk situations individuals utilise distinctive attentional processing styles which allows them to be

classified as a 'monitor' or 'blunter' (Miller 1995). When faced with a health related risk, monitors generally seek information, magnify disease related cues and display greater dissatisfaction about the amount of information provided. Alternatively, blunters psychologically distract themselves from health related risk information and desire less knowledge. People can be classified as (high or low) monitors and (high or low) blunters using the Miller Behavioural Style Scale (MBSS) and this scale could have explanatory potential in terms of why some consultations about death and dying work better than others.

Communicating realistic information about different treatment options and the likelihood of successful treatment or adverse effects and symptoms is also difficult (Matsuyama, Reddy et al. 2006). The literature indicates that patients who have cancer would choose chemotherapy for much smaller improvements in outcome than would health care professionals (Matsuyama, Reddy et al. 2006). This makes supportive and holistic palliative care that is patient centred, proactive and based on shared decisions extremely difficult. If a patient wishes to continue with aggressive treatment, it could be that they are unlikely to engage in end-of-life care preference discussions. However, patient autonomy and choice should always be valued and thus patients' treatment options should always be presented in a balanced manner (Earle 2006), and preference discussions and a palliative approach should be entered into mutually. However, there is a subjective discrepancy in how aggressive palliative treatment is viewed by patients, bereaved relatives and health care professionals. Both bereaved relatives and health care professionals who have experienced aggressive treatment for palliative care patients would avoid it, giving more time to plan hospice and end-of-life care (Earle 2006). However, in focus groups, terminally ill cancer patients who by virtue of still being

alive had not experienced the whole course of their illness were more inclined to consider aggressive palliative treatment (Earle 2006). This discrepancy suggests that there is a gap between the informed opinions of bereaved relatives and health care professionals, and the decisions of patients'. Slevin, Stubbs et al. (1990) makes this more explicit, stating that 53% of cancer patients are willing to contemplate aggressive chemotherapy if chances of a cure were increased by as little as 1%. Furthermore, patients have stated that they would accept chemotherapy or radiotherapy despite being aware that it would have no clinical benefit and no gain in survival chances (Palda, Llewellyn et al. 1997, Jansen, Kievit et al. 2001). This could be due to explanations from those providing the treatment being unclear or due to a fear of death. A quote from de Haes and Koedoot (2003) suggests that oncologists prefer to give treatment as opposed to deny it, despite doubtful expectations about a positive result.

> "Giving chemotherapy, rather than watchful waiting, is what I have been educated to do; *that's* what I have to sell in my shop." (de Haes and Koedoot 2003, p. 45).

Earle (2006) suggested that primary care health care professionals may feel uncomfortable in communications about palliative care due to a lack of tools in conveying pros and cons; the subject being too emotionally distressing to discuss; patients being unable to comprehend the realistic outcomes; and attempt to not be totally honest in order to preserve hope (Earle 2006). However, if these discussions do not take place it is difficult for proactive care, patient centred care and shared decision making to occur.

Litigation in palliative care

Around 3,800 years ago, the Code of Hammurabi stated that health care professionals who harmed their patients would have their hands cut off (Selkin 2011). Since then, health care professional-patient relationship has produced potential civil, criminal and administrative liability (Selkin 2011). Often physicians learn the law as defendants in malpractice claims, thus the systems are adversarial (Selkin 2011). Few health care professionals know the different factors that constitute negligence and can be confused about informed consent; this can lead to inappropriate defensive medicine, such as cardiopulmonary resuscitation (CPR) in palliative care patients, where it is unlikely to succeed (Selkin 2011). Furthermore, it is not only health care professionals who face litigation but also those who care for palliative care patients outside of the medical domain, such as care home workers. Due to the litigious society in which we reside it is difficult for health care professionals and carers to make decisions surrounding palliative care, with caveats needed in terms of CPR, capacity, autonomy and patients' best wishes. This makes patient centred care difficult, as despite the knowledge of patients' wishes, supporting documentation may be required to avoid litigation. If this documentation cannot be produced (for example, is lost) or is not valid (for example, not signed) in a crisis, patient centred care cannot be carried out due to the health care professional or carer's self-preservation (to avoid litigation).

Definitions of palliative and end-of-life care

The terms palliative and end-of-life care are often used interchangeably in practice and the literature, preference in terms has changed in the last 30-40 years, specific meanings of terms have changed and definitions vary by organisation and country (Izumi, Nagae

et al. 2012). In the UK curative care is care that is focused on ultimately preserving life: remission and stabilisation of illness. As stated earlier, palliative care is defined as:

> *"An approach that improves the quality of life of patients and their* families facing the problem 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"* (World Health Organisation 2014)

End of life care is considered by the General Medical Council as focussed on patients who are likely to die within the next twelve months. This includes patients who are: expected to die within the next few hours or days; those with advanced incurable conditions, those with general frailty and co-existing conditions; those with existing conditions who are at risk from dying due to a sudden crisis in their condition; life-threatening acute conditions caused by sudden events such as accident or stroke (NHS Choices 2013). Thus, palliative care is considered as a more holistic form of care. However, there is great variation not only in practice but also in the literature in terms of definitions for end-of-life care, especially in relation to time. Lunney, Lynn et al. (2003) and Chan and Webster (2010) state end-of-life care focuses on the last days and hours of life, as opposed to the last twelve months. Confusion about and between palliative care and end-of-life care may make it difficult for shared decision making to take place with patients. They may become distressed if a health care professional attempts to be proactive by suggesting a palliative approach. Furthermore, palliative care does not mean that a patient does not require active care. A frail elderly patient who health care professionals view as appropriate for palliative care may fall and break her wrist; being a palliative care patient does not mean that this person should not receive appropriate, patient centred medical attention for this injury.

Aids to translating policy into practice

There has been a drastic increase in literature about research-practice-policy links in recent decades (Nutley, Morton et al. 2010). Despite this, there remains a well-recognised and significant translational gap between these domains. As discussed above, there are issues in implementing conceptual notions from the political mandate (such as proactive care, patient centred care and shared decision making) into practice. However, there are techniques (Continuous Quality Improvement) and theories (Diffusion of Innovation and Normalisation Process Theory) that may aid the implementation of these concepts into practice.

Continuous Quality Improvement

Quality improvement is not a new feature in health care. It dates back to the nineteenth century, with Ignaz Semmelweis introducing hand washing to medical care and Florence Nightingale identifying that poor living conditions were a leading cause of death (Chassin and Leob 2011). However, quality improvement in health care has developed significantly, with a systems approach used to describe and improve existing services termed Continuous Quality Improvement (CQI) (Radawski 1999). Thus CQI can aid the translation of national policy into practice. It is a philosophy of continual improvement of the processes associated with providing a service that meets or exceeds customer expectation (Shortell, Bennett et al. 1998). The basis of CQI is the assumption that problems in producing a quality outcome arise commonly due to poor job design, failure of leadership or unclear purpose, as opposed to lack of will, skill, or malign intention from those involved in the process (Graham 1995). Another premise of CQI is that of a blameless culture; establishing trust and respect and avoiding retribution are

advocated (Radawski 1999). Honest communication and collaboration about implementation and use of an intervention as well as flexibility to make changes to these procedures is also important in CQI. This gives health care professionals responsibility and empowerment in relation to an intervention. The NHS is now tasked to ensure that services are driven by a cycle of CQI that includes clinical aspects of care (Ferlie and Shortell 2001), making CQI an important factor for new services and palliative care in general. In order to undertake CQI, revision of the way an intervention is performed is executed through examination of outcome data (Radawski 1999). The goal of CQI is to understand and improve the underlying work processes and systems in order to add value, as opposed to correct individuals mistakes (Shortell, Bennett et al. 1998). Most studies evaluating CQI in clinical practice have reported favourable results, with quality and outcomes of care being improved (Shortell, Bennett et al. 1998). Thus CQI can be an aid to health care professionals using a new service that is implemented due to national policy and can be seen as a facilitator to new service diffusion in practice.

Diffusion of Innovation

Diffusion is a process where an innovation is communicated over time to and amongst the members of a social system (Rogers 1995) and can be thought of as a way to bridge the gap between policy and practice. It can be considered as a special type of communication as it is concerned with the spread of messages that are perceived as new and ideal. Diffusion is distinctive because of the novel idea in the message content, thus in health care some uncertainty and perceived risk must be associated with the new innovation that is to be diffused in practice (Rogers 1995).

New services or interventions require diffusion into practice in order to be successful, and the health care domain and its ability to implement and diffuse innovations has created great research interest (Greenhalgh, Robert et al. 2004, Länsisalmi, Kivimäki et al. 2006). The need for innovation in service delivery has been highlighted since the early 1980s (Hunter 1983), but the implementation of innovations still presents significant challenges (Barnett, Konstantina et al. 2011), regardless of their potential benefits. This is also despite the perception of health care organisations as the most knowledgeable and scientific based institutions (Barnett, Konstantina et al. 2011).

The innovation decision process gives informative insight into how and why individuals adopt a new innovation. This process consists of five stages:

1. Knowledge - when the individual is exposed to the innovation and understands how it operates.

2. Persuasion - when the individual forms a positive or negative view of the innovation.

3. Decision - when the individual engages in activities that lead to a choice to accept or reject the innovation.

4. Implementation - when the individual puts an innovation into use.

5. Confirmation - when the individual seeks confirming evidence for an innovation-decision already made. The individuals may change their decision if they are exposed to conflicting evidence about the innovation (Rogers 1995).

This process highlights how individuals adopt new services, and thus how national policy can be adopted by front line staff. However, there are some criticisms of

diffusion research including the pro-innovation bias (Rogers 1995). This is the suggestion of most diffusion research that an innovation should be rapidly diffused to and adopted by all members of a social system, and that the innovation should not be re-invented or rejected. This ethos is therefore counter to CQI which enforces that new services can be implemented differently and yield better (or potentially worse) results.

Factors that can aid innovation diffusion can be perceived attributes of the innovation itself, such as relative advantage (Rogers 1995). Alternatively, innovation diffusion can be facilitated by key individuals, such as champions or opinion leads (Greenhalgh, Robert et al. 2004). Both perceived attributes of the innovation or key individuals may enhance the translation of national policy into practice.

The five perceived attributes of innovations

Rogers (1995) names five attributes of innovations that make it more likely to be adopted: relative advantage, compatibility, complexity, trialability, and observability.

Compatibility is the degree to which an innovation is perceived as consistent with the pre-existing values, past experiences, and needs of potential users (Rogers 1995). An innovation can be compatible or incompatible with - sociocultural beliefs and values; formerly introduced ideas; or client prerequisites for the innovation (Rogers 1995).

Complexity is the perceived difficulty of the innovation (Rogers 1995). Any new intervention can be situated on the complexity-simplicity continuum – some new innovations are clear to the potential users whereas others are not (Rogers 1995). Trialability is the degree to which an innovation may be experimented with on a limited basis (Rogers). An intervention that lends itself to a trial can be adopted more rapidly

than one that does not (Rogers). Observability is the extent to which the results of an innovation are visible to others (Rogers 1995). Finally, the last perceived attribute of an innovation is its relative advantage, which is the degree to which an innovation is perceived as being better than the preceding idea (Rogers 1995). Innovations that have a clear, unambiguous advantage in either effectiveness or cost effectiveness are implemented and adopted more easily (Greenhalgh, Robert et al. 2004). Thus for a new service to be implemented, health care professionals and other associated organisations who are involved with it will have to believe that it will make a difference to the care they provide to their patients. Greenhalgh, Robert et al. (2004) describe relative advantage as 'sine qua non' for adoption, without which potential users will not consider it further. Therefore it is a corner stone of any new innovation and can be considered as an aid when implementing new services or interventions. However, relative advantage in isolation is not enough to ensure the adoption of an innovation (Greenhalgh, Robert et al. 2004).

The perceived attributes of an innovation state that if an innovation is comparable to the norms of those who use it, simple to use, trialable, observable and advantageous then it is more likely to be adopted into practice. Thus interventions aiming to diffuse key concepts from policies into practice may be more successful if they have these characteristics.

Champions and opinion leads

Greenhalgh, Robert et al. (2004) state that peer and expert opinion leaders and champions can have a particular influence on the beliefs and actions of their colleagues.

An opinion leader exerts influence through their representativeness and credibility and can have a positive or negative influence on how a new innovation is adopted (diffused into routine practice). A champion can aid innovation diffusion as they exert influence on others. A champion can be:

1. The organisational maverick, who provides health care professionals with freedom from the organisations rules, processes, and systems in order to generate innovative solutions to current problems.

2. The transformational leader, who creates support from other members of the organisation.

3. The organisational buffer, who forms a flexible monitoring system to ensure that innovators properly use the organisation's resources while still allowing them to act inventively.

4. The network facilitator, who develops cross-functional partnerships within the organisation (Greenhalgh, Robert et al. 2004).

Champions and opinion leads therefore could be pivotal in translating national policy into practice through new interventions or services. They provide support for others and could facilitate enhanced team work, coordination or communication.

Both CQI and innovation diffusion literature highlights that these two roles could aid the translation of national policy into practice through the support they provide to health care professionals using a new service. They could therefore potentially contribute to overcoming some of the difficulties referred to in the previous section.

Normalisation Process Theory

The Normalisation Process Theory (NPT) (May and Finch 2009) is a sociological theory that has been extensively promoted as a way to understand implementation, embedding and integration of innovations, especially in health care settings (McEvoy, Ballini et al. 2014). Thus it has been advocated as a means of bridging the translational gap between policy and practice (Murray, Treweek et al. 2010, Morrison and Mair 2012, McEvoy, Ballini et al. 2014). The NPT emphasises the fluid, vigorous and interactive processes between context, actors and objects and is consequent of studies aiming to understand implementation of complex interventions in health care settings (McEvoy, Ballini et al. 2014). The NPT has four main theoretical constructs – coherence, cognitive participation, collective action, and reflexive monitoring.

Coherence refers to the development understanding that individuals and organisations must work to achieve in order to promote or inhibit the routine embedding of a practice (Finch, Mair et al. 2012). Cognitive participation refers to the work that individuals and organisations have to do for individuals to register and engage with the new practice (Finch, Mair et al. 2012). Collective action is the work that individuals and organisations have to do to enact the new practice (Finch, Mair et al. 2012). Finally, reflexive monitoring is the appraisal of a new practice once it is in use, to assess its advantages and disadvantages.

NPT is not concerned with the relationships between individual attitudes and intentions and behavioural outcomes and thus does not focus on how knowledge is created within or across professional groups (McEvoy, Ballini et al. 2014). However, similar to the Diffusion of Innovation (Rogers 1995), the NPT focuses on the legitimacy of the intervention and the role of opinion leads. Thus it explores understanding, trust and

interpersonal relationships within social networks as they impact on the implementation of an intervention (Doumit, Wright et al. 2011, Harris, Provan et al. 2012).

Summary of aids to translate policy into practice

CQI, diffusion of innovation and NPT are all concepts that can explain, and in some cases, aid the diffusion of policy into practice. They offer explanatory potential as to why some interventions are not adopted by practice or why they are only adopted by some organisations and not others.

Chapter Summary

Palliative care has been termed since the 1970s and is gaining increasing significance in health care. However, there are still prominent barriers to the implementation of palliative care in practice related to disease type (cancer or non-cancer), health care professional ethos and the constraints of systems created to 'cure' people. This is understandable given the complexities of palliative and end-of-life care (Vissers, van den Brand et al. 2013). It is currently not explicitly known how these barriers affect the care that is provided in practice. However, in order to provide preference based palliative care, these barriers must be overcome. The literature indicates that most patients would prefer to die at home. However, a home death requires discussions and planning, which are often stunted by the societal taboo of death and dying. Efforts have and are still being made in breaking down this taboo by the public, through the media and policies related to palliative and end-of-life care. National guidance strongly advocates the use of proactive care, patient centred care and shared decision making to

provide high quality, preference based palliative and end-of-life care. Although these philosophies are of good standing and can result in positive outcomes for patients, they can be difficult to implement in primary care. There are some theories and tools that can be used to understand and, in some cases, improve, the implementation of interventions into practice including CQI, diffusion of innovation and NPT.

The next chapter describes how ICPs can structure palliative and end-of-life care and aim to provide proactive, patient centred care using shared decision making. The chapter will describe an ICP and explore one of the most well-known ICPs related to end-of-life care. ICPs in palliative care will be described and the ICP under study in this thesis will be explored in detail.

Chapter 2: Integrated Care Pathways

A detailed explanation of ICPs will be provided including how they are defined and described in the literature. Following this, the ICP implemented in the locality will be described in full, including the locality and GP practices' characteristics, the commissioning process and all the tools that can be used within the pathway. Published research will then be used to highlight what is known about ICPs in palliative care and identify a clear gap in the literature regarding underlying generative mechanisms.

What is an integrated care pathway?

To meet patients' needs as stated in national policy, a whole-systems approach is required which co-ordinates care across professional and organisational boundaries (Addicott and Ross 2010). ICPs offer a system of multidisciplinary care planning based around the principle of clinical audit and on the understanding and practice of clinical staff, which facilitate the management of defined patient groups with a specific clinical problem (Hotchkiss 1997, Campbell, Hotchkiss et al. 1998, Atwal and Caldwell 2002). They have been formulated as a strategy, thus provide a potential link between the publication of national guidelines and their implementation in local clinical practice (Campbell, Hotchkiss et al. 1998). Therefore an ICP can reasonably be expected to constitute an effective tool for the translation of proactive care, patient centred care and shared decision making into practice.

ICPs aim to: reach or exceed existing quality standards; improve multidisciplinary communication, health care professional-patient communication and patient satisfaction; reduce unwanted practice variation; and enable new staff to learn key interventions for specific conditions quickly (Campbell, Hotchkiss et al. 1998). Furthermore, they are a strategy for improving the collection and analysis of clinical data from practice in order to promote change (De Luc 2001). ICPs are primarily considered to be tools for designing care procedures, implementing clinical governance, unifying delivered care, improving the quality of clinical care, and ensuring that clinical care is based on current evidence (Riley 1998, De Luc 2001). They can consist of one document acting as a care plan, detailing the essential steps in the care of patients with a specific clinical problem, and offering description of expected progress (Campbell, Hotchkiss et al. 1998, Chan and Webster 2010). However, a palliative care ICP of this format would be very difficult to formulate for all palliative care patients due to the great variety of conditions and needs. Yet all palliative care patients have underlying similarities in needs that require attention from health care professionals; most prominently the need to plan for a good death which can be achieved through the use of proactive care that is patient centred through use of shared decision making. Thus the ICP studied here uses an advance care plan as one of a number of potential resources (as described in full later in this chapter). Although it is not validated, Croucher's work (2005) provides a helpful set of criteria to frame the service provided in this study. To be considered an ICP a service must be:

- A plan of expected clinical care – this is in all the documentation and information in the service being evaluated

- On some form of timeline, whether that is days, hours or stages.

- A multidisciplinary document.

- The actual clinical record.

- Based on evidence-based guidelines.

- A system to review performance.

- Able to cross organizational boundaries.

- An evolutionary and dynamic tool that is therefore never cast in stone (Croucher 2005).

Thus the palliative care ICP in this study is a long term integrated service that includes aspects of the traditional ICP but has been edited to work with the palliative care patient population. Due to meeting most of the criteria described by Croucher (2005) and the term ICP encompassing the general approach of the service this study evaluates, the service will be referred to as an ICP throughout the thesis.

ICPs provide benefits which lead to patient centred care, increased patient satisfaction, a reduction in documentation and inappropriate lengths of stay in secondary care (Kitchiner and Bundred 1996, Hotchkiss 1997). Use of ICPs can reduce errors and ineffective clinical practice, therefore improving outcomes (Kitchiner and Bundred 1996). However, there are concerns about ICPs and barriers to their implementation. These include discouragement of clinical judgement of individual cases, restriction of innovation, and the requirement of guidance, energy, high quality communication and time for successful implementation (Campbell, Hotchkiss et al. 1998). Other barriers to implementation include reluctance to change, lack of suitable evidence based guidelines, inadequate resources to develop guidelines locally, disruptive interpersonal politics, lack of recognition of the need for improvements in the quality of care, difficulty in identifying cost savings, insufficiently informed leader or a leader who is

not of high enough standing within the organisation (Campbell, Hotchkiss et al. 1998).

ICPs for palliative and end-of-life care management are used widely around the world

and have been regarded as the gold standard (Chan and Webster 2010). They have also

been set as the main part of the End of Life Care Strategy in the UK (Department of

Health 2008) and are part of the NHS's GSF (Thomas 2003). ICPs provide a key tool in

translating policy into practice but practitioners nevertheless have been reported to face

some implementation barriers (Campbell, Hotchkiss et al. 1998).

The Liverpool Care Pathway for the Dying Patient

Historically dying patients received insufficient attention from senior medical staff and

nursing staff, and experienced inadequate symptom control (Mills, Davies et al. 1994).

This prompted the development of the LCP, the most well-known ICP in palliative and

end-of-life care in the UK for the dying phase of palliation (Chan and Webster 2010).

The LCP was developed by the Royal Liverpool University Trust and the Marie Curie

Centre Liverpool to transfer the high standard of hospice care to secondary care

(Ellershaw, Foster et al. 1997, Ellershaw and Ward 2003). It is a standardised approach

to care for dying people which is intended to ensure that consistently good care is given

to everyone considered to be dying within a maximum of three days, regardless of

location (hospital, nursing homes, own home) (Ellershaw and Murphy 2005, Neuberger,

Aaronovitch et al. 2013). The LCP monitors not only the physical care of a dying

patient, but also addresses their psychosocial and spiritual needs such as the religious

and spiritual aspects of care (Ellershaw, Gambles et al. 2007, Veerbeek, van Zuylen et

al. 2008) Other objectives of the LCP are to encourage cost-effective health care

through appropriate prescribing, and avoiding crisis interventions and inappropriate

hospital admissions (Chan and Webster 2010). The document was developed from surveys, focus groups, expert opinion and consensus on best practice, with an aim of being patient centred and addressing holistic care needs. The LCP defines nineteen goals considered essential in the management of dying patients and for the care of their relatives and carers after death (Ellershaw, Foster et al. 1997, Ellershaw and Ward 2003). After the development of the LCP numerous other groups developed ICPs for the dying based on similar principles (Pooler, McCrory et al. 2003, Fowell, Russell et al. 2004, Bookbinder, Blank et al. 2005). Due to substantial criticism including claims of premature diagnosis of imminent death, the LCP masking signs of improvement in patients, and dissatisfaction from carers and family members (Delvin 2009, Smith 2009), the LCP was subject to an independent review in 2013 (Neuberger, Aaronovitch et al. 2013). This report concluded that there was poor understanding among health care professionals of existing guidance in care for the dying and a need for improved skills and competencies was identified. Furthermore, there was a reluctance to discuss the prospect of death and its clinical uncertainties with patients, their relatives and carers (Neuberger, Aaronovitch et al. 2013) due to a lack of openness and candour among clinical staff. A lack of compassion was also highlighted, and a need to put the patient, their relatives and carers first, treating them with dignity and respect was elected as pivotal for future care of the dying. This echoes the principles explored in the previous chapter (Chapter 1, p.6) regarding the difficulties of translating policy and evidence in to practice due to difficulties surrounding communication in palliative and end-of-life care.

The difficulties described resulted in the decision to 'phase out' the LCP across the NHS, with a replacement service for end-of-life care currently being developed. The

national and regional guidance for the care of patients in the last three days of life is that the 'proper' use of the LCP (or its equivalent) should continue until new care planning tools are introduced (Appendix 1). Thus, the locality health care professionals now explain the pros and cons of the LCP to patients and their family members and they make a decision as to whether they would like to have the LCP or not. If the patient or their family members (making a decision through best interests) chooses not to have the LCP, health care professionals ensure that the patient still receives the same standard of care (that identified within the LCP) and discuss all relevant care decisions with relatives. This illustrates the highly sensitive national debates which form the backdrop to this study.

One limitation of the LCP is its usability only in the three days prior to death; this doesn't sufficiently fulfil the need for proactive care, which should occur much earlier in the illness trajectory. However, it is important that end-of-life care is given unique attention, which the LCP, or other end-of-life ICPs which focus on the last three days of life, can do. They are part of palliative care, which includes the end-of-life phase and thus many palliative care ICPs use the LCP for end-of-life care. A Cochrane systematic review aimed to assess the effects of end-of-life care ICPs (including the LCP) in comparison to usual care or care guided by another ICP (Chan and Webster 2010). The study aim was to focus on the impacts of end-of-life care ICPs on symptom severity and quality of life for the patient, their family and carers, and health care professionals. The authors planned to include randomised controlled trials (RCTs), cluster RCTs and quasi-RCTs. The initial literature search identified 920 potentially relevant titles, but no studies met criteria for inclusion in the review. The review concluded that there was insufficient evidence to make recommendations regarding the use of such end-of-life

care pathways for the dying. However, the inclusion and exclusion criteria for this study were very stringent, and the study focussed on whether these interventions work. Furthermore, there are ethical issues associated with RCT designs when focusing on patients at the end-of-life; randomising patients to a study arm that does not include an intervention which many clinicians believe to be effective (Chan and Webster 2010). The LCP is an inherently complex intervention, with human factors playing an important part that are difficult to control for. The outcome measures in the study were physical symptom severity, memorial symptom assessment, psychological symptom severity, quality of life, and harms, all of which are extremely difficult to assess during the end-of-life phase, especially as the patient can be unconscious or sedated. The traditional RCT design has not yielded the outcomes needed to make informative decisions about end-of-life care ICPs effectiveness or worth.

Studies using research designs which do not match Cochrane review inclusion criteria can however provide informative results - Bailey, Burgio et al. (2005) implemented an end-of-life care intervention in a tertiary care Veterans Affairs medical centre. The intervention included staff education and support to identify dying patients and implement care plans for the last days or hours of life. The study found the intervention resulted in significant increases in the mean number of symptoms documented, the mean number of care plans, opioid medication availability and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms. This palliative care intervention improved outcomes for those with end-of-life care needs. Similarly, Veerbeek, van der Heide et al. (2008) investigated the effect of the LCP on the documentation of care, symptom control and communication, in hospitals, patients' homes and nursing homes. The study found that in comparison to the baseline period, when the LCP was used the

documentation of care was more comprehensive and symptom burden was significantly lower. Thus both studies found that end-of-life ICPs have the potential to improve symptom management. Other studies assessing end-of-life ICPs found improvements in clinical documentation and assessment (Bookbinder, Blank et al. 2005, Luhrs, Meghani et al. 2005, Veerbeek, van der Heide et al. 2008), knowledge of end-of-life care amongst internal medicine students (Okon, Evans et al. 2004), prescription of medications for end-of-life (Bailey, Burgio et al. 2005, Mirando, Davies et al. 2005) and bereavement levels for relatives (Veerbeek, van Zuylen et al. 2008). Whilst these do not provide irrefutable proof of ICPs effectiveness at the end-of-life, they nevertheless present themselves as promising.

The Integrated Care Pathway under study

The locality that the primary care based palliative care ICP is implemented in covers a predominantly semi-rural and rural geographical area in the North East of England. The business cases initially proposed in 2008 and 2009 for the ICP by the Locality Practice Based Commissioning Group were developed and delivered in line with the national strategies on ACP and end-of-life care (Department of Health 2008). This strategy encourages all health and social care services to acknowledge and value high quality care in the final years of life. It also emphasises a co-ordinated pathway approach. Key components in the palliative and end-of-life care journey should be: to identify individuals approaching end-of-life; to assess and agree how needs and preferences of patients can be met through use of ACP; well planned and coordinated care; provision of high quality services regardless of location; managing the last days of life; supporting

families and carers. The eleven point action plan developed by the locality was as follows:

1. Palliative care registers needed to be developed that were meaningful and resulted in actions.

2. Planning (ACP) needed to define patients' preferences.

3. Capacity to provide home care needs to increase.

4. 20% of deaths in the locality occur in care homes, the care is currently reactive but needs to be proactive ('care home' will be used as a collective term to refer to nursing homes, care homes and residential homes, from here on in this thesis. This is because the data used in analysis does not allow for differentiation between the different types of care homes).

5. Deaths in hospital are at around 47% which is suboptimal.

6. OOH services need to be integrated.

7. Ambulance services need to be integrated.

8. Standards should adhere to the GSF.

9. Data on performance was required which could be feedback to practices.

10. Education and training was needed for all health care professionals using the ICP.

11. A pathway must be created through commissioning to allow capacity & alternatives in providing palliative care.

In line with the End of Life Care Strategy (Department of Health 2008), the aim of the ICP business case (prompted by the eleven point plan) was to provide proactive and patient centred care. This was via an improved range of services which result in the early identification of those with terminal conditions, the opportunity to discuss and plan care, thus resulting in high-quality palliative and end-of-life care across all terminal conditions, regardless of diagnosis. Previously in the locality, palliative care had focused on people with cancer diagnoses and palliative care registers were poorly developed and not used in a purposeful way. This was due to a number of reasons: terminal cancer diseases are easier to identify, cancer trajectory has a more predictable course (than in non-cancer conditions), and cancer registers were available in some practices that allowed these patients to be closely monitored. The premise of the ICP developed was that patients with life limiting illnesses should be identified early and at a point in their illness when active treatment is no longer likely to extend their life, but while their need for medical, nursing and social care input is relatively low. These patients should then be placed on the practice palliative care register, which should trigger the offer of ACP. This ACP should result in shared decision making about preferences for the end-of-life, which can then be documented, thereby encouraging choice, implementing planning and making home, care home and palliative care unit deaths more viable. This ICP is thus an implementation of the three key concepts identified in the palliative care policies: proactivity, patient centeredness and shared decision making.

Once the ICP was designed a large multidisciplinary education event was held, at which the theory and practicalities of ACP in relation to end-of-life care were discussed. Feedback regarding the proposed ICP and documentation was collated and utilised to

refine the ICP, meaning that it was tailored to local needs and therefore there was a strong sense of ownership of the ICP from those who were going to implement it. The event was attended by sixty individuals representing members of primary health care teams, secondary care, voluntary sector organisations, patients and carers. The ACP document designed by the locality was passed to the Medical Protection Society for medico-legal comment. Further development of the ICP through feedback from the various stakeholders was also sought. The local urgent care services and local ambulance service were both informed about the ICP.

Initially, twelve primary care practices agreed to implement the ICP in April 2009. Two additional practices joined at a later date, thus the ICP involved a total of fourteen primary care practices. This meant that the population covered increased from 60,000 in 2009 to 78,000 in 2010. A Local Enhanced Service (LES) was developed to encourage GP practices to take part in the project. This LES rewarded practices for setting up the necessary systems, allocating more time to visiting patients in their own homes, for attending education sessions and for agreeing to return practice information and feedback questionnaires. Each GP practice was paid an initial sum of £750 to sign up to participate in the ICP. The ICP is still in place and still coordinated by a multidisciplinary steering group that has service user involvement.

The new ICP for those with life limiting illnesses requiring palliative care involved six newly commissioned services: advance palliative care registration, palliative care incentive scheme, 'Hospice at Home' care (from a local registered charity), three community palliative care beds in a local care home, two sessions of medical cover per week for these beds, support from a local charity to provide complementary therapies to those in the community palliative care beds. The three community palliative care beds

were commissioned as an alternative to hospital admission, to widen choice and to offer a pragmatic hospice, as all hospice provision prior to this was approximately eighteen miles away from the locality. A wide range of appropriate services is pivotal in maintaining patients' quality of life (Ellershaw and Ward 2003, Agar, Currow et al. 2008).

Unfortunately the two-year pilot was not fully funded to continue. The third sector organisations (Hospice at Home charitable organisation and complementary therapy local charity) and the three community palliative care beds at the local palliative care unit were not initially re-commissioned. However, public campaigning led to the re-commissioning of two of the palliative care beds with reduced funding for these beds; medical cover for these beds; the charitable organisation providing Hospice at Home support had its funding cut from pilot level but would remain above baseline for the following year. Advance palliative care registration and the palliative care incentive scheme were continued. This highlights how the ICP is not a static intervention; it evolved in response to local commissioning stimuli. The palliative care incentive scheme includes several interventions: preference discussions, ACP, OOH notifications, MDT meetings, the traffic light system of wellbeing (adapted by the ICP founder for the locality from the GSF), use of anticipatory medication, and use of the LCP. All of which are described in detail below. Additionally, Palliative Care Quality Visits (PCQVs) to GP practices were carried out by the founder of the ICP, to ensure ICP diffusion and implementation. Thus the ICP has multiple components and is implemented by many different people in different job roles and is inherently complex.

Advance palliative care registration

Palliative care registrations consist of a confidential list in each GP practice, which details the patients who require palliative care. A patient should be considered as requiring palliative care if they have a life limiting illness and active treatment is no longer likely to extend their life. Health care professionals from the locality assess this by using 'the surprise question', adapted from the GSF as part of their prognostic indictor (Department of Health 2008, The National Council for Palliative Care 2009, The National Gold Standards Framework Centre 2009, NHS North East 2012). The surprise question asks, "Would you be surprised if the patient were to die in next six months?" Use of the palliative care register has resulted in early identification (proactive care), planning and co-ordinated care nationally (Omega: the National Association of End of Life Care 2010). Ideally, advance palliative care registration should occur when the patient's need for medical, nursing and social care is still relatively low and whilst their symptoms are not severe. By strengthening practice palliative care registers, patients who require palliative care can be identified and health care professionals can plan with the patient in a more effective and efficient way for the future when their care needs increase. Palliative care registrations should trigger preference discussions and ACP.

Preference discussions and advance care planning

Preference discussions are carried out using shared decision making and elicit patients' preferences for care when they have been identified as requiring palliative care. As part of the palliative care incentive scheme, these preference discussions should be recorded formally. At the start of this PhD the advance care plan was one document that was

developed by the locality. Throughout data collection this has changed, according to the local Deciding Right (2012) documentation. ACP is now used as an umbrella term and refers to the process of documenting preferences which can include the use of four independent documents: the advance statement, the DNACPR form, the advance decision to refuse treatment (ADRT) and the emergency health care plan (EHCP) or Personal Welfare Lasting Power of Attorney (PW-LPA) including health (all described below). ACP is now centred on shared decision-making, with these documents as an outcome of a preference discussion between a patient and a health care professional. Regardless of the outcome of ACP (advance statement, DNACPR form, ADRT or EHCP) it should be a process of voluntary discussion and review to help an individual anticipate how their condition might affect them in the future and identify their preferences in different situations (NHS North East 2012). It is important to note that all of the outcomes from these documents are invalid whilst the person retains capacity for those decisions, and none of these documents can be used with individuals who do not have capacity according to the Mental Capacity Act (Justice 2007, NHS North East 2012). Furthermore, an automatic and rigid approach to ACP should be avoided; the patient should be willing to engage in ACP for it to be successful and to avoid distress.

- Advance statement

The advance statement is a document that is written by the patient to clarify and document their wishes, feelings, beliefs and values about their future care (Deciding Right, 2012). This document is not legally binding but will be taken into account by health care professionals and carers if the person is to lose capacity in the future.

- Do Not Attempt Cardiopulmonary Resuscitation form

The DNACPR form is a document that a person can have if they do not wish to have CPR. It is the most frequently used document in ACP and has the advantage of simplicity as it only addresses one decision. However, this also means that the document is inflexible in complex situations (NHS North East 2012). The form needs to be from the Deciding Right documentation to be accepted by the North East Ambulance Service and must be present in the person's home and valid (in date, signed and witnessed). CPR decisions should only be made for those whom they are appropriate for; those who have capacity for that decision where an arrest is anticipated and CPR could be successful.

- Advance Decision to Refuse Treatment

The ADRT is a legally binding document that states the refusal of a specific treatment regarding a person's future care if they should lose capacity to make this decision. To be legally binding it must be valid and applicable to the circumstances. Because of the time needed to evaluate the validity and applicability of an ADRT, they are not always supportive in acute emergencies that require immediate treatment, but must be adhered to when time allows (Deciding Right, 2012). The ADRT has now replaced the Living will.

- Emergency Healthcare Plan

The EHCP is a care plan covering the management of an anticipated emergency (Deciding Right, 2012).

- Personal Welfare Lasting Power of Attorney including health

A PW-LPA including health is also an outcome of ACP. A PW-LPA including health acts according to a patient's best interests, which is the bringing together of health or

social care professionals' and the individual's understanding and opinion of the proposed care. For those who do not have capacity the MCA (2007) provides information on how a best interest decision should be made. It can be used in life sustaining treatment decisions, but only supersedes the ADRT if it was appointed after the ADRT was made by the individual and if the conditions of the PW-LPA including health cover the same issues as stated in the ADRT (Deciding Right, 2012).

Home and hospice care

Three community palliative care beds were commissioned as part of the ICP in a local care home as an alternative to hospital admission, to widen choice and to offer hospice care in a palliative care unit, as the nearest hospice prior to this was approximately eighteen miles away from the locality. Two medical cover sessions per week for these beds were also commissioned with support from a local voluntary organisation to those in the community palliative care beds. Increased capacity to support home care was also commissioned from a Hospice at Home organisation. This charity includes a team of registered nurses and health support workers who fill gaps in care, provide respite sitters and night care. The ICP ensured the appointment of a lead nurse to assure that clinical governance issues were being identified and managed.

Out of Hours notifications

OOH notifications are alerts that are sent to the local GP OOH service to make them aware that a person is on the palliative care register.

Traffic light system

The traffic light system of wellness was created by the locality to encourage patient centred, appropriate and timely care, taking inspiration from the GSF needs based coding that consists of five colours. The locality traffic light system has only three colours: green, amber and red. A patient is considered within the green section of the system when they are thought of by health care professionals as being at a point where active treatment is no longer likely to extend their life, even if they appear to be relatively well and have few symptoms. The amber section of the system is for patients who have begun to deteriorate. The red section of the system is for the final days and hours of life. The traffic light system also acts as a prompt to health care professionals to ensure that additional measures such as facilitating access to financial benefits (green), providing anticipatory medication (amber) and initiation of the LCP (red) are implemented (when data was collected the LCP was nationally used, currently the patient or their family decide on the care the patient receives. See the section above on the LCP, p.43).

Multidisciplinary Team Meetings

A MDT within the ICP consists of professionals who work in the community and the GP practice. A MDT meeting will involve the discussion of palliative care patients identified using the palliative care register and manage complex problems associated with palliative care guided by the traffic light system of wellness. A palliative and end-of-life care MDT team meeting should occur regularly to discuss progress with patient care and treatment options. Most practices include this as part of their general clinical meeting.

Anticipatory care medication

This is medication that can be used to aid end-of-life symptom control; it is provided proactively prior to actual need so that these medicines can be administered to the patient if required without delay, especially at night, at weekends or over bank holiday periods. Anticipatory medication can be provided for patients who are currently being cared for at home, in a care home or in a community palliative care bed and can be administered subcutaneously by health care professionals for nausea, sickness, pain, respiratory secretions or agitation (Pellett 2009).

The Liverpool Care Pathway for the Dying Patient

In the UK, the LCP was created to transfer the high standard of hospice care to secondary care (Ellershaw, Foster et al. 1997). The LCP is a standardised method to monitor the care of a dying person, considering their physical, psychosocial and spiritual needs (Veerbeek, van Zuylen et al. 2008). As previously discussed, the LCP is now being phased out in the NHS as a result of the government's acceptance of an independent report (Neuberger, Aaronovitch et al. 2013). However, data collection for this study began in February 2012, thus preceding the publication of this report. Therefore this thesis will refer to the LCP and report outcomes related to it.

Palliative Care Quality Visits – Continuous Quality Improvement

PCQVs promote CQI and are carried out by the ICP's founder. These clinical governance visits consist of a visit to the GP practices' MDT meetings to feedback data, discuss the practice's performance, discuss how the practice staff would manage a

fictional palliative care patient from diagnosis to death, talk about difficult issues experienced when using the ICP and identify and provide potential solutions for common problems. Thirteen out of fourteen GP practices involved in the ICP have received a PCQV. Additionally it allows for insight into how each individual GP practice interprets, adapts to and uses the ICP.

The service delivered in the locality and evaluated in this study qualifies for the title of ICP in all domains but that of it being one document. The ICP facilitates the introduction of multidisciplinary guidelines into routine practice and is based on clinical experience from recently treated patients with the same condition (Kitchiner and Bundred 1996). Members of the health care team using the ICP may stray from it, but this must be justified clinically. This encourages adherence to the ICP and its supporting national guidelines therefore decreasing variations in the care that is provided (Kitchiner and Bundred 1996). The ICP has a founder who developed and facilitated the introduction, implementation, professional education and review of patients' progress. The founder also analysed variations from the ICP implementation modes in order to make appropriate revisions, ensuring it had flexibility to integrate best practice exemplars (Kitchiner and Bundred 1996). Furthermore, the ICP under study meets the criteria stated on the ICP key elements checklist, developed by Croucher (2005) and detailed above (p.41). The creation of this ICP also avoids the 'tick box' criticisms that some ICPs face, such as the LCP (Stocker and Close 2013).

This concludes the description of the ICP and its component parts. The next section focuses on the current literature surrounding ICPS in palliative care.

Evidence of Integrated Care Pathway effectiveness in palliative care

While end-of-life care is concerned with the last days and hours of life (Lunney, Lynn et al. 2003), palliative care focuses on "the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement" (Chan and Webster 2010, World Health Organisation 2014). Palliative care ICPs are less visible in the literature than end-of-life ICPs (such as the LCP), due to the unpredictable nature of palliative care and variability in diagnosis and prognosis. Several searches of the literature databases CINAHL (CINAHL 2013) and Web of Knowledge (Web of Knowledge 2013) were conducted to identify palliative care ICP evaluations. The core terms 'palliative care', 'service*', 'pathway*', 'integrated care pathway*', 'preferred place of care', 'home death*', 'communit*', and 'evaluat*' were entered either singularly or in combination. Titles and abstracts were screened for original research with adult palliative care patients in Western contexts evaluating an ICP, service or pathway implemented by primary care or a care home. The following discussion is based on these literature searches, snowballing searches of bibliographies and reference lists as well as RSS feeds of relevant journals.

Smith (2012) found that the palliative care needs of patients with advanced heart failure were not being adequately addressed in the locality through use of a baseline audit of services. The audit included the number of patients who had been referred to specialist palliative care services, had discussions around anticipatory care planning, had a documented preferred place of care and had a documented actual place of death. A MDT process mapping event highlighted issues with the current service provision and identified the aims and scopes for the project: the development of a palliative care

pathway for end-stage heart failure patients, collaboration between clinicians, managers, commissioners and patients to enable patient choice and access to palliative care services both in hospital and the community. A steering group was established including clinicians, managers, patient representatives, ambulance service representatives, local palliative care teams and the cardiac network. Secured funding allowed a palliative care clinical nurse specialist to work collaboratively on the service with the heart failure nurse specialist. Outcomes of this collaboration were joint visits to patients and an increased understanding of job roles. Several tools were created for the new service. The GSF (The National Gold Standards Framework Centre 2009) was used to develop a 'cause for concern' trigger tool that aided community heart failure nurses to identify patients with advanced diseases who may require palliative care. This is similar to the surprise question used in the ICP under study. The health care professionals in the study could then discuss these patients who they were concerned about at the newly established advanced heart failure multidisciplinary forum, with a view to improving patient care and reducing hospital admissions. A patient and carer assessment (PACA) tool was developed from the GSF (The National Gold Standards Framework Centre 2009) for use by community heart failure nurses to facilitate holistic assessment. This tool also contained referral criteria for specialist palliative care. An aide-mémoire was developed to trigger conversations with patients and assist symptom management or end-of-life care. Out of Hours (OOH), GP and Ambulance Service palliative care or end-of-life forms were used to highlight identified patients to the services. A regular collaborative cardiorespiratory and palliative care nurses meeting was established that included teaching sessions as a forum to improve communication and discuss complex cases. A red folder containing relevant information for all of the services involved in the patient's care (when being cared for in the community) was left in each patient's home.

Finally, the heart failure nurse specialist assumed the role of key worker, liaising with other health care professionals involved in the patient's care.

The introduction of these tools into clinical practice was expected to improve coordination between acute and community clinicians and palliative care nurses. A second audit (of the same criteria as the first) executed eighteen months post implementation identified: improved access to palliative care for advanced heart failure patients; improved choices at the end-of-life (more patients dying in their preferred place of care); provision of holistic heart failure service spanning referral to palliative care and then end-of-life. The main difficulties highlighted within this study were the challenge of working collaboratively across services and job roles, and ensuring patients' wishes were communicated to all relevant health care professionals. However, this study highlights that improvements in communication and multidisciplinary collaboration have resulted in better access to palliative care services for patients and more choice with an increased number of patients dying in their preferred place of care. Although the study identifies positive outcomes, it does not explain why they might have occurred. The aim of the intervention was to increase coordination between services, but this is highlighted as one of the challenges, thus this may not be the explanation for the outcomes observed. The resources used in this ICP need to be identified in order to understand why the health care professionals involved changed their behaviour, resulting in the outcome of improved access to palliative care services and increased home deaths.

Reymond, Israel et al. (2011) implemented the residential aged care end-of-life care pathway (RAC EoLCP). This care pathway involved the promotion of: ACP, proactive care, multidisciplinary management of residents (patients) and their family members,

death in current residence (care home), optimal symptom management and increased competence in managing palliative care cases. Those working in the care home were also given palliative care training to enhance their care capacity. The implementation of the RAC EoLCP resulted in 98.3% of residents dying in their place of choice (the care home) and significantly less hospital admissions in comparison to those not on the RAC EoLCP. Staff perceived an improvement in their satisfaction with, and quality of, palliative and end-of-life care provided by the care home after the introduction of the RAC EoLCP. One staff member reported that, "before (RAC EoLCP implementation) staff had little training in palliative care and sometimes were very scared of caring for the dying" (Reymond, Israel et al. 2011). Bereaved relatives evaluations of palliative and end-of-life care did not increase from the pre-implementation to post-implementation phase; satisfaction remained consistently high. Thus, Reymond, Israel et al. (2011) highlight that training leads to increased use of ACP and LCP, however they do not explicitly identify the tools (although it could be assumed to be ACP and LCP) or thought processes of individuals implementing the new service. Furthermore, they do not refer to the context of this intervention. The same positive outcomes may not have been achieved if this were an intervention outside of a care home or if the recipients of the training had not seen the relative advantage of the new service. However, outcomes of this study indicate that palliative care ICPs that have a focus on ACP and multidisciplinary working can facilitate death in the patients' current place of residence.

A three year non-blinded randomised controlled trial took place to compare the effects of early palliative care integrated with a standard oncology care service in comparison to standard oncology care alone, for newly diagnosed metastatic non-small cell lung

cancer patients (Temel, Greer et al. 2010). Patients assigned to the early palliative care integrated with standard oncology care service met with a member of the palliative care team within three weeks of enrolment and at least monthly thereafter in an outpatient setting till death. Additional visits were scheduled at the discretion of the patient. Meetings focused on the assessment of physical and psychological symptoms, founding goals of care, helping with individual decision making regarding treatment and coordinating care. Patients in the palliative care integrated group had a higher quality of life in comparison to the control group (standard oncology care), as measured by the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale. Of the patients who died, those in the standard oncology care group had more aggressive treatment. Despite receiving less aggressive treatment palliative care group patients survived longer. Finally, more patients in the palliative care group had resuscitation preferences documented. Again, this palliative care ICP documents positive outcomes for those in the intervention group. However, the study does not identify what factors explain the choice of patients in the intervention group to have less aggressive treatment.

Bakitas, Lyons et al. (2009) conducted a RCT for nearly 5 years with patients who had advanced cancer. It is rare to find an RCT in this domain that is so long term; this is an asset to the study. Patients were randomly allocated to receive either standard care (n=161) or a multicomponent, psycho-educational intervention: Project ENABLE (Educate, Nurture, Advise, Before Life Ends) (n=161), implemented by advanced practice nurses. The intervention consisted of four weekly educational sessions and monthly follow-up sessions until death, which encouraged patient activation, self-management, and empowerment. Patients who received the intervention had higher scores for quality of life and mood than those receiving usual care. However, they did

not have improvements in symptom intensity scores or reduced days in hospital visits. No details are provided as to why intervention group patients' quality of life or mood improved apart from that they had educational sessions. The content of these sessions is described but no description of what elevated mood or quality of life specifically is provided.

Implementation of the Gold Standards Framework to enhance palliative care services

Many studies describe implementation of the GSF; a systematic, evidence-based approach to aid health care professionals in identifying patients in the final years of life, assessing their needs, symptoms and preferences and planning care on that basis and empowering patients to live and die where they choose (The National Gold Standards Framework Centre 2009). It supports care pathways that are patient and carer centred (Thomas 2003, Pellett 2009). Hockley, Watson et al. (2010) implemented the Gold Standards Framework for Care Homes (GSFCH) and the LCP over eighteen months. Significant in-house training was provided for staff with GSFCH facilitators visiting the care homes every ten to fourteen days. Residents' (n=228) notes were reviewed and qualitative interviews with bereaved relatives were conducted pre and post implementation of the pathway (GSFCH and LCP). Use of DNACPR forms, ACP and LCP (which are all also used in the ICP under study) increased significantly and hospital deaths were reduced from 15% pre ICP implementation to 8% post implementation. Therefore, it can be concluded that the GSFCH was successful in improving outcomes for care home residents with palliative care needs who died. However, similar to all of the studies described, this study does not explain why these

outcomes occurred; it only provides the outcomes and tools used, and an assumption of causality between the two. Hall, Goddard et al. (2011) also implemented the GSFCH. Nine care homes were involved and semi-structured interviews were conducted with all care home managers, eight nurses, nine care assistants, eleven residents and seven family members. Perceived benefits of the GSFCH were improved symptom control, team communication, staff confidence and adhering to patients' preferences. However, there were some perceived barriers to the GSFCH as well. These included lack of understanding about end-of-life care and an increase in paperwork (Hall, Goddard et al. 2011). Several of the tools in the GSFCH focus on improving communication in palliative care (The National Gold Standards Framework Centre 2009). Hall, Goddard et al. (2011) found that the GSFCH improved communication within homes and with external providers including GPs and specialists in palliative care. Tools created to improve communication were similar to those used in the ICP under study and included palliative care registers, coding predicted stages of illness and ACP. These tools were perceived as beneficial in the study however some participants felt they required more experience of using these. There were also concerns about discussing death and dying (Hall, Goddard et al. 2011). Hall, Goddard et al. (2011) suggest that the use of the GSFCH tools have improved communication, but they do not explicitly state how this increase might have occurred – stronger team cohesion or improved multidisciplinary collaboration, for example. Furthermore, they highlight barriers to implementing the GSFCH but do not state explicitly if or how these barriers have affected the implementation or outcomes.

Bower, Roderick et al. (2010) evaluated the use of the GSF in two GP practices, one rural and one urban, with the aim of improving integrated team working to facilitate

death in the patients' place of choice. Despite the use of the GSF increasing health care professionals' workload, through early identification of patients, they were able to work with patients prior to a crisis in the last few weeks of life. Additionally, community nurses, practice nurses and GPs all felt empowered to identify patients with any illness requiring palliative care who may have been in their last year of life, despite a previous focus on cancer patients. Increased and structured MDT meetings allowed patients to be monitored and individualised care plans to be altered to meet care needs. A lead GP was allocated to each patient to ensure continuity of care. Recent deaths were reflected on in MDT meetings to facilitate practical learning. Once identified at the MDT meeting, relevant information about palliative care patients (medication, next of kin, current input, potential risks) was faxed to OOH services in order to create an advanced service. The patient's notes (at home) provided information for all health care professionals to use and provided information for patients and their relatives about who to contact (GP or nurse) during the day and at night; this relieved feelings of anxiety that can occur due to isolation from services out of normal working hours. Health care professionals worked closely with patients to assess the need and timely implementation of anticipatory medication (a tool used in the ICP under study). An audit of twenty-one patients who died with community nurse involvement indicated that high quality MDT working with the GSF is effective in supporting patients to die in their place of choice (90% of patients died in their place of choice). However, limitations of the intervention were reported by health care professionals who stated that completing notes in the patient's home and then duplicating these notes electronically at the practice was time consuming. There were also already strong working links between GPs and nurses; specialist palliative care expertise in the community nursing team; and an 'open to change' ethos in both practices. This questions whether the same service would work as

effectively in a practice where the context was not as favourable; changes in practice may have taken longer to implement and have been faced with more barriers. It must also be noted that this study had a small sample size (n = 21); larger scale implementation may have created issues. However, small-scale findings indicate that implementation of palliative care tools promoted by the GSF result in improved outcomes.

What is known so far?

Some overlaps can be seen between the palliative care ICP under study and those in the literature. They all aim to increase patient centeredness and have a focus on providing proactive care. Some use shared decision making in the form of ACP or educational sessions that promote decision making about the patient's care. Decision aids and cause for concern trigger tools have similar properties to the surprise question and the traffic light system in the ICP under study. The GSF studies use many similar tools to the ICP under study including palliative care registers, the traffic light system, ACP and the LCP. Many of the studies have working collaboratively or enhanced communication as an aim in the implicit expectation that this will allow patients better access to palliative care services. MDT working was perceived to integrate team work and enhance patient centred care. However, it is highlighted that working collaboratively can be a challenge. Confidence was highlighted as important in providing high quality palliative care and the perceived ability to provide palliative care may be important in ICPs. Health care professionals may also need to feel empowered in order to identify palliative care patients regardless of diagnosis (cancer or non-cancer). Many of the ICPs and GSF studies aimed to reduce hospital deaths and increase home deaths which they did

successfully. Again, this highlights how health care professionals in these studies are operating within a patient centred framework. However, barriers to using palliative care ICPs were also identified in the literature including understanding about palliative and end-of-life care, increases in paper work and time constraints, and difficulties discussing death and dying.

It is acknowledged that the ICP under study is not always congruent with the ICPs reviewed in the literature. For example, the ICP under study does not use regular meetings with palliative care experts or educational sessions with patients, as Temel, Greer et al. (2010) and Bakitas, Lyons et al. (2009) did. However, consultations can be seen as meetings with experts (health care professionals) and thus some learning can still be taken from these studies.

However, in all of the studies reviewed the causality between the introduction of practice tools and improved outcomes is at present assumed rather than understood in depth. Studies evaluating palliative care ICPs state that an intervention that promotes early identification of patients in need of palliative care and the use of ACP, collaborative working and specialist palliative care services have positive effects in terms of quality of life, place of death and resuscitation orders. However, although the palliative care intervention studies described have shown improvements in care, they report these favourable outcomes but do not identify why they occur. All of the interventions described have one thing in common: they involve multiple tools and professionals. It is therefore very difficult, within the research designs employed, to decipher any detail on the causality chains which might have led to favourable outcomes. Furthermore, the studies discussed pay no attention to context such as location, population, disease type, socioeconomic factors, or understanding of palliative

care. The interventions all show promising outcomes, but none go in to much depth to explain which components of the inherently complex and multifactorial interventions might have worked best for whom, and in what circumstances.

The studies reported leave a clear gap in knowledge: what actually works, for whom and in what circumstances? Thus, this thesis will investigate whether a palliative care ICP using care planning principles for those with life limiting illnesses leads to positive outcomes, how, for whom and in what circumstances.

Currently, there is no specific way to provide palliative or end-of-life care in the UK. Studies focusing on palliative care interventions are limited and difficult to identify in the literature and thus an evaluation providing information on context, underlying mechanisms and related outcomes is warranted. This is important not only to policy makers and health care professionals in order to deliver a high standard of care, but also to patients, who wish to die in their current place of residency.

ICPs in palliative care provide promising results in terms of translating policy into practice. They indicate that they increase proactive care, patient centeredness and shared decision making which results in a good death that is often in the patient's place of choice. However, the complexity of these multicomponent interventions means that it is not clear which tool worked best for whom (for example, professionals, patients, primary or secondary care, care homes) and in what circumstances (type of illness, timing of patient identification as terminal prior to death). Furthermore, the assumptions made in most of these studies between intervention strategies and outcomes pose a significant challenge to implementation in other contexts.

Chapter Summary

The ICP has been developed in line with national and local policy that identifies palliative and end-of-life care as a local regional and national priority and continues to develop (Department of Health 2008, The National Council for Palliative Care 2009, The National Gold Standards Framework Centre 2009, NHS North East 2012). It aims to translate national policy and guidelines about proactive care, patient centred care and shared decision making into practice.

The facets of the ICP have been described and issues with funding and changes in commissioning have been discussed. The changes made in the re-commissioning of services has resulted in the ICP functioning differently now in comparison to when it was initially implemented. However, use of the core tools (palliative care registration, ACP, anticipatory medication use) that are based on proactive care, patient centred care and shared decision making have remained unchanged despite this, as recommended by regional and national policy. Publication of regional policy, Deciding Right (NHS North East 2012), has the same underlying principles as the ICP and therefore it should be an enforcing factor to the proper use of the interventions of the ICP, including ACP. However, undoubtedly, these changes will all have had an effect on the ICP, the way it functions, those who implement it and those who are in receipt of care. Yet, development of an ICP is a dynamic process, which is likely to be affected by change which can come from local or national policy, or due to economic factors, especially in the current economic climate which is resulting in significant changes to the NHS.

The introduction of Deciding Right (NHS North East 2012) has meant that some of the documentation used in the ICP has changed (the advance care plan form has become the advance statement, with ACP now acknowledged as an umbrella term for a process

which results in several formal outcomes of preference discussions in the form of documents). Workshops have been run in the locality to further explain and implement Deciding Right (NHS North East 2012) which has the same underlying principles as the ICP.

Individual case studies from the pilot before limited re-commissioning have shown that the ICP improved patient experience, avoided hospital admissions in individual cases, informed the OOH GPs' decision making, and facilitated patients' wishes around end-of-life care decisions (Locality North East Clinical Commissioning Group 2012). However, the ICP required more formal evaluation, investigating if the ICP worked, how it worked and in what circumstances.

The complexity highlighted in this chapter means that the ICP does not lend itself easily to a quasi-experimental design, and indeed, the literature has demonstrated the limitations of such designs to evaluate multifactorial ICPs. The next chapter will explain the methodology used to evaluate such a complex ICP, realist evaluation. The principles of realism, realist evaluation and realist inquiry will be explored alongside the data collection tools. The research question will be formulated which will aid in the design of the programme theories that will be tested in order to guide the evaluation.

Chapter 3: Methodology

This chapter will begin with an exploration of realism that will address questions of ontology, epistemology and methodology. An introduction to realist evaluation will then be provided with the realist logic of inquiry explained, to help understand how the ICP will be evaluated in terms of Context, Mechanism and Outcome Configurations (CMOCs). The research question will be stated which prompted the development of programme theories to be tested through data collection. Following this, a data collection and analysis framework will be presented which has been developed specifically to meet the needs of this research, using both quantitative and qualitative data tools.

Policy, such as the End of Life Care Strategy (Department of Health 2008) is delivered through active social programmes, such as the ICP, to active subjects (health care professionals and patients) and this has major implications for research methodology. In clinical trials human volition is regarded as a contaminator and the aim is to minimise its impact, hence the use of placebos, blinding and randomisation. However, social programmes work through the reasoning of subjects and knowledge of that reasoning is integral to understanding a programme's outcomes. Since the ICP is such a complex system that includes many people providing and receiving services, it must be investigated using a methodology that embraces human volition, as well as this complexity, rather than minimises it.

Realism

Realism is not a research method but a methodological orientation; an approach to constructing and selecting research methods (Pawson, Greenhalgh et al. 2005). It is a logic of investigation that is grounded in the philosophy of science and social science (Bhaskar 1978, Harre 1978, Bhaskar 1979, Putnam and Conant 1990, Collier 1994). In these writings, realism is considered as the principal post-positivist perspective and provides an explanation of phenomena that sits between empiricist and constructivist accounts of scientific explanation (Pawson 2006). Realism regards social change as transformational as opposed to linear, it values both qualitative and quantitative research methods and is not nomothetic or idiographic (Sayer 1992, Archer 1995, Sayer 2000). Realism is a methodological orientation due to its understanding of causation, the constitution of the social world, and the stratification of social reality (Pawson 2006), all of which are questions of ontology, epistemology and methodology and are developed further below.

There are two streams of realism in social science: critical realism (Archer, Bhaskar et al. 1998, Bhaskar 2002) and empirical realism (Pawson 1989, Hedstom and Swedberg 1998, Williams 2000, Carter and New 2004), also known as scientific realism, emergent realism, analytic realism, 'realism pane e burro' and middle-range realism (Pawson 2006), although no consistent nomenclature has been assigned to this school of thought. It shall be referred to as empirical realism for the purpose of this thesis. The schism between critical realism and empirical realism is due to the open systems nature of social explanation. Critical realism assumes that there will always be an excess of explanatory possibilities, some of which will be mistaken (Pawson 2006). It is therefore the primary task of the critical realist to be critical of the lay thought and actions that lie

behind false explanations (Bhaskar 2002). Empirical realism assumes that a researcher should still aim to decide between alternative explanations, despite the knowledge that further explanatory potentials remain without investigation in the open systems in which people live (Pawson 2006). Furthermore, empirical realism suggests that classic apparatus, including clear hypothesis making, critical comparisons and empirical patterns, are of use in research underpinned by realism. Empirical realism is embraced by realistic evaluation, the methodology used in this study.

Questions of ontology, epistemology and methodology in realism

Ontology questions the form and nature of reality and therefore what can be known about it (Guba and Lincoln 1994). Realism suggests that there is a real world within which people interact and that individuals construct meaning in this world. Whilst theories, concepts and perspectives may generate a valid understanding of a phenomena, they cannot and do not exhaust it, as all knowledge is contextual and partial; other conceptual schemas and perspectives are always possible and theories, concepts and findings are grounded in values and perspectives (Altheide and Johnson 2011). For example, whilst death is an inescapable reality, its meaning is mediated by individuals' understanding and experiences of it. Two separate individuals who experience the death of a grandparent may have differing reactions due to context, resources and reasoning. Additionally the way in which an individual reacts to their grandmother's death may be very different to the way they react to a sibling's death. Therefore a theory on relatives' experiences of a loved one's death will generate understanding of this topic, but is not definitive as all knowledge is contextual and partial. The current literature focusing on palliative care ICP evaluations generates understanding but does not acknowledge that it

is contextual, or that the findings are grounded in values and perspectives. For example, Smith (2012) states that a holistic heart failure service increases choice for palliative care patients. However, this does not mean that the same holistic heart failure service implemented in another locality would achieve the same outcomes. The findings may be different due to the differing values and perspectives of those implementing and receiving the service.

From a societal or organisational perspective, death is a process that needs to be managed and the ICP, a complex system in itself, is one way of implementing this management. Realism suggests that regularities in the ICP are attributable to the underlying mechanism that is constituted by people's reasoning and the resources they have in a specific context (Pawson and Tilley 1997). Realists state that the embeddedness of all human action within a wider range of social processes is the stratified nature of social reality (Pawson and Tilley 1997). Even the most repetitive and commonplace actions are only understandable because they contain innate assumptions about a wider set of rules and institutions (Pawson and Tilley 1997). For example, the act of visiting a GP is routinely accepted as what most people would do if they felt unwell for a significant period of time. However, this is only because it is known that visiting the GP is part of a wider institution (the NHS) within which Hippocratic rules dictate that efforts are deployed to manage patients' illnesses. The causal power between visiting the GP and managing the illness does not reside in the GP themselves or the drugs they prescribe but in the organisational structures which they form. One action leads to another due to their accepted place in the whole (Pawson and Tilley 1997); the patient makes an appointment with the GP, the GP prescribes medication if appropriate, the pharmacist dispenses the drug and the patient adheres to the drug

regime. Therefore human action and understanding is not linear and is understood in terms of its location within different layers of social reality. This explains why realists shun the secessionist view of causation (Pawson and Tilley 1997).

Epistemology considers the nature of the relationship between the knower or the would-be knower and what can be known (Guba and Lincoln 1994). The answer to the epistemological question is always constrained by the answer to the ontological question. What can be known about any social programme is not definitive. For example, the heart failure service described by Smith (2012) may not achieve the same results in a different locality and is thus not a definitive finding. This is due to the complexity of social reality meaning that people have different understanding, values and meanings and thus a social programme is never exactly replicated. However a decision can be made between opposing explanatory theories (the heart failure service may have worked due to improved communication between the clinical team, as Smith (2012) suggest, however they do not unpack explicitly how improved communication has led to the outcomes achieved). Realist evaluation begins with a theory of causal explanation known as a CMOC, which is based on the idea of the generative mechanism exposed further here (Pawson and Tilley 1997). The researcher searches for causal powers within objects or agents or structures under investigation and expresses them in terms of CMOC (Pawson 2006). It requires complex and systematic understanding of causal powers which takes into account the underlying constructs that connect two events, and the context in which that relationship occurs (Pawson 2006). Generative mechanisms explain the causal link between social programmes and outcomes. Using Smith (2012) as an example again, if improved communication between the team has led to more home deaths, the generative mechanism explains why this is, in relation to

resources and reasoning. Thus it could be hypothesised that the mechanism could be the key worker identified for each patient (resource), who liaises with all other health care professionals involved in the patient's care to improve communication (reasoning), which has led to more home deaths (outcome) in the context of improved access to palliative care services. In another hypothetical example grounded in primary care, the mechanism could be information provided by a GP in a consultation (resource), which set in the context of a long standing and trusting GP-patient relationship, results in a reasoning of trusting the information provided, absorbing it and leads to an outcome of acting on it. However, there are often cases that go against the trend, which realism embraces, and our understanding of the causal link (content of consultations) may survive even in the face of irregularities; patients may have researched their condition using the internet as opposed to receiving the information in the consultation or the GP and patient may not have the aforementioned long standing and trusting relationship. Put simply, what causes something to happen has nothing to do with the number of times it is observed happening (Sayer 2000). Therefore gathering data on regularities is misguided, however these may suggest where to look for causal mechanisms (Sayer 2000), one of the integral concepts in realist evaluation.

Individuals may be aware of patterns of regularities into which their lives are shaped, the choices that channel their activities and the wider social forces that limit their opportunities (Pawson and Tilley 1997). This can result in individuals wishing to change the pattern. This change may or may not happen as the individual may or may not have the resources to do so, or their efforts may be overcome by an opposing group who have more resources. Furthermore, individuals have incomplete knowledge of the contextual conditions in which they reside and these contextual conditions may limit

their actions, and the proposed change mechanism itself may have unanticipated consequences (Pawson and Tilley 1997). For example, recently medication availability has been affected by locality in the UK. Patients may wish to have a course of medication but cannot due to this contextual factor. Social programmes or interventions are an attempt to change the current regularity in a domain through generative mechanisms.

Methodology considers how the would-be knower can go about finding whatever he or she thinks can be known (Guba and Lincoln 1994). This question is constrained by the answer given to the first two questions. Realist evaluation (Pawson and Tilley 1997) has been created for researchers to investigate the world from a realist perspective and focuses on the development and refinement of CMOCs. Realism and realist evaluation have further explanatory potential in relation to death and dying and palliative care ICPs. They can offer an understanding that is grounded in the locality but provides more macro knowledge about death and dying and palliative care ICPs. It opens up the 'black box' and links outcomes to explanations that are mindful of contextual factors and the individuals who implement and receive social programmes. Previously the management of death has been considered in a very causal way; improved communication will lead to more home deaths (Smith 2012). Realist evaluation allows for a deeper understanding that embraces human volition and the complex social systems in which people reside. Realist evaluation of this palliative care ICP will therefore provide novel insights.

Theoretical framework: realist evaluation

The conceptual approach in this study is realist evaluation (Dalkin, Jones et al. 2012) (Appendix 2), as it enables in-depth analysis of interventions through the means of

realist programme theories, embracing both qualitative and quantitative research (Pawson, 2013). Programme theories have been developed and iteratively refined for each section of analysis. Analysis will highlight what Contexts (C) need to be present so that the relevant mechanisms (M) are likely to be triggered to cause observed outcomes (O). The purpose of this is to generate understanding of how resources provided by the ICP interact with contexts to trigger the necessary mechanisms to produce positive outcomes. Social programmes, realist logic, and CMOCs are explained in detail below.

Social Programmes

To understand realist evaluation, an understanding of social programmes or interventions must be developed. Social programmes are active, they do not operate in laboratories, they are affected by contexts which are changeable and thus although two social programmes may have the same name, they will never behave in exactly the same way. The ICP can and will thus be considered as social programmes in this thesis.

'Realistic Evaluation' (Pawson and Tilley 1997) is the main text for realist evaluation. The subject matter of a realist evaluator is a social programme (intervention), otherwise understood as social systems. They consist of the complex interactions between individuals and institutions and of micro and macro social processes (Pawson and Tilley 1997). A realist approach states that social programmes are theories incarnate; this is plural as one social programme is likely to have several theories. Social programmes are delivered under the hypothesis that if the programme is delivered in a certain way it will improve outcomes (Pawson 2006). This means that whenever a social programme is implemented, it has an underlying theory about what might cause change, which is being tested. However, this theory is not always explicit. It is the role of the realist

evaluator to make these theories explicit, and ensure that the right questions are asked of the data. For example, the underlying theory in ACP may be that planning for a good death results in more patients dying in their location of choice.

Interventions are implemented into existing social systems that are believed to account for a particular problem, such as difficulty talking about death or issues identifying palliative care patients. The fresh input the social programme gives to the system is expected to improve patterns of behaviour, events or conditions via changing and rebalancing the system (Pawson 2006). The underlying theories of the ICP are discussed later in this chapter (Research questions section, p.88). In order to describe a social system or programme, realists use three predominant concepts: context, mechanism and outcome. These three concepts produce a generative mechanism to explain causality.

- **Context**

In realist evaluation, mechanisms work in partnership with context to lead to outcomes in a causal way (Pawson 2006). In other words, the relationship between causal mechanisms and their effects (outcomes) is not fixed, but contingent on context (Sayer 1984). Thus realist approaches make explicit use of broader insights in order to explain the impacts of interventions in context, as will be done in the analysis in this thesis. All social programmes/interventions are introduced into pre-existing social contexts, therefore there is sometimes a struggle for them to prevail in these contextual conditions, hence, they are contingent. It is impossible to establish a straightforward relationship between intervention and outcome without identifying pre-existing contexts. Each social programme implemented has a great number of different contextual constraints and facilitators and the interrelationships, institutions and

structures in which it is embedded all affect its success (Pawson 2006). Context refers to not just the physical, but to the culture and drivers (professional cultures, power dynamics within GP practices, cost effectiveness, disease specific clinical reasoning), institutional features (patient list sizes in GP practices, shared nursing teams, staffing levels in care homes) and ethical issues (equality of care, capacity to make a decision).

Context works by constraining the choices of stakeholders in a social programme. Stakeholders in the ICP can be programme leaders, programme policy makers, clinical staff, social care staff, voluntary organisations, palliative care patients and bereaved relatives. The subjects of a social programme are always faced with a choice about whether to participate (Pawson 2006). Subjects have different pre-developed or pre-given characteristics that leave some well prepared and some badly prepared for the programme theory, resulting in varying success for individuals, whether this is those implementing the social programme or those receiving it. They also have different pre-existing relationships, which means that some are well placed and some are ill placed to use the opportunities provided by the social programme (Pawson 2006). For example, the ICP has a focus on being patient centred. However, the policy context encouraging proactivity and patient centredness may compete with pre-existing systems. Alternatively, from the patients' point of view, a patient who is less familiar with their GP may be less likely to engage with the ICP (through, for example, ACP), than a patient who has built a relationship with their GP over their life-time. Additionally, on a more macro level, some GP practices may have more flexible systems that make explicit allowances for patient involvement. On an even higher level, societal taboos about death and dying can be a prominent context, meaning that death is often not discussed and is shrouded in mystery. Currently there is an effort to change this taboo

through the National End of Life Care Strategy (Department of Health 2008) and documentation such as Deciding Right (NHS North East 2012). Although these documents are tailored for, and aimed at, health care professionals, they encourage early discussions about death and dying with patients. This social change in the way GPs regard and discuss death and dying is a social change that will have effects on any social programme in palliative and end-of-life care. Despite this, it could be that some GPs and patients may be reluctant to talk about death and dying due to this societal taboo. This would make the resources of the social programme, such as ACP, very difficult to use. The context thus has clear implications for the successes and failures resulting from a social programme.

It is not expected that massive contextual change will occur during a programme or as a result of a programme; a social programme does not aspire to cause the downfall of existing cultural and social order (Pawson and Tilley 1997). However, an accommodating context is crucial for implementation of a successful social programme that aims to change behaviour. If a context is inhospitable, the programme mechanisms are unlikely to be activated and therefore will not combat or neutralise the original problem mechanisms that were sustaining the bad outcome pattern. A physical analogy of this could refer to gunpowder; a spark causes an explosion. However, there will be no explosion if the conditions are not right – damp, insufficient gunpowder, inadequately compact, no oxygen present, or no heat applied (Pawson and Tilley 1997). Thus in research it is necessary to identify the social and cultural conditions necessary for change mechanisms to operate.

- **Mechanism**

The explanatory mechanism is the most characteristic tool of realist evaluation and is often referred to as underlying mechanism or generative mechanism (Pawson and Tilley 1997, Pawson 2006). The term 'mechanism' relates to causation. Processes that produce events, or patterns of events, can be seen as causal mechanisms. Mechanisms explain causal relations by describing the powers built in to a system, including the reasoning of stakeholders (such as health care professionals, patients, carers or bereaved relatives), and resources of the social programme (such as ACP, palliative care registration, peer support from MDT meetings) (Pawson 2006). Yet in all cases, it is something about context and a combination of resource and reasoning which form a mechanism with explanatory potential for the observed outcome. Therefore the mechanism explains what it is about the system that makes things change (Pawson 2006). Mechanisms can often not be directly observed, and the evaluator must hypothesise which mechanism is likely to have 'fired' and then test this theory with data. For example, if it is thought that the number of patients who have anticipatory medication is higher (outcome) in practices (context) where the ICP is more embedded and adopted as routine practice (mechanism), then the degree of how embedded the ICP is must be investigated by the evaluator, despite embeddedness not being an explicitly measurable factor. The evaluator can also investigate whether there are any other practices where the ICP is not as embedded. Scientific knowledge begins to accumulate when the same mechanism is commonly attributed to the same outcome or the absence of a mechanism is linked to the lack of an observable outcome. For example, if more regular use of anticipatory medication (outcome) is commonly attributed to practices where the ICP is more embedded (mechanism), then scientific knowledge starts to build that purports that there is a relationship between anticipatory medication and how embedded the ICP is.

It is also important to note that social programmes offer resources, however it is the reasoning of the subjects in combination with the resources provided by the social programme that result in outcomes (Pawson and Tilley 1997, Pawson 2006). Social programmes only work if the people involved choose to make them work by adhering to the programme theory (reasoning) and using the resources as intended (Pawson 2006). The acknowledgement of reasoning is one of the key strengths of using realist evaluation (together with the importance of context), as most other evaluations assume a relation of straightforward causality between the resources introduced by an intervention and the outcomes observed. However, as with most practice development efforts, interpersonal relationships between health care professionals and patients embody the intervention. They are the resource that is intended to bring about change (Entwistle and Cribb 2013). Thus, in order to help understand the mechanisms of the ICP in detail they will be unpacked in terms of reasoning and resources throughout the thesis. This is represented in Figure 1 below, as well as throughout the findings. Taking the example about how embedded the ICP is, we can now ask what are the resources and reasoning of this mechanism? Resources could be informed practitioners who have access to anticipatory medication. The reasoning is the decision to provide the anticipatory medication in advance of a decline in health requiring the medication, and the outcome would be an increase in the use of anticipatory medication.

- **Outcome**

In realist evaluation outcomes are not a sufficient base for establishing causality, yet they are important in science (Pawson 2006). In social science, strict regularities are not always viable, as they are in engineering or chemistry where total control of variables is

the objective. Therefore, evidence based policy would aim to choose an intervention that has a high chance of repeating the positive outcomes achieved elsewhere. To do this, outcome patterns must be sought rather than outcome regularities. Significant outcome patterns are embedded and dependent on the introduction of not only suitable ideas and interventions (mechanisms) but also the appropriate existing social and cultural conditions (contexts). In metaphoric terms, causality is thus attributed to the right substance being activated in the right conditions (Pawson and Tilley 1997).

How is a social programme evaluated?

Social programmes provide resources (such as ACP, the traffic light system of wellness, the new palliative care unit), which activate people's reasoning (M). However, the activation of the mechanism is dependent on the characteristics and circumstances of subjects, situations and societies (C), resulting in a varied pattern of impact (O) (Pawson 2006), as detailed in Figure 1. These three concepts are the crucial sources of evidence in realist evaluation. Realist evaluation does not ask if a social programme works, instead it focuses on the fundamental question, "what works for whom, in what contexts, in what respects and how"? Thus, in order to evaluate social programmes, the theories within a programme must be made explicit, by developing clear hypotheses about how, and for whom, programmes might work. This is done by identifying context (C), mechanism (M) and outcome (O) configurations (CMOC) because causal outcomes following from mechanisms acting in contexts is the base upon which all realist explanation builds (Pawson and Tilley 1997). A CMOC, as depicted in Figure 1, is a suggestion that states what it is about a social programme which might work, for whom, in what circumstances. A programme theory or initial CMOC is the starting point for

evaluation, and refinement of this CMOC through data analysis leads to the concluding finding of an evaluation (Pawson and Tilley 1997). This is an iterative process. In order to construct and refine CMOCs, evaluators need to engage with policy makers, practitioners and participants (Pawson and Tilley 1997). This is especially important when refining CMOC. Since data collection needs to provide evidence for CMOCs and engage with several different forms of participants, it must be wide reaching and varied in content and pitch. It will not only concentrate on impacts but also on the process of implementation, context and underlying mechanisms that may lead to changes. This is why integration of the researcher into the locality was so important in this project. Knowledge of the locality and different GP practices involved with the ICP was essential in understanding and refining the initial programme theories.

Although the findings from this study will be specific to the locality, they will have translational potential. They will offer explanatory potential to the broadest of palliative and end-of-life care scenarios, thus enhancing transferability. The study findings will enhance understanding of the crucial mechanisms within palliative and end-of-life care and how resources put into specific contexts lead to specific outcomes, both intended and unintended.
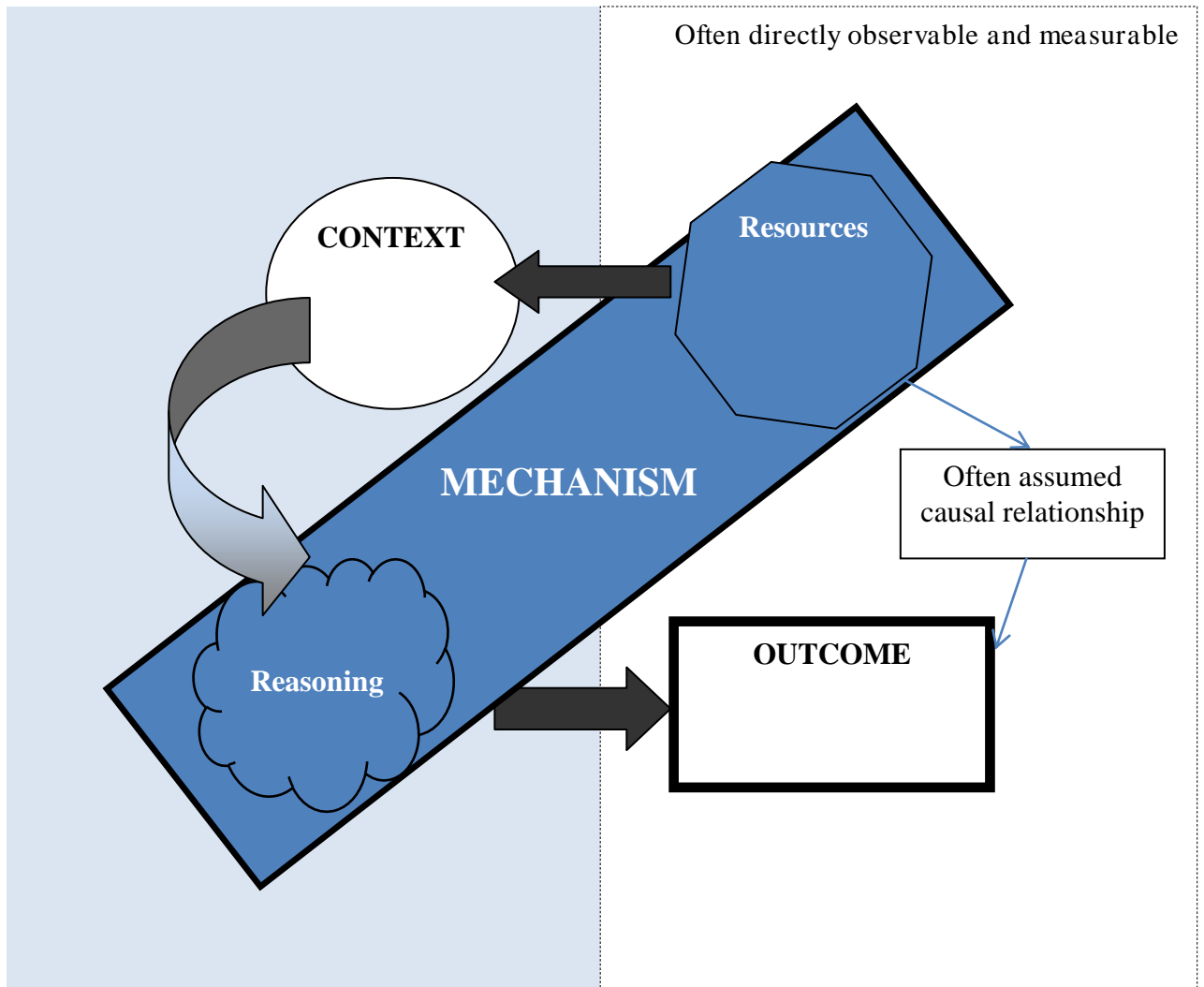
Figure 1: Context, Mechanism and Outcome Configurations in realist evaluation

Traditional research formats aim to demonstrate a relationship of causality between resources inputted by a social programme and observed or measured outcomes. As exposed in 'Mechanism' above (pg.83) realist thinking posits that this causality is mediated by the context within which the resources are implemented and the reasoning this triggers in key stakeholders, which results in them acting in a different way and leads to observable outcomes. Causality is thus more complex, and reliant on often

unobservable and unmeasurable parameters, which the realist evaluator endeavours to shed light on.

In order to make explicit the distinction between the intervention components (visible and known to practitioners) and the kind of reasoning this triggered in certain contexts (assumed or implicit), it was decided to disaggregate resources and reasoning throughout the thesis, as demonstrated in Figure 1. This is in order that readers from all backgrounds and prior knowledge of realist thinking can engage with the concept of 'causal mechanisms'. Figure 1 depicts how resources are introduced into pre-existing contexts which in collaboration result in reasoning of an individual which leads to an outcome. The reasoning border has softer lines to identify its psychological nature. The outcome box has a thick box surrounding it to depict its observable nature.

In the description of CMOC throughout the results chapters they will be described in the following format: outcome, mechanism then context. This is because the inquiry usually started from an outcome. From here, relevant mechanisms and contexts that might have led to the outcome were identified. The only exception to this is Chapter 7 (p.231) where the presentation is context, mechanism, then outcome. This is because inquiry in this part of the thesis began with context.

Research questions and programme theories

- In terms of the ICP, what works, for whom, in what circumstances?

The main research question stated above was very broad to allow the formulation of programme theories. Programme theories are the underlying assumptions about how an intervention is meant to work and what impacts it is expected to have (Pawson,

Greenhalgh et al. 2005). There is usually more than one programme theory per intervention and they differ from normal theory in that they include the two additional key components from realist methodology, context and mechanism. The programme theories in this study were prompted by outcomes of the ICP, the palliative care ICP literature, integration in the locality and consultation with practitioners implementing the ICP. Data available from the GP practice systems (MIQUEST and Death Audit) guided the formulation of the programme theories, as it provided crucial outcomes. The literature identified gaps in knowledge and highlighted why a realist evaluation was appropriate to address these, as exposed in Chapter 2 (p.40). It also contributed towards the initial programme theories. Furthermore, there was a lot of learning that occurred as a result of integration into the locality; in order to develop programme theories for the ICP immersion in the field was essential. This was achieved through observing consultations between GPs and palliative care patients, attending Palliative Care Partnership meetings, local research and education meetings, locality organised educational workshops, PCQVs, spending time at the locality palliative care unit and reading the ICP business cases and reports. Additionally, close contact with the ICP founder was established. This learning allowed my knowledge of the ICP and the locality to increase and formulate testable programme theories. Five programme theories were developed for the ICP. They are stated at the beginning of each Findings chapter and refined using the data collected; the refined programme theory is then stated at the end of each chapter. The five programme theories are stated below and accompanied by subsidiary questions:

Programme theory 1

Integration into the locality has resulted in a basic knowledge of how the fourteen different GP practices work, the ethos they have in relation to the ICP and the outcomes they achieve. From this knowledge and literature surrounding communication, co-ordination and team working in palliative care ICPs (Smith 2012), the following programme theory was developed.

The number of people who die in their chosen location (outcome) will depend on the GP practice (context) they are registered with and how embedded the ICP is as indicated by the number of interventions used per patient (outcome). Thus, this is a programme theory about the process of implementation, considering implementation as an intermediary outcome.

-       Does the use of more interventions result in better outcomes?

-       Do CQI initiatives increase intervention use?

-       What characteristics do 'high performing' GP practices have?

Programme theory 2

The GSF states that palliative care patients should be identified early (The National Gold Standards Framework Centre 2009). Bower, Roderick et al. (2010) highlighted that using the GSF empowered health care professionals to identify patients with any illness early in their trajectory. From this knowledge and integration into the locality the following programme theory was created:

Palliative care registrations should increase (outcome) due to a focus on identifying patients early using the palliative care register (mechanism) in a health care domain that appreciates the palliative care needs of patients (context).

- Are palliative care registrations increasing in the locality and if so why?

- Are both cancer and non-cancer patients appropriately put onto the palliative care register?

Programme theory 3

The ICP promotes the use of preference discussions with patients and ACP. ACP is also explicitly advocated by UK policy in The End of Life Care Strategy (Department of Health 2008, Addicott and Ross 2010) and has been used in previous studies that have produced positive outcomes for patients (Hockley, Watson et al. 2010, Hall, Goddard et al. 2011, Reymond, Israel et al. 2011). Early integration into the field highlighted an increased awareness of the importance of documenting preferences. This prompted the following programme theory:

There will be an increase in the use of preference discussions and ACP (outcome) as health care professionals become more confident with broaching the subject of death and dying with patients (mechanism) and aware of the importance of having and documenting preference discussions, which has been highlighted by recent policy (context).

- Are preference discussions increasing and if so why?

-       Are preference discussions occurring earlier in a patient's illness trajectory (green traffic light phase)?

-       Is the number of locality advance care plans carried out with patients increasing and if so why?

-       Do preference discussions predict the use of advance care plans?

Programme theory 4

The literature highlighted that communication about death and dying can be difficult (Buckman 1984, Ptacek and Eberhardt 1996, Ptacek and Ptacek 2001, The National Council for Palliative Care 2009). Literature in psychology suggests that in health related risk situations individuals utilise distinctive attentional processing styles which allows them to be classified as a monitor or blunter (Miller 1995). It could be that matched coping styles could help examine why some palliative care consultations lead to more proactive discussions than others. Thus, the following programme theory was developed:

The innate coping style of the GP and patient (context) facilitates a consultation if matched (mechanism), making a preference discussion and use of the locality advance care plan more likely to occur (outcome).

-       Are matched coping style consultations more successful (in terms of producing outcomes such as preference discussions and advance care plans)?

-       Can matched coping styles facilitate practice?

Programme theory 5

Using a patient centred framework based on shared decision making is advocated in policy and in translational tools used in practice. In the literature chapter it was identified that Hockley, Watson et al. (2010) and Bower, Roderick et al. (2010) found using ACP (amongst other resources), which is based on shared decision making, resulted in a decrease in hospital deaths and an increase in home deaths, respectively. This knowledge and that gained from integration into the locality resulted in the following programme theory:

The ICP can facilitate preferred place of death (outcome) and prevent emergency admissions (outcomes) through identifying patient preferences (context) and using ACP (mechanism).

- Are home deaths increasing?

- Are care home deaths increasing?

Gaps in knowledge led to the formulation of the research question. Knowledge of the quantitative ICP outcomes available, reading the literature and access to contextual knowledge then enabled the formulation of programme theories and of questions to be asked of the data. The literature in Chapter 1 (p.6) highlighted gaps in knowledge which the programme theories address. For example Smith (2012) identified an increase in home deaths due to implementation of a palliative care heart failure service, however the findings do not highlight what contexts and mechanisms were necessary for this

outcome to occur; programme theory 5 aims to identify not only if home deaths are increasing in the locality but how and why, through investigation of patient preferences and ACP. The programme theories above recognise and illustrate key components of the programme (ICP) and include its strategies, functions or activities. Programme theories also map out the outcomes the ICP intends to generate and the specific components that contribute to particular outcomes.

Data Collection and Analysis

It is possible to use and integrate different combinations of data sources, methods and types of data as part of a study (Plowright 2011). Contributions of different data types and analyses were not confined to specific programme theories but some data analysis did feature more prominently in specific programme theories. Realist evaluation values mixed methods and states that data type should be selected on the basis of how informative it will be to the study. For more than a century, the supporters of quantitative and qualitative research paradigms have engaged in dispute (Johnson and Onwuegbuzie 2004). From these disputes, purists have emerged on both sides (Campbell and Stanley 1963, Lincoln and Guba 1985). Quantitative purists (Ayer 1959, Popper 1959, Schrag 1992, Maxwell and Delaney 2004) express assumptions consistent with a positivist philosophy and maintain that social science inquiry should be objective (Johnson and Onwuegbuzie 2004). Thus they pursue time and context free generalizations (Nagel 1986). Qualitative purists (Smith 1983, Smith 1984, Guba and Lincoln 1989, Schwandt 2000) reject positivism and are also known as constructionists or interpretivists (Johnson and Onwuegbuzie 2004). They state that time and context free generalisations are neither possible nor desirable, and that research is value bound.

They also contend that it is impossible to differentiate causes and effects fully. Both quantitative and qualitative purists view their paradigm as the ideal for research meaning these paradigms and associated methods should not be mixed (Johnson and Onwuegbuzie 2004). However, to include only quantitative or qualitative methods falls short of the major approaches being used in the social and human sciences (Creswell 2003). Currently, research practice is often not purely quantitative or qualitative but on a continuum between the two, using mixed methods (Creswell 2003). Mixed methods is a third research paradigm which recognises that both quantitative and qualitative research are important and useful and thus uses a combination of at least one quantitative and one qualitative component in a single research study (Bergman 2008). The goal of mixed methods research is to draw from the strengths of both quantitative and qualitative research whilst minimising the weaknesses in single research studies and across research studies. It employs strategies of inquiry that involve collecting data either simultaneously or sequentially to best understand research problems (Creswell 2003). Thus by using mixed methods numbers can be used to add precision to words, pictures, and narrative and a broader and more complete range of research questions can be answered (Johnson and Onwuegbuzie 2004). Furthermore, the use of mixed methods produces more complete knowledge that is necessary to inform theory and practice which is essential in this study (Johnson and Onwuegbuzie 2004). However, mixed methods can be more time consuming and expensive and some of the details of mixed methods research remain to be worked out fully (Johnson and Onwuegbuzie 2004).

Framework

There are five types of data collection within this project. This is in order to understand and evaluate the ICP in a variety of ways, find evidence to support the programme theories and allow generation of multifaceted CMOCs. Each data collection form and analysis is explained further below and in Table 1.

Fourteen of the fifteen practices implementing the ICP took part in the study. GP practices were lettered to maintain anonymity. All fourteen practices provided MIQUEST and GP practice data. Health care professionals from all fourteen practices were invited to take part in the focus groups, along with members from other key organisations such as the ambulance service, social services, and OOH services. Three of the GP practices were chosen as sites to collect data from patients and bereaved relatives. Practice H collected questionnaire data, practice D acted as gatekeepers and referred bereaved relatives and patients for interviews, and practice E acted as gatekeepers and recorded consultations with palliative care patients. Data collection was sited to avoid over burdening health care professionals, palliative care patients and bereaved family, friends and carers of palliative care patients. Practice D is in a large town (urban), practice E is in a smaller town (semi-rural) and practice H is in a village in a sparsely populated area (rural).

All strands of data collection took place simultaneously. This allowed the generation of CMOCs across data sources, and allowed for further exploration of one factor through another data collection method. Furthermore, all different data collection forms were sited at different practices (Practices D, E and H) in order to only invite each potential participant to take part in the overall study once.

Table 1: Data framework

Major Research Question Answered	Programme Theory Tested	Participants Providing Data	Data Source	Data Analysis
Does the palliative care ICP work?	Programme Theories 1, 2, 3 and 5	Palliative care patients from one of the practice sites	MIQUEST data base/ Locality Death Audit	Statistical analysis
	Programme Theories 3 and 5.	Relatives of deceased palliative care patients and the health care professionals previously involved in the patients palliative care	Quality of Dying and Death Questionnaire	Descriptive comparisons
What are the conditions of effectiveness of ICPs in palliative care?	All programme theories	Health care professionals involved with the ICP	Focus Groups	Soft systems methodology
	Programme Theory 3 and 5	Palliative care patients and their families and bereaved families of palliative care patients	Interviews	Thematic analysis
Who does the ICP work for?	Programme Theory 4	Palliative care patients and their GPs	Coping Style Questionnaire	Classified as monitor or blunter
	Programme Theory 4		Voice Recording of Consultations	Thematic analysis

1. MIQUEST and Locality Death Audit data (contributes to programme theories 1, 2, 3 and 5)

Recruitment: No recruitment was needed for the GP practice data as it was already available from NHS North of Tyne PCT. Permission to use the data was sought from the GP practices using an invitation letter (Appendix 3), information sheet (Appendix 4), and consent form (Appendix 5). Permission for its use was also given by the Research and Development (R&D) manager at NHS North of Tyne PCT.

Data Collection: Quantitative data available from the fourteen pilot sites is available in the form of the Death Audit and Morbidity Information Query and Export Syntax (MIQUEST). Both sets of data are routinely collected by practices: Death Audit data retrospectively since 2007 and MIQUEST searches have been run routinely since 2009. Whilst some of the data overlap, other data, such as that on locality advance care plans and sudden deaths, do not. This data is mostly about identifying outcomes of the ICP and the structure of the ICP implementation so that essential mechanisms that lead to these outcomes can be explored, identified and tested.

Data Analysis: Statistical analysis was performed on MIQUEST and Death Audit data using IBM SPSS 17.0. The statistical tests used were: descriptive statistics, correlation, multiple regression, repeated measures t-test and cluster analysis. These tests investigated the tools the ICP uses, the good death outcomes the ICP generates and the embeddedness of the ICP. The embeddedness of the ICP refers to how many ICP interventions a GP practice uses; the more interventions that are used, the more it can be assumed the ICP is becoming routine in that GP practice. Practice comparisons were viable using statistics and contributed to essential contextual evidence. All the analyses have been undertaken in the knowledge that intervention recording rates can vary. However, since realist approaches seek to develop

understanding of how, for whom and in what circumstances interventions work (as opposed to seeking absolute proof that they do), this was not considered an issue.

2. The Quality of Dying and Death Measure (contributes to programme theories 3 and 5)

Recruitment: Nurses from GP Practice H identified bereaved relatives systematically by looking at patients who died six months before data collection began (01/02/2012). Bereaved relatives were sent the invitation letter (Appendix 6), information sheet (Appendix 7) and consent form (Appendix 8) in the post by the GP practice (H) on headed paper. If they responded, the response was sent to me at Northumbria University. The bereaved relative was then sent the QDDM and an email was sent to the GP practice nurse, who asked the relevant GP (who had previously had a significant involvement with the bereaved relatives loved one) to also fill in the same questionnaire. The GP was also provided with an invitation letter (Appendix 9), information sheet (Appendix 10) and consent form (Appendix 11). This was then emailed to me. Questionnaires were then matched and analysed. All bereaved relatives recruited to the study were between four and six months post bereavement; this was an inclusion criteria stated by the study and followed by the GP practices. All potential participants were discussed with the founder of the ICP who is a retired GP with an interest in palliative care, to ensure that they were suitable and deemed fit to participate in the study.

Data Collection: There are several 'good death' measures available in the literature; however a recent systematic review found the QDDM (Curtis, Patrick et al. 2002) to be the most widely studied and best validated (Hales, Zimmerman et al. 2010)

(Appendix 12 includes statistics about the psychometric properties of the measure). The QDDM was used to determine whether individuals who experience the ICP had a good death. This measure was distributed to bereaved families and key health care workers involved in a patient's care. This section of data collection concerns the experiential and perceived outcomes of GPs and bereaved relatives. Experiential and perceived outcomes are extremely important, as the quantitative data lacks this rich quality.

Data Analysis: The questions were used to identify areas within palliative care that GPs and bereaved relatives perceive similarly and differently to support CMOC.

3. Focus groups with health care professionals and key organisation workers (contributes to all programme theories)

Recruitment: Consent to contact staff who were eligible to take part in the three focus groups was obtained through R&D approval (Appendix 13) and letters to relevant organisations (Appendix 14). The date and time of the focus group was arranged and emailed to all the relevant potential participants (GPs, community matrons, social care workers, OOH staff, ambulance service, urgent care staff, voluntary organisations and relevant hospices including the locality palliative care unit) along with an invitation letter (Appendix 15), information sheet (Appendix 16) and consent form (Appendix 17). Participants were asked to read the study information provided, reply to the email to confirm their attendance and to bring their completed consent form with them to the focus group. Spare copies of the consent form were available at the focus group for those who forgot to bring it. Focus Group 1 (FG1) aimed to highlight how the ICP functioned in practice on a

regular basis. It took place in May 2012 and had twelve attendees (three GPs, two community matrons, two ward staff nurses, one social care team lead, one junior doctor, one palliative care unit project manager, one palliative care unit deputy manager, one team leader for the OOH nursing service). Focus Group 2 (FG2) took place in October 2012 and aimed to get constructive feedback on primitive CMOC; it had eight attendees (two GPs, one MacMillan nurse, one ward staff nurse, one community matron, one social care team lead, one district nurse, one palliative care unit deputy manager). Focus Group 3 (FG3) had six attendees and took place in October 2013 (four GPs, one care home manager, one social care team lead). This focus group aimed to refine final CMOCs. FG1 and FG3 did not require participants to do pre-focus group work (materials to review). FG2 required participants to study Soft Systems Methodology (SSM) maps that had been created based on the ICP (example provided, see appendix 37). This allowed participants to become familiar with the maps, generate ideas prior to the focus group and encouraged them to be confident in the discussion of them. FG2 participants were sent the SSM maps to review before they participated in the focus group.

Data Collection: Focus groups were chosen in order to get input from all those involved with the ICP from different job roles. They have been identified as an effective technique for exploring the attitudes and needs of staff (Denning and Verschelden 1993) and allowed for collaborative discussion between health care professionals in order to refine ideas. They highlight the respondents' attitudes, priorities, language and framework of understanding (Kitzinger 1995), all of which are of interest in this evaluation and can provide essential knowledge for CMOC. The interaction between participants also allows them to generate and answer their own questions and share common experiences, which generates deeper

understanding (Kitzinger 1995). Furthermore they allow essential interaction between the participants and the researcher allowing me to pose follow up questions or probe a particular topic of interest more deeply. Thus the focus group allowed for the role of the participants in producing interaction and the role of the researcher in guiding this interaction (Morgan 1996). FG1 provided essential knowledge to understand what exactly it is about the ICP that makes a difference to health care professionals and patients, in order to refine the initial programme theory. The information gained from the first focus group allowed the development of SSM maps which detail essential transformations within the pathway and can also be understood in terms of CMOC (discussed further in data analysis). FG3 was used to discuss and refine the studies final CMOC.

The focus groups have contributed to CQI in the locality; informing decisions on documentation and data recording (for more information please see Chapter 6: Preference discussions and the locality advance care plan, p.199).

Data Analysis: FG1 and FG3 were used to stimulate thoughts about how the ICP worked and refine final CMOCs, respectively. FG2 used knowledge from integration into the locality and findings from FG1 to create SSM maps - visual tools to collect and make sense of the data. It formulates carefully built models of systems which are used to represent and analyse a real world situation. The maps created were set against perceptions of the real world by a process of comparison which initiated debate between FG2 participants (Checkland and Scholes 1992). The epistemology of SSM is similar to that of realism in that the building of models accounts for the phenomenon being examined and these models are hypothetical descriptions which reveal underlying mechanisms of reality which can only be known by constructing ideas about them (Blaikie 2007). It was recognised that not

everyone understands mechanisms in a realist sense, however most people can relate to inputs, outputs, transformations and environmental factors. Therefore SSM maps were used as a form of CMOC as they allowed the health care professionals and key organisation workers in FG2 to talk in terms of CMOC, using terms such as 'transformations' (to refer to underlying mechanisms) which occur through an 'input' (mechanisms and resources), and produce an 'output' (reasoning and outcomes). The transformation is affected by 'weltanschauung' meaning worldwide view (context), 'owners' referring to those who can stop something from happening in practice (context) and environmental constraints (context). Furthermore, the visual presentation of SSM maps enabled FG2 discussions to be framed and generate further comments in a way that CMOC may not have; participants could see several factors in one domain, for example, several inputs, and discuss which was the most important for a particular transformation, such as ACP. This meant that FG2 participants evaluated several CMOC initially generated by the ICP founder and myself and generated their own CMOC through discussions initially triggered by the maps. This model helped highlight the contexts and mechanisms that are key to producing effective outcomes and allowed the research project to reflect practitioners' combined organisational memory, experience and wisdom. SSM maps provided participants with an opportunity to think about their practice in a different way which enabled the surfacing of prior assumptions and implicit considerations, for example, a proactive GP is necessary to engage in early preference discussions.

4. Interviews with palliative care patients and bereaved relatives (contributes to programme theory 3 and 5)

Recruitment: Patients and bereaved relatives were identified by GPs in Practice D. All bereaved relatives were four months post bereavement; this was an inclusion criterion of the study. Once a potential participant was identified by a GP, they were discussed with the founder of the ICP (retired GP with an interest in palliative care) to ensure that they were suitable and psychologically stable to participate in the study. Once it was agreed that the patient or bereaved relative was suitable they were sent an invitation letter (Appendix 18 for patients and appendix 19 for bereaved relatives), information sheet (Appendix 20 for patients and 21 for bereaved relatives) and consent form (Appendix 22 for patients and 23 for bereaved relatives) with a stamped addressed envelope, addressed to me at Northumbria University. Family members of palliative care patients were also provided with an information sheet (Appendix 20) and consent form (Appendix 24) if they wished to participate. The consent form for patients and bereaved relatives asked for the provision of a contact telephone number, so once the consent form was received I could telephone the participant and organise a convenient time for interview. All interviews were recorded in the participants' homes. Researcher safety measures were put in place - I would inform my supervisors when I was scheduled to visit a participant's house and then I would telephone my supervisors once the interview had finished and I had left the participant's home. Four bereaved relatives and three palliative care patients were interviewed; all participants were given pseudonyms.

Data Collection: Semi-structured interviews were conducted with palliative care patients, their families and friends and bereaved families. Interviews can overcome the poor response rates of a questionnaire survey (Austin 1981) and are appropriate

for exploration of participants' attitudes, values, beliefs and motives (Richardson, Dohrenwend et al. 1965, Smith 1975), which are essential in the formulation of CMOC. Interviews provide the opportunity to evaluate the validity of the participant's answers through observation of non-verbal cues (Gordon 1975); this is particularly useful when discussing sensitive issues such as palliative and end-of-life care. Semi-structured interviews were used because they provide comparative data whilst allowing for follow up questioning that is specific to the individual (Barriball and While 1994). Furthermore, they are appropriate for the exploration of the perceptions and opinions of participants regarding complex and sensitive issues (Barriball and While 1994). They also enable the researcher to probe for more information and clarification of answers (Barriball and While 1994). This provided rich, in depth, qualitative data about the ICP and bereaved relatives' and patients' experiences of it, whether it was working for patients and their families, and if it contributes/contributed to a good death. Thus the interviews allowed for initial programme theory testing by asking about personal experiences of the ICP.

Data Analysis: Interview transcripts were analysed thematically (Braun and Clarke 2006). Thematic analysis is an accessible and theoretically-flexible approach used in the analysis of qualitative data. The method allows the researcher to identify, analyse, and report patterns (themes) within the data. It organises and describes the data set in (rich) detail. Additionally, thematic analysis can be used to interpret aspects of the research topic (Boyatzis 1998).

5. GP consultation recordings with palliative care patients (contributes to programme theory 4)

Recruitment: Patients were recruited by GPs at GP practice E. Patients were approached verbally by GPs and if they showed an interest were given the invitation letter (Appendix 25), information sheet (Appendix 26) and consent form (Appendix 27). They then filled this in and returned it to the GP who provided them with the MBSS. The participant filled this in and returned it to the GP. The GPs were also provided with invitation letters (Appendix 28), information sheets (Appendix 29) and consent forms (Appendix 30) about the study as they too were participating by being audio recorded and completing the questionnaire. The GP completed their consent form and the MBSS and all forms were posted to me at Northumbria University. It is acknowledged that palliative care conversations take place over time, therefore GPs had the opportunity to record up to 3 consultations with one patient.

Data Collection: Both a palliative diagnosis or information about palliative care can be classed as distressing, health threatening information which is difficult for the doctor to deliver, and for the patient to receive (Buckman 1984, Ptacek and Eberhardt 1996, Ptacek and Ptacek 2001). The literature suggests conversations about death occur infrequently and that this may be due to professionals not feeling at ease with broaching the subject (The SUPPORT Principal Investigators 1995, Hoffman, Wenger et al. 1997, National End of Life Programme 2011). It is proposed that in such health related risk situations individuals utilise distinctive attentional processing styles which allows them to be classified as a monitor or blunter (Miller 1995). When faced with a health related risk, monitors generally seek information, magnify disease related cues and display greater dissatisfaction

about the amount of information provided. Alternatively, blunters psychologically distract themselves from health related risk information and desire less knowledge. People can be classified as (high or low) monitors and (high or low) blunters using the MBSS (Appendix 31). The proposed use of coping style classification in this project was to investigate whether matched coping styles between patients and health care professionals offer any explanatory potential for outcomes achieved. For example, if a monitor health care professional and a monitor patient (classified through use of the MBSS) (Miller 1995) have a consultation, it is hypothesised their conversation about palliative care and death will be facilitated by their inherent coping strategy. In this study GPs and patients are classified as high or low monitors and blunters using the MBSS; following this, recordings of consultations about palliative care were made. This section of data collection sought to find if matched coping style resulted in a better outcome (testing programme theory 5).

Data Analysis: The MBSS data was analysed by classifying individuals as high or low monitors or blunters. The audio recording of the consultation was transcribed and examples of high and low monitoring between GP and patient were sought. Due to a growing interest in medical stressors and coping style, an instrument was developed specifically to assess coping style when faced with medical threat, the Threatening Medical Situations Inventory (TMSI) (van Zuuren and Wolfs 1991, van Zurren and Hanewald 1993, van Zurren 1994). The TMSI describes four health threatening situations and has satisfactory reliability and validity (van Zurren and Hanewald 1993, van Zuuren, De Groot et al. 1996). However, the use of this scale was not employed in this study. The reasons for not using this scale are due to its relation to health care, and the hypothetical situations that are posed. One question asks the participant to "Imagine you suffer from headaches and dizziness for some

period of time already. You visit your doctor. He or she tells you things don't look too well and refers you to a specialist for a rather trying medical examination". This type of hypothetical situation may be very close to a palliative care patient's actual experience and may cause distress.

There is substantial academic as well as clinical debate about whether trait measurement is an adequate way of understanding peoples' behaviours and attitudes. This focuses on states versus traits. Traits are stable, enduring characteristics that are consistent across situations, for example conscientiousness. States are transient experiences that are subject to change, such as emotional states or generosity. Difficulties in the differences between traits and states become apparent when focusing on anxiety. Cattell (1966) emphasised the importance of distinguishing between anxiety as an emotional state and individual differences in anxiety as a personality trait. Correspondence with the MBSS creator Dr. Suzanne Miller confirmed that Monitoring and Blunting are traits (Appendix 32). Dr. Miller stated:

> *"Yes it is a trait.* They (monitors and blun*ters) don't change how they* respond to the items on the questionnaire, but their (coping) strategies may change over time as the situation changes. Also some people are in the middle (a subset, perhaps a quarter) so that they are more influenced by changes *in the situation"*

Thus if a person is classified as a monitor they are likely to remain a monitor despite changing situations. Therefore a person would be a monitor three weeks after receiving their terminal diagnosis and three months after receiving it; the trait is stable over time. However, coping strategies can change over time, meaning that denial could be primarily used before acceptance. Yet some people are influenced more readily by situational factors than others.

The operationalisation of the data collection into realist evaluation

The five programme theories stated earlier were refined using the five data collection strands, although there was not one specific data strand for one specific programme theory. Outcomes were often investigated using GP practice data. These were retrieved and analysed early in the project time line in order to provide an engaging anchor for focus group discussions and to then help refine each programme theory as the project progressed. For example, information from FG1 refined the programme theories stated above (pg.88), which were tested in FG2 (using SSM maps to help health care professionals make sense of the ideas presented). The interviews with bereaved relatives and patients were conducted using an interview schedule which was approved by the NHS REC and could thus not be amended in response to theory development. Thus, programme theories could not be refined in between data collection from individual patients/bereaved relatives, as this would mean asking very different questions. Similarly, the questionnaire was a standardized questionnaire which was approved by the NHS REC and could not be changed, and the consultation recordings were conducted by GPs thus giving me no opportunities for input. Furthermore, these consultation recordings were meant to be a representation of a true palliative care consultation and therefore asking the GP to ask specific questions would not have been appropriate.

The multiplicity of data collection strands that could work in conjunction with one another was designed to allow for an in-depth investigation of all possible mechanisms. Thus if a question was raised by one data collection strand, the answer would either be found in other strands, in informal discussions with practitioners during field visits, in focus groups, in PCQV or in discussion with the ICP founder.

In conjunction, all these (formal and informal) interactions with the data were used to refine and/or confirm programme theories as data was analysed. The complex data collection strategy also mitigated against the constraints of the requirement for ethics (including questionnaires and fixed interview schedules), so that theories could be developed and tested across datasets.

The inclusion of the ICP founder as a supervisor in the team and attendance at locality PCQV acted as a further safeguard against the limitations of fixed data collection strategies. They meant that candidate explanatory theories were made explicit from early on, and refined on an informal basis as I familiarised myself with the field and discussed any confirming or disconfirming data finding with the founder. This process was not considered part of the formal data collection (as it might have been in other realist projects), but rather used for its theory refinement potential. This was because the ongoing involvement of the ICP founder enabled co-production of sense making that was grounded in practice experience and instrumental to the theory refinement process. Working in partnership, the founder was not a research participant but an invaluable source of knowledge that ensured greater practice validity of the findings. The focus groups, for which the schedule had been left open from the outset, came in addition to that. This was an iterative relationship between theory development and refinement and data analysis which is core to realist sense making processes.

Figure 2: The operationalisation of the method

All data strands fed into one another to refine and confirm programme theories

Initial programme theories for each chapter (formulated from the literature and integration into the field)

GP practice data analysed early in the project to provide programme theory outcomes

Interviews with bereaved relatives and palliative care patients

Programme Theories Refined after each focus group

Focus Group 1

Focus Group 2

Focus Group 3

Ongoing discussions and programme theory refinement with the ICPs founder and from PCQVs

Quality of Dying and Death Measure

Consultation recordings

Final (refined) programme theories for each chapter

The data collection design allowed for confirming and disconfirming evidence to refine programme theories (see Figure 2). If the findings from one data collection strand contradicted an initial programme theory, this theory was refined to further understand this. There was never an instance where two data sets completely contradicted one another, as there was always explanatory potential in all data strands. Thus, where it initially seemed that data strands showed different results, when combined they created a stronger, refined programme theory.

This concludes the description of the data collection framework. Table 2 highlights the type and number of participants in each data collection activity.

Table 2: The type and number of participants in each data strand

	Type of participant	**Number of participants**
MIQUEST and Death Audit data analysis	Patients	4, 182 patients (who died between 2007 and 2012)
QDDM	Bereaved relatives and health care professionals	4 bereaved relatives and 4 health care professionals
Focus groups (1, 2 and 3)	Health care professionals	FG1 = 12 attendees FG2 = 8 attendees FG3 = 6 attendees
Semi-structured interviews	Patients and bereaved relatives	3 patients and 4 bereaved relatives
Consultation recordings	Patients and health care professionals	3 patients and 3 health care professionals

The data collection activities include interviews and consultation recordings with palliative care patients and bereaved relatives. The analysis from the interviews and consultation recordings are used throughout the findings chapters (Chapters 4, 5, 6, 7, and 8) intermittently, as all data is presented cohesively in order to refine the programme theories. Hence, a table is now provided in order to introduce the palliative care patients and bereaved relatives (Table 3).

Table 3: A table to introduce the palliative care patients and bereaved relatives who participated in the study

Pseudonyms	Participant	Data collection tool
Ned and Caroline	Bereaved relative	Interview
Mark	Bereaved relative	Interview
Linda	Bereaved relative	Interview
Rachel	Bereaved relative	Interview
Doris (and her son Richard)	Palliative care patient	Interview
Janet (and her daughter Jill)	Palliative care patient	Interview
Michael (and his wife Barbara)	Palliative care patient	Interview
Mary	Palliative care patient	Consultation recording
John (and his wife Janice)	Palliative care patient	Consultation recording
Susan	Palliative care patient	Consultation recording

Ethical approval

Ethical approval was granted from the School of Health, Education and Community studies on 28/09/2011 (Appendix 33). Following this the NHS local ethics committee approved the study (REC reference number: 11/NE/0318) on 13/12/2011 (Appendix 34). Research & Development approval was gained from four different

trusts, and relevant voluntary organisations and the local council were informed about the research.

Chapter Summary

This chapter has situated the research in a philosophical and methodological context that will allow the complexities of the ICP to be acknowledged throughout the evaluation. Realism does not aim to eradicate confounding variables but embraces them in the complex social nature of reality. The research question has been specified which has generated specific, testable programme theories. Finally, a data collection framework has been created in order to generate data that can test the programme theories and that will produce the most informative findings.

Findings chapters

The findings are presented in five distinct chapters matching the programme theories:

- Embeddedness of the Integrated Care Pathway as a new initiative.

- Identifying palliative care patients and registering them appropriately.

- Preference discussions and the locality advance care plan.

- Facilitating difficult conversations in palliative care.

- Facilitating a home death.

Although the chapters are presented separately, they do relate to one another. Many discuss the same tools or concepts but in different aspects. For example, the

chapters 'Facilitating difficult conversations in palliative care' and 'Facilitating a home death' both include comments around ACP. However, in each I refer to and use ACP in a different way to provide explanations about crucial aspects of the ICP. Understanding how the chapters relate to one another and why this is significant will be discussed in depth in the discussion.

The chapters are ordered chronologically in terms of the patient's palliative care journey. The first findings chapter (Chapter 4, p.117) concentrates on the embeddedness of the ICP, as for the patient to receive the ICP it must first be embedded into the GP practice. The chapter explores if and how the service has been adopted and used within the locality and to what extent. This includes consideration of variations in use of the ICP between practices. Chapter 5 (p. 163) moves on to discover CMOCs related to the palliative care register. Issues with non-cancer patients and the palliative care register are explored and understood over time in relation to practitioners' self-efficacy. Chapter 6 (p.199) concerns preference discussions and the locality advance care plan, specifically it highlights the importance of markers for initiating preference discussions; the role of false hope; time constraints; and the MCA. The final CMOC in this chapter explores the CQI element of this study, demonstrating how a change from the locality advance care plan to the advance statement from Deciding Right (NHS North East 2012) occurred. Chapter 7 (p.231) focuses on how ACP takes place in practice and explores the role of behavioural traits in the consultation. Finally, Chapter 8 (p.262) explores how a home death is facilitated in the locality with a focus on open communication strategies both at home and in the care home.

The key domains (chapters) emerged from the data analysis and were used as a framework to refine the programme theories and to answer the subsidiary questions. This is explicitly explored at the end of each chapter.

Chapter 4: Embeddedness of the Integrated Care Pathway as a new initiative

This chapter will explore a CMOC related to innovation diffusion, or 'embeddedness'. The more the ICP is used by the locality GP practices, the more confidence they build in using the ICP interventions, the higher the probability that it will not be considered as 'new' by the staff anymore and thus transform into routine practice; it will become embedded. Embeddedness is therefore considered as an intermediate outcome. Alternatively, the enthusiasm about the ICP could diminish, resulting in less use of the ICPs interventions (Pawson 2013). This chapter considers how the locality GP practices have used interventions over time, and compares GP practices to identify and understand if and why the ICP has embedded to different levels in the fourteen GP practices from the locality.

Initial questions asked of the data

The programme theory and subsidiary questions that this chapter focuses on were first stated in the methodology chapter and are stated below.

Programme theory 1: The number of people who die in their chosen location (outcome) will depend on the GP practice (context) they are registered with and how embedded the ICP is, as indicated by the number of interventions used per

patient (outcome). Thus, this is a programme theory about the process of implementation, considering implementation as an intermediary outcome.

- Does the use of more interventions result in better outcomes?

- Do CQI initiatives increase intervention use?

- What characteristics do 'high performing' GP practices have?

Four CMOCs are presented below that relate to embeddedness. CMOC1 explains how the introduction of the ICP changed the capacity and capability to provide palliative care in the locality and what outcomes this resulted in. CMOC2 describes how the ICP interventions have been used within the locality, whilst CMOC3 indicates which practices have adopted the ICP more proficiently and provides an explanation of why some practices are 'high performers'.

CMOC1 – Integrated Care Pathway intervention use and preferred place of death

Outcomes: Intervention use predicts presumed preferred place of death

The relationship between the number of ICP interventions administered per patient and the number of patients who achieved their presumed preferred place of death was investigated using a Pearson product moment correlation co-efficient, executed on MIQUEST data. The presumed preferred place of death refers to the patient's own home, care home or a palliative care unit; deaths in these locations require planning and therefore are likely to be the patient's preferred place. This relationship was investigated to test the informal hypothesis that the more interventions that are used per patient, the more likely they are to die in their

presumed preferred place of death, which is at home, in their care home or in a palliative care unit. This correlation showed that the number of ICP interventions administered per patient and the number of patients who achieved their presumed preferred place of death had a strong positive correlation ($r = 0.54$, $n = 14$, $p < .05$). The least squares regression line (line of best fit) in Figure 3 also displays this relationship.
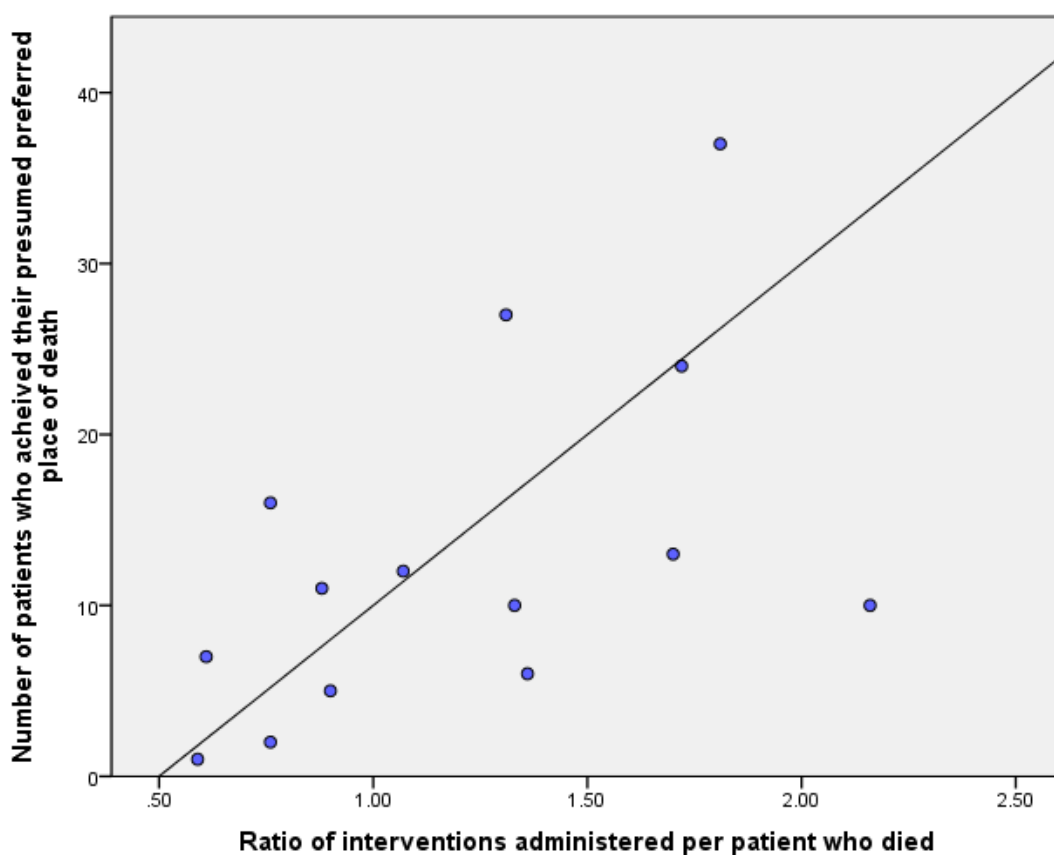
Figure 3: A correlation between the number of ICP interventions administered per patient and the number of patients who achieved their presumed preferred place of death

A multiple regression was used to assess the ability of the ratio of interventions administered to patients who died to predict presumed preferred place of death. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. The model was significant ($F(1,12) = 4.87$, $p < .05$). The total variance explained by the model as a

whole was 22.9% (Adjusted R^2 = 0.229). Adjusted R^2 was used due to the small sample size (fourteen practices). This means that the ratio of interventions used per patient who died accounts for 22.9% of the variance in achieving a death in the presumed preferred place. This means that the ratio of interventions used per patient is a good predictor of presumed preferred place of death. Thus this suggests that the ICP (and the interventions it advocates) are leading to good deaths for patients, when used appropriately, at least in terms of place of death. Thus the ICP 'works'.

Mechanism - The ICP and increasing perceived capability and capacity

The ICP, in providing newly commissioned services, interventions and a planned pathway for palliative care patients (resources) provided the health care professionals in the locality with greater capacity and better capability to provide palliative care. Education and information about palliative and end-of life care for health care professionals (through Quality Improvement Skills for Primary Care days, Practice Based Commissioning Group, PCQV and PCP) and financial incentives through the formulation of Locally Enhanced Schemes (LES) for the ICP (palliative care registration and advance care plans) also supported the provision of this care (resources). The introduction of these new resources altered the reasoning of health care professionals as they now had a perceived improved ability and capacity to provide palliative care in the community (reasoning). Thus health care professionals working within the locality by using the ICP were able to provide high quality palliative and end-of-life care that could be patient centred and preference based.

Context: Palliative care at the top of the political agenda

Prior to the introduction of the ICP, there were gaps in care which resulted in hospital admissions, OOH services were not routinely informed about palliative care patients unless they were nearing end-of-life, and there were few alternative options to a home or hospital death apart from a hospice outside the locality. In 2008 the policy context for palliative and end-of-life care changed significantly, with the publication of the End-of-Life Care Strategy by the Department of Health (2008). This was the year the ICP was introduced to the locality. A policy push of this type, which occurs at the early implementation stage can facilitate an innovation's chance of success (Greenhalgh, Robert et al. 2004). This change (context) resulted in a focus on equality of resource provision for all palliative care patients. Early identification of palliative and end-of-life care patients in the End-of-Life Care Strategy (Department of Health 2008) may have contributed to the commissioners' decision to fund the ICP, and instigated a desire for change in health care professionals in the locality. Thus, the publication of policies in palliative and end-of-life care may have increased motivation to adopt the ICP in the locality (Greenhalgh, Robert et al. 2004), as prior to its introduction capacity to facilitate home death was limited in the locality in terms of commissioned services, interventions and health care professional education.
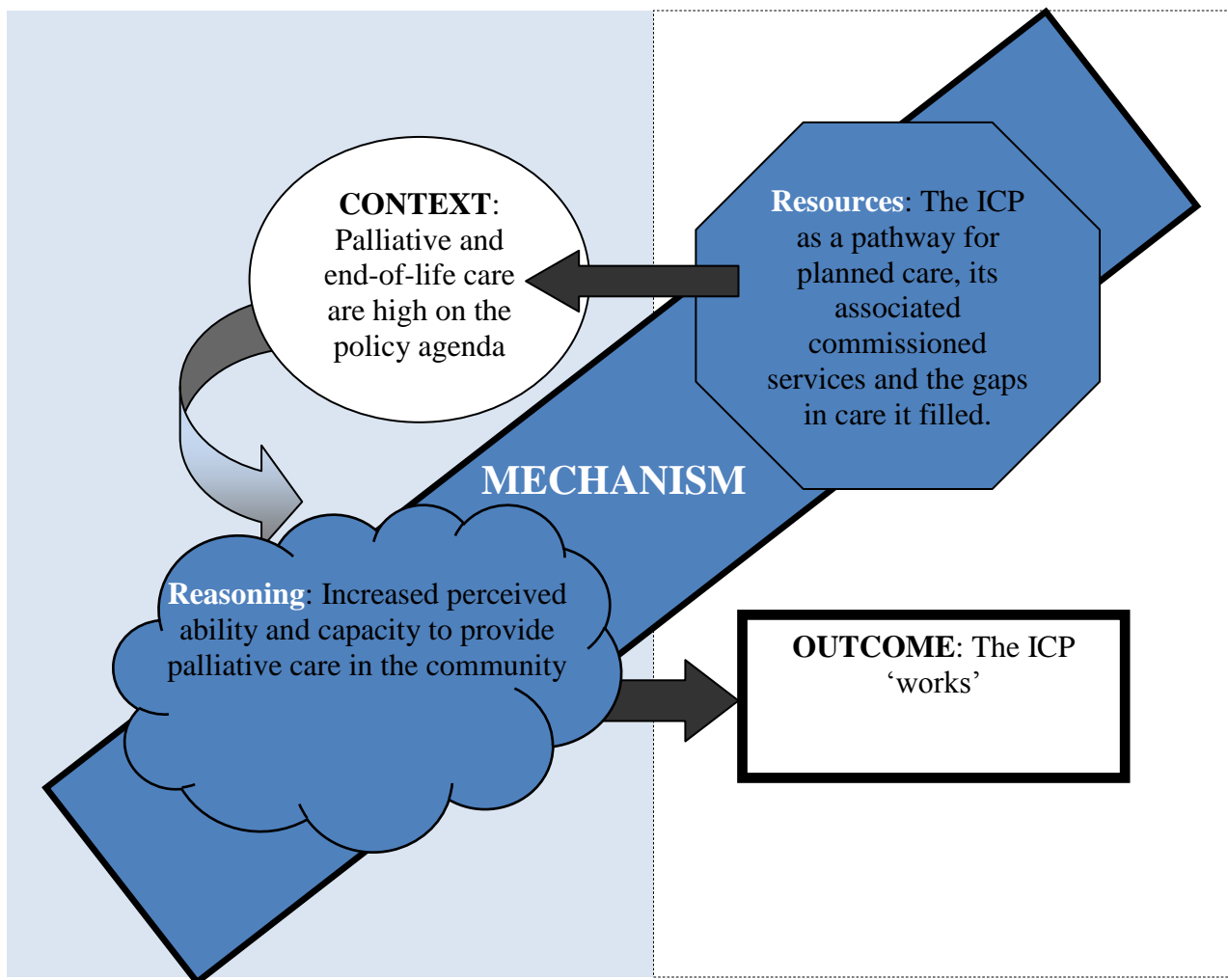
Figure 4: CMOC1, ICP intervention use and preferred place of death

Summary

The publication of the End-of-Life Care Strategy (Department of Health 2008) identified a need for enhanced palliative care services and put palliative and end-of-life care at the top of the political agenda in health care (context). At the time of this policy publication the locality introduced the ICP to provide enhanced services for those with palliative care needs approaching the end of their life (resources). This improved perceived ability and capacity to provide palliative care in the community (reasoning), with incentive from political directives. The ICP provided commissioned services, interventions and a planned pathway (resources) for patients that health care professionals could readily use. This instigated a change in

reasoning in health care professionals, enhancing their capacity to provide palliative and end-of-life care in the community. Increased intervention use has a strong positive correlation with increased presumed preferred place of death; a regression analysis identified that intervention use predicts presumed preferred place of death (outcome). This indicates that the ICP 'works' in terms of outcomes for patients, as most people would least prefer to die in hospital (Gomes, Calanzani et al. 2011). CMOC1 (Figure 4) shows this in diagrammatic format.

CMOC2 – Commissioned services in the ICP

Outcome: Variable commissioned service use

Interviews with palliative care patients and bereaved relatives highlighted that use of the palliative care unit and the Hospice at Home service (commissioned services) was variable. However, variable uptake does not reflect lack of value, but rather highlights the breadth of what was on offer to supplement people's natural support networks. Quantitative data was not available to support the qualitative findings from the interviews in relation to commissioned service use.

Mechanism: Increased support for palliative care patients who need it

The commissioned services provided more support for palliative care patients and their family members (resource) and were highlighted in interviews with some palliative care patients and bereaved relatives. It is beyond the remit of this study to explain how commissioned services have been made use of and whether they have

been effective. However, interviews with palliative care patients and bereaved relatives highlighted that use of the services was variable. This was often due to individual patients' or family members' reasoning.

Interviewees explained why they did not accept offers from health care professionals to arrange their end-of-life care in the palliative care unit. Linda (bereaved relative) described how the district nurse offered this service very early in Linda's husband's palliative care journey. However, Linda's husband was very clear that he wanted a home death, therefore when the palliative care unit was offered, he refused it.

> Linda (bereaved relative): *"No, he made it very clear from the first visit of the, of the nurse, because she, the district nurse pointed out that there was erm, very nice 24 hour doctors' beds in (name of palliative care unit)?"*

The health care professionals involved in Mark's (bereaved relative) mother's care mentioned the palliative care unit to Mark. However, he never took this offer further as his mother was content at her care home.

> Mark (bereaved relative): *"Yeah I'd heard of it and I was aware what they did and I have friends who, a very good friend who's mother is there at the moment, erm, so, it was mentioned, erm, but I don't think she'd have wanted to go there, I don't think, she was very happy where she was."*

The aforementioned participants' loved ones were informed of the palliative care unit's services early in their palliative and end-of-life care journey. Rachel (bereaved relative) was offered this service much later and it may be that the timing of this offer was inappropriate, as she felt that she and her husband had overcome the most challenging parts of her husband's end-of-life journey.

> Rachel (bereaved relative): *"So that was, er there was twice Dr. (name), she was lovely, she said, erm, it was the Saturday night she said would you like us to get him into (palliative care unit) for a couple of nights and I said no not now I've done the worst, you know."*

However it must also be noted that similar to Linda's husband, Rachel's husband also had a strong wish to be at home and this may have contributed to her decision to refuse admission to the palliative care unit. A palliative care patient's wife, Barbara, described how the palliative care unit had not been offered by primary care, but by secondary care.

> Barbara (Michael's wife): "Yeah, they mentioned that at the hospital to you, you know, they said do you want to go to the (palliative care unit) we said no. Yes we prefer to be at home. They did mention that at the (hospital in town), but we did say he wanted to be at home."

Again, a desire to stay at home prompted the refusal of the palliative care unit. Another palliative care patient who was decreasing in physical wellness and starting to require social care help was asked about the palliative care unit.

> Interviewer: *"Yes and have you ever stayed there?"*
>
> Doris (palliative care patient): *"No."*
>
> Interviewer: *"No. And has that ever been mentioned to you?"*
>
> Doris (palliative care patient): *"No."*

Doris (palliative care patient) had not been informed about the palliative care unit. However she too had a great desire to remain in her own home for as long as possible, which she stated, but which was also evident due to her decreasing health and wish for social care help as opposed to consideration of a care home.

Doris (palliative care patient): "*Oh I'd stay at home as long as possible, definitely.*"

Similar to Doris, Janet (palliative care patient) and her daughter Jill had also not been informed about the palliative care unit. However, unlike Doris they felt the palliative care unit was something they would definitely consider for Janet's end-of-life care.

Janet (palliative care patient): "*That sounds interesting actually I might…*"

Jill (Janet's daughter): "*I'll ask about that.*"

Jill explained that she hadn't known about the palliative care unit, but then blamed herself for not investigating available palliative care and just presuming there was only the one well-known hospice in the city centre 20 miles away.

"Jill (Janet's daughter): Yeah, I mean, I, I, you know you mentioned a few, a few things about the (palliative care unit), I *didn't realise that, I didn't realise*"

Janet (palliative care patient): "*No, no, that is interesting*"

Jill (Janet's daughter): "*But you probably should go and find out about it anyway.*"

The interviews highlighted that the palliative care unit (resource) commissioned by the ICP was being offered to patients from both primary and secondary care, which is extremely important as it shows cohesion between services. Refusal of the palliative care unit was often due to the desire to remain at home (reasoning). However, the inappropriate timing of offering the palliative care unit could also be a factor, with relatives feeling they have experienced 'the worst' of their loved one's end-of-life care journey and not wishing to give up on their aim to enable a home

death. Furthermore, it is very difficult for a relative to deny a dying person their preferred place of death (home) and resort to a palliative care unit, particularly when it is unplanned. This is even in the case of respite as often this can result in full end-of-life care due to an unexpected decline in symptoms making it unfeasible for the patient to be transported back home, in case of death during the journey. However, two current palliative care patients had not been informed about the palliative care unit, one of whom was very interested in their services and planned to investigate it after the interview. It must be noted that despite people's strong preferences to die at home it is to their advantage to be aware of other options excluding hospital. However, it must also be noted that all of the patients who participated in the interviews or were discussed in the interviews (by bereaved relatives) were living or had lived at home or in a care home with strong support networks around them; therefore they may have had less need to plan for a death elsewhere. The data indicates that the offer of care from the palliative care unit (resource) is often not taken due to personal circumstances including a strong will to die at home (reasoning).

Hospice at Home Service

A Hospice at Home service was commissioned by the ICP and available for those patients living in their own home. Two of the bereaved relatives who cared for their husbands at home had very different experiences with the Hospice at Home service, one having contact from the start of her husband's palliative care journey and the other not being aware of the service.

> Linda (bereaved relative): *"Erm, I could have done, they were very good, they did ring me up."*

> Rachel (bereaved relative): *"I've never been in contact with* (Hospice at Home)*, they've never been in contact with me."*

Linda used the Hospice at Home's night sitters in her husband's end-of-life period, as did Caroline. However, Caroline had night sitters for around two weeks prior to her mother's death, whereas Linda only had them on the evening of her husband's death. Both bereaved relatives had a positive experience with the Hospice at Home night sitters and appreciated their efforts to prognosticate the dying process so that they could be with their loved ones when they passed away.

> Linda (bereaved relative): *"I did have them at the last day, the last* night, *they sent a, because I'd been up the night before, and* friends and myself had, erm, kind of, did a shift during the night because (husband) was unconscious so we kind of err had no sleep that night, and as Dr. (name) said, he thought it was a good idea that, somebody from the hospice came out, and I had a nurse on the night (husband) died. There was, there was a nurse sitting with him while I was in another room but getting up at a you know, sort of at an interval, and she got me in time to be with him. So yes the *(Hospice at Home)."*

> Caroline (bereaved relative): *"Um and it was a lady from the* (Hospice at Home) who was there when mummy died who woke me so I was there for her last minutes and that was very, *wonderful. Absolutely wonderful."*

Doris, a palliative care patient explained how she had used the Hospice at Home's transport service to get to her hospital appointments. Doris really valued the one to one nature of the transport service and the way it allowed her to attend appointments without using an ambulance. Doris evaluated the Hospice at Home transport service positively, describing how she has never felt the need to use another transport service.

Doris (palliative care patient): *"I tell you they've (Hospice at Home) been very very good that way. Very good… I have always, always used them I haven't ever used anybody else actually."*

One of the palliative care patients interviewed had not been informed about the Hospice at Home service, but the other two palliative care patients interviewed were aware of it. Three out of four of the bereaved relatives were aware of the Hospice at Home service. Reasons for not using the service included personal circumstances, as Rachel, Linda and Barbara (palliative care patient's wife) explained.

Rachel (bereaved relative): *"Right, right then, well to be fair I* used to, well I was still sleeping with (husband) I slept in the bed with him every night because that was the way he wanted it. Erm, even the night before he died I was still in the bed with him so that would *never have worked really because he wouldn't have let us* go into another room you know, because he was frightened. So *that (night sitters), that wouldn't have worked I don't think."*

Linda (bereaved relative): "So yes the (Hospice at Home). I could have u*sed them more, but, I didn't have the need to. I had friends, and family around me. I didn't, you know, if I needed them to sit in* with (husband), because he was never left, I would have used them more, my only reason for not using them was because I had other support.*"*

Barbara (palliative care patient's wife): *"Ah the neighbours, you know, they come in and, yesterday, last week, and there's a one coming tomorrow afternoon, just, erm as I say we've got good neighbours, there's a gentleman along the street and there's a lady along the other side. They're all, they're all good."*

A perceived strong home support system was pivotal in not requiring Hospice at Home services, as highlighted by Linda and Barbara above. Personal circumstances and preferences (reasoning), as Rachel explains, are also very important in reference to uptake of the service.

To summarise, the Hospice at Home service was relatively well known, although there was one palliative care patient and one bereaved relative who hadn't been informed about the service. Experiences of the service were all positive, including night sitters and transport services. Reasons for not using the service were mainly due to a lack of need which was often related to a strong support system and personal preferences (reasoning), but also may have included a lack of information about it in the cases of those who were not informed about it.

Commissioned services are being used variably by patients. The palliative care unit should be offered as early as possible in a patient's palliative care journey and not used solely as a respite or unplanned option near to the end-of-life. Patients need to be aware of their options in order to have extended choices. However, it must be acknowledged that home deaths are preferred to hospice deaths (Gomes, Calanzani et al. 2011) which is why uptake may be limited in this rural locality. The Hospice at Home service was evaluated positively by those who had used it and those who did not expressed that they had not had a need to, due to strong support networks. ICP commissioned services should be offered to all patients yet may be of most use to those with weak support networks who will not have the capacity to stay at home, thus it is essential health care professionals identify this vulnerable population early to avoid a hospital death. However, in order for services to be utilised, patients, relatives and carers must have knowledge of them, which in some cases they did not. To conclude, in the context of increased palliative care services, the palliative care unit and Hospice at Home service provided increased support for palliative care patients and their families (resource), however uptake of this support was based on patients' and family member's preferences and needs (reasoning).

Context: Increased need for palliative care services

Additional palliative care services were required in order for patients' preferences to be met. An alternative outlet for hospice care (palliative care unit) and increased palliative care services in the community (Hospice at Home service, complementary therapy charity) were required. The provision of the palliative care unit and Hospice at Home service (resources) met this need and allowed the mechanism to 'fire' for those who required additional support.

Summary
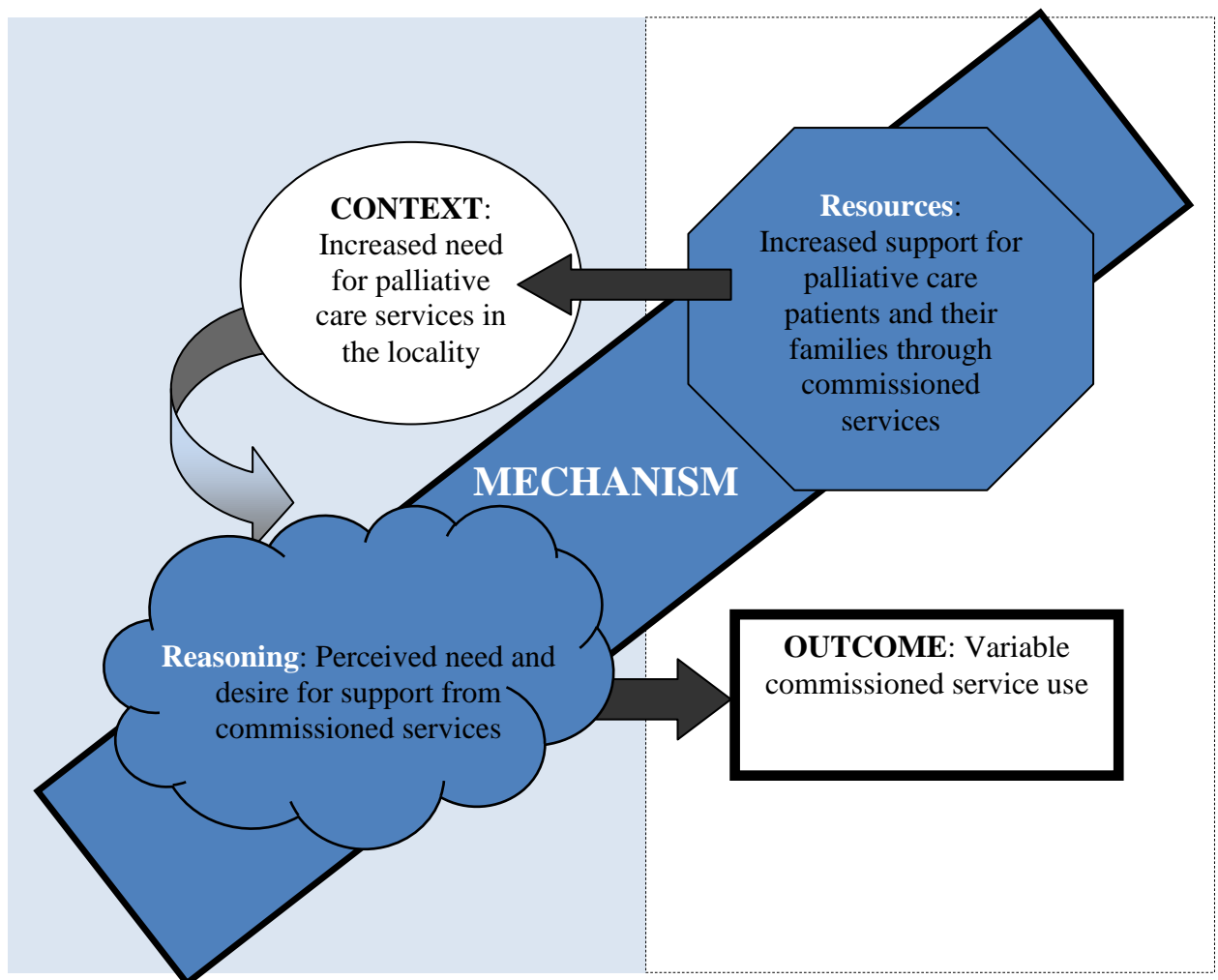
Figure 5: CMOC2, commissioned services in the ICP

The locality was in need of enhanced services for palliative care (context). The provision of commissioned services such as the palliative care unit and the Hospice at Home Service have resulted in increased available support (resource) for palliative care patients and their family members. Whether patients and family members use the services is dependent on personal circumstances (reasoning), with a perceived strong support network often stated as a reason to decline the use of services (reasoning). This has resulted in variable uptake of the palliative care unit and the Hospice at Home service in the locality. CMOC2 is displayed diagrammatically in Figure 5.

CMOC3 – Continuous quality improvement and intervention use

Outcome: Increased use of Integrated Care Pathway interventions

Comparisons of intervention use over time indicate whether the ICP's components are being delivered more regularly and thus whether they are becoming standard practice. Clinical audits undertaken before and after the inception of quality improvements are an effective way of assessing whether the attempts are working (Sullivan and Garland 2010). Increased use of the ICP interventions over time means that they are being used for more palliative care patients, thus more appropriately. It must be noted that from 2009 to 2010 the population who received the ICP increased by 60,000 to 78,000 due to two additional practices joining the locality group and implementing the ICP. This means that these practices would not have had the same level of input in 2010 as the practices which joined in 2009; therefore they were not as experienced in the ICP interventions and may not have achieved the outcomes they could have if they had joined in 2009. Additionally,

values for 2007, 2008 and 2009 do not include the two additional practices. However, the calculations controls for these missing values. The interventions that have been focused on are: palliative care registration, preference discussions, the locality advance care plan, anticipatory medication and LCP use.

Palliative Care Registration

A one-way repeated measures ANOVA was conducted to compare numbers of palliative care registrations from 2008 to 2012, using Death Audit data. Death Audit and MIQUEST data both provide values for palliative care registrations; Death Audit data was used as it provided an additional 2 years of data. Mauchly's Test of Sphericity was significant ($p < .05$), meaning that sphericity was not assumed and Greenhouse-Geisser values are reported. There was a significant effect of time on palliative care registrations ($F(2.74, 30.17) = 9.93$, $p < .001$, $\eta_p^2 = 0.47$). Using the guidelines proposed by Cohen (1988) for the η_p^2 ($0.01 =$ small, $0.06 =$ moderate, $0.14 =$ large effect), this result suggests a large effect size. The means and standard deviations for palliative care registrations from 2007 to 2012 are presented in Table 4, the means show an overall increase in palliative care registrations from 2008 to 2012. However there is a small decrease in the mean from 2010 to 2011. This is depicted in Figure 6.

Table 4: Descriptive statistics for palliative care registrations conducted in the GP practices signed up to the ICP over time, using Death Audit data.

Time Period	Number of practices	Mean	Standard Deviation
2007	12	9.33	10.77
2008	12	10.33	9.23
2009	12	14.33	11.4
2010	12	19.83	16.24
2011	12	18.42	11.11
2012	12	26	16.85
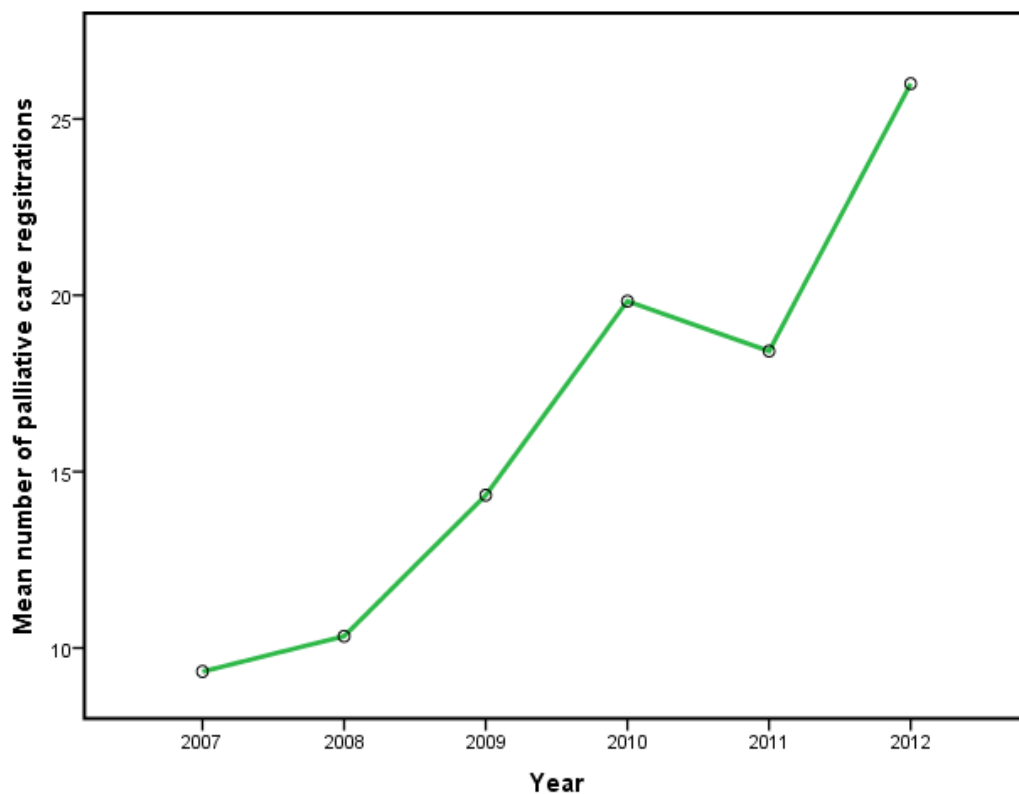
Figure 6: Mean number of palliative care registrations between 2007 and 2012, using Death Audit data.

Preference Discussions

A one-way repeated measures ANOVA was conducted to compare numbers of preference discussions that were documented on the data system in 2009/10, 2010/11 and 2011/12. The means and standard deviations are presented in Table 5; the means show an increase in preference discussions recorded on the data system over time. Mauchly's Test of Sphericity was not significant so sphericity was assumed. There was a significant effect of time on preference discussions recorded on the data system ($F(2, 22) = 15.95$, $p < .001$, $\eta_p^2 = 0.59$). Using the guidelines proposed by Cohen (1988) for the η_p^2 (0.01 = small, 0.06 = moderate, 0.14 = large effect), this result suggests a large effect size. The increases over time in preference discussions recorded on the data system are identified in Figure 7.

Table 5: Descriptive statistics for preference discussions recorded on the data system conducted in the GP practices signed up to the ICP over time, using MIQUEST data.

Time Period	N	Mean	Standard Deviation
2009/10	12	2.58	4.06
2010/11	12	5.58	8.2
2011/12	12	10.75	7.61
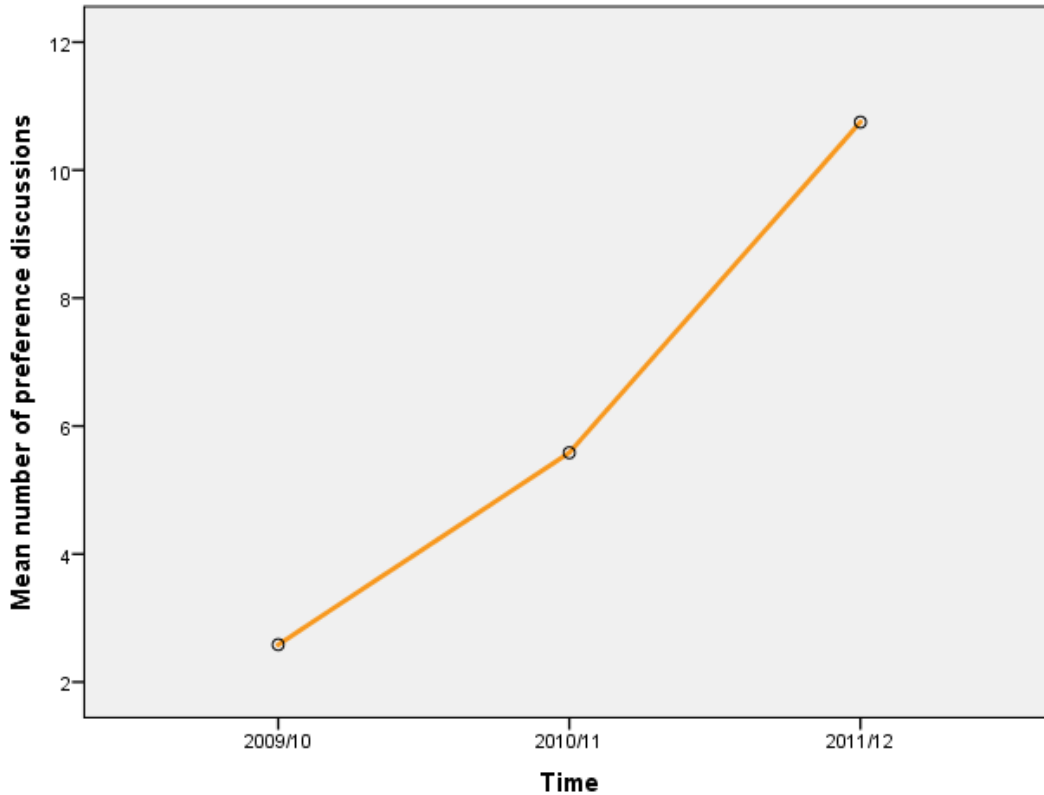
Figure 7: Mean number of preference discussions between 2009/10 and 2011/12, using MIQUEST data.

The number of practices involved in the analysis (N) is twelve instead of fourteen as SPSS accounts for there being no data for two of the practices in 2009/10 as they joined the ICP at a later date. These missing values are not regarded as an issue as the reason they are missing is not related to the data or intervention.

Locality advance care plan

A one-way repeated measures ANOVA was conducted to compare numbers of locality advance care plans completed in 2009/10, 2010/11 and 2011/12. There was no significant effect of time on locality advance care plans completed ($F(2, 22) =$

0.21, p > .05, $\eta_p^2 = 0.2$). This means that the number of locality advance care plans being carried out since the introduction of the ICP has not significantly increased.

Anticipatory medication

In order to assess whether the use of anticipatory medication has increased over time a one-way repeated measures ANOVA was conducted. There was no significant effect for time on anticipatory medication used ($F(2, 22) = 2.67$, p > .05, $\eta_p^2 = 0.2$). Therefore, despite Figure 8 displaying that anticipatory medication is increasing, this increase is not statistically significant.
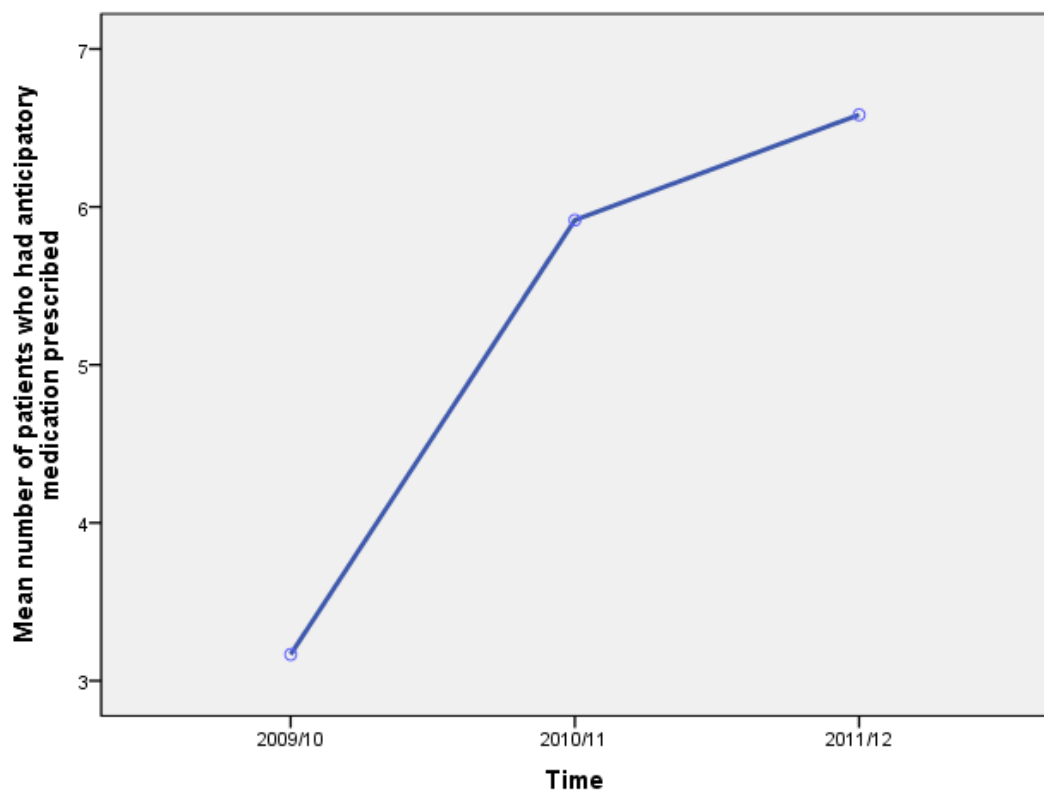
Figure 8: Anticipatory medication prescriptions from 2009/10 to 2011/12.

Liverpool Care Pathway for the Dying Patient

A one-way repeated measures ANOVA was conducted to compare numbers of patients who died with the LCP. The means and standard deviations are presented in Table 6; the means show an increase in LCP use over time. Mauchly's Test of Sphericity was not significant so sphericity was assumed. There was a significant effect for time on LCP use ($F(2, 22) = 3.67$, $p < .05$, $\eta_p^2 = 0.25$). Using the guidelines proposed by Cohen (1988) for the η_p^2 (0.01 = small, 0.06 = moderate, 0.14 = large effect), this result suggests a large effect size. Therefore it can be concluded that the GP practices are significantly increasing their use of the LCP since the introduction of the ICP, this increase is shown in Figure 9. The means and standard deviations indicate a large increase from 2009/10 to 2010/11.

Table 6: Descriptive statistics for LCP use in the GP practices signed up to the ICP over time, using MIQUEST data.

Time Period	N	Mean	Standard Deviation
2009/10	12	5.83	5.70
2010/11	12	9.58	10.1
2011/12	12	10.17	9.95
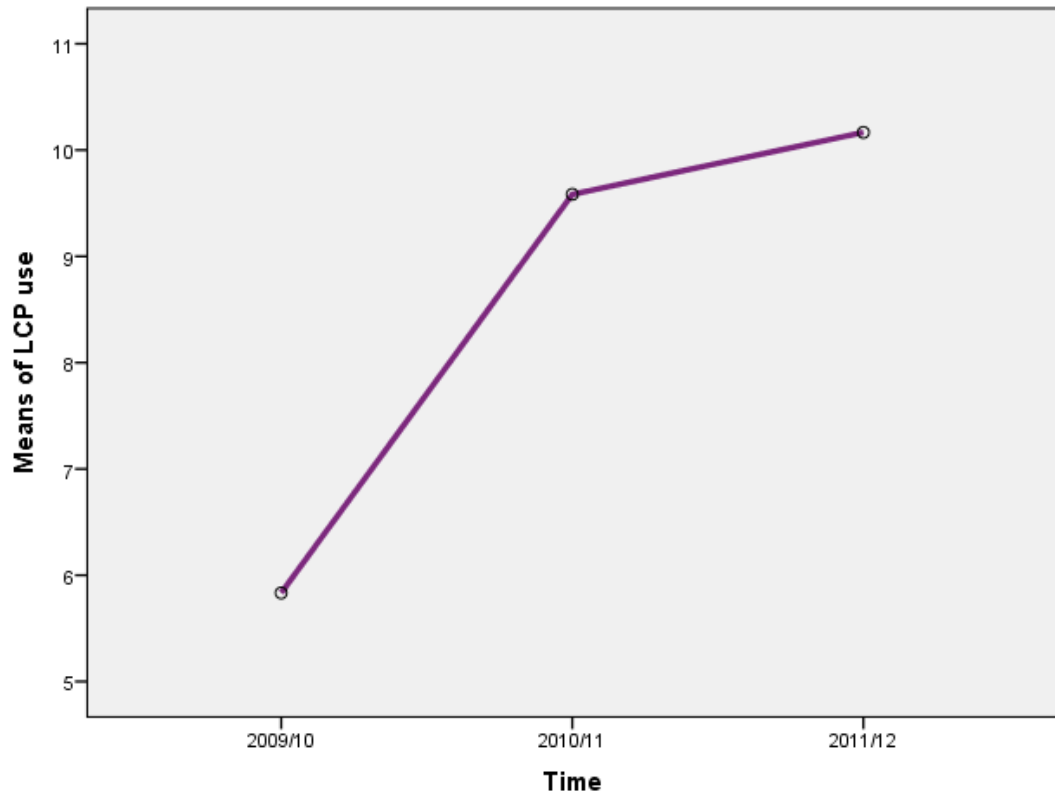
Figure 9: Mean number of LCP use between 2009/10 and 2011/12, using MIQUEST data.

Summary of ICP intervention analysis

The statistical analysis of GP practice data suggests that the use of some of the ICP interventions is increasing over time: palliative care registrations, preference discussions and LCP. All of these interventions indicated a significant increase in use from implementation of the ICP to 2012. Furthermore, Cohen's (1988) effect sizes indicated that all of the significant increases in intervention use were large. However, neither anticipatory medication nor locality advance care plans showed significant increases over time. In terms of locality advance care plans, this non-significant increase might be due to health care professionals' difficulties with the documentation (discussed later in chapter 6, p.199).

Mechanism: Continuous Quality Improvement

In the ICP CQI takes the form of PCQVs which utilise GP practice data (Death Audit and MIQUEST) to feedback information on performance to practices. It is a resource that the ICP provides, as CQI requires leadership (from the ICP's founder) and financial resources (through ICP commissioning streams) to educate and enable health care professionals to evaluate themselves. It involves not only identifying issues with the ICP and problems in practice but also gives recognition of effort (reward systems) in both verbal and written forms (McLaughlin 1994). These clinical governance visits consist of the founder of the ICP visiting the GP practices MDT meeting to: feedback data, reflect on the practice's performance, discuss how the practice staff would manage a fictional palliative care patient from diagnosis to death, talk about difficult issues experienced when using the ICP, and identify and provide potential solutions for problems specific to that individual practice. Thirteen of the fourteen GP practices involved in the ICP and this study have received one PCQV. The PCQV were evaluated positively by both a community matron and a GP, who felt that they received constructive feedback tailored to the individual practice (resource) which helped them to improve as a team.

> Community Matron 2 (FG1): *"(I've) b*een involved with two *because we cover two practices, and they've both been very different and they've been constructive, very honest, but* constructive and ac*tions have happened as a consequence."*

> GP3 (FG1): *"Yeah, (inaudible) brought the team together to* discuss it with (ICP founder) and we did get very helpful feedback *which we took on board"*

GP2 suggested that the PCQV resulted in practices engaging with the ICP more (reasoning), due to the information that they were provided with about their performance.

> GP2 (FG2): *"And I wondered if under input, and again it's a more* general comment, whether we should be putting something about audit, feedback, education process into this, and I was thinking *specifically about (ICP founder's) visits to practice, because I* know that a lot of the practices, you know, have engaged a lot *more, further, after one of (founder's) visits becaus*e of the information that was fed *back to them."*

Community Matron 2 and GP2 then built on the above quotes by explaining how even just the prospect of the PCQV resulted in them improving their performance (reasoning).

> GP2 (FG2): *"Yes I think there's, there's, before you're about to* hav*e it there's a stimulus, after you've had it because of the feedback there's a stimulus and I know I've, in the past our statistics improved because it stimulated us."*

> *Community Matron 2 (FG1): "There's something about, which I've thought about since t*he beginning of this meeting, is that *there's been a great leadership with this, these visits, it was the* same with others, like diabetes and heart quality visits that there *was, exactly what you said, before we've got to get it ready, we've* got to get it right and then you do sort of pick up on the points and *then it's just human nature everything drops off again and I think if the leadership doesn't keep going it's sort of keeping that, gotta* keep it going, so there is something about that (inaudible) tha*t's lost."*

This highlights how CQI is itself modifying the delivery of the programme. The knowledge of an upcoming PCQV visit (resource) is enough to make staff feel they need to adhere to the programme (ICP) specification more rigidly. However, the negative facet to this is that post PCQV, after initial motivation and enthusiasm

from the visit has peaked and then diminished, health care professionals may begin to lose sight of the ICP goals and ethos and make less use of the associated interventions. Pawson (2013) highlights that enthusiasm is time bound and can dip as the ICP (social programme) is used more by those who implement it. The social programme then becomes less capable of inspiring change through enthusiasm for a new innovation. This could be the case in the ICP, as palliative care registered patients are increasing (see the quantitative analysis above, p.128) and thus it could be assumed that the ICP is less capable of producing change, due to the enthusiasm about the initiative depleting. However, as will be discussed in chapters to come, palliative care registrations are increasing for some palliative care patients, but not all (See Chapter 5: Identifying and registering palliative care patients, p.163). This means that the PCQV are still capable of inspiring change, educating, increasing motivation and enthusiasm, which is demonstrated in the quotes from the focus groups, from the health care professionals who deliver the ICP. The participants describe benefitting from several outcomes of the PCQV (resource): education, feedback, evaluation, motivation and renewed enthusiasm. In a large scale systematic review by Greenhalgh, Robert et al. (2004) it was highlighted that the capacity to evaluate an innovation was crucial to its successful diffusion into routine practice. If suitable systems and skills are present to monitor and evaluate the innovation (ICP) this leads to a higher probability of it becoming embedded, assimilated and sustained (Greenhalgh, Robert et al. 2004). Thus, PCQVs should help the ICP to become embedded.

In summary, the health care professionals' reasoning is changed, as they improve their performance and use of ICP interventions, due to the knowledge of an upcoming PCQV or in reaction to feedback from a PCQV (resource). This then

leads to the more frequent use of interventions advocated by the ICP, as described in the outcome section to follow.

Context: Proactive and patient centred care

Many of the ICP interventions are focused on proactive care (palliative care registration, preference discussion, ACP, anticipatory medication), meaning that in the use of the interventions GPs are implicitly being proactive. Thus the medical and political drive for proactive care is a factor that will affect the use of ICP interventions. Patient centred care is another philosophy that is widely advocated in health care (Little, Everitt et al. 2001, McCormack, Treiman et al. 2011, Mulley, Trimble et al. 2012) and can also be considered as a context that affects the use of the ICP interventions and consideration of place of death. Patient centred care is the process of providing care that is responsive to individual personal preferences, values and needs and ensures that patient values are central to all clinical decisions. Some of the ICP interventions, such as preference discussions and ACP, explicitly present operationalisations of patient centeredness. All health care professionals in the focus groups were very aware of the notion of patient centred care and highlighted it in FG2 as the most important context in regard to several interventions that the ICP uses: the ICP overall, palliative care registration, ACP, MDT meetings and the traffic light system. CQI also aims to improve services with a view to providing patients with a good death (being patient centred).

FG3 highlighted that proactive and patient centred care were the crucial context in this CMOC, with the NHS drive for CQI acknowledged but not pivotal. The NHS drive for improvement is actually incorporated in the social programme and forms part of the mechanism resource.

GP3 (FG3): *"I would suggest that proactive and patient centred care is the most important context… Well of the two, whilst the NHS drive for CQI is there in the background I don't see it as something that drove us."*

GP4 (FG3): *"No I m*ean I, I agree, the NHS drive for the CQI is there in a lot of domains but I would say that locally, the end-of-life care is *one of the things that we did really progress, and I think that's* probably come from the feedback from (palliative) care quality visits. Erm that was one of the reasons I think that we were more enticed *into that role than all the other stuff that was sent to us really"*

Despite the important role of CQI as a mechanism, it was not considered to be a contextual factor that drove the use of ICP interventions.

Summary
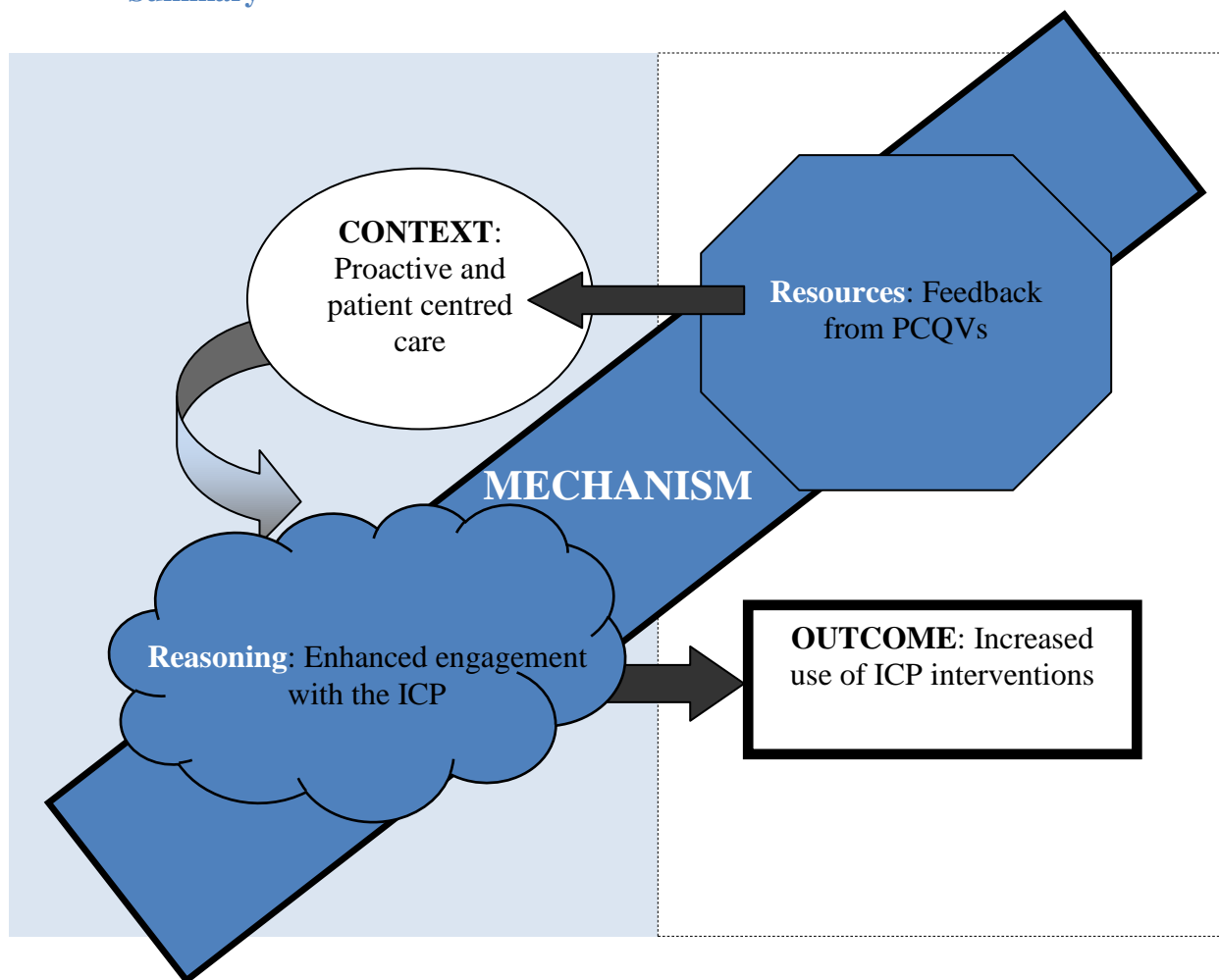
Figure 10: CMOC3, CQI and intervention use

The drive to provide patient centred and proactive care in the locality (context) means that the education and feedback PCQVs provide (resources) result in motivation and enthusiasm from the health care professionals, both prior to and post PCQV. This makes them engage with the ICP more (reasoning). This mechanism results in increased use of interventions (outcome): palliative care registration, preference discussions, LCP. However, locality advance care plans and anticipatory medication use have not significantly increased. Explanation of the non-significant increase in locality advance care plans will be discussed elsewhere in the thesis (Chapter 6: Preference discussions and locality advance care plans, p.199). Anticipatory medication may not have significantly increased because GP practices can be very variable in their recording of anticipatory medication. This CMOC demonstrates the importance of the PCQV in continually improving the ICP and increasing intervention use and recording through motivating and educating the health care professionals who deliver it. CMOC2 (Figure 10) illustrates the relationship between the contexts, mechanisms and outcomes in this configuration.

CMOC4 (I) – Peer support, leadership and embeddedness of the ICP

Outcome: Embeddedness - three high performing practices

Cluster analysis can be used to discover structures in data but does not explain why they exist. Thus in this analysis it will be used to identify relatively homogeneous

groups of GP practices based on selected characteristics (such as ICP interventions or place of death outcomes), input by the analyst, which will be stated below in each cluster analysis. Two separate cluster analyses were conducted - one focused on outcomes (place of death, number of interventions administered and number of palliative care registered deaths), the other focused on a number of intermediate outcomes from ICP interventions (palliative care registration, the locality advanced care plan, OOH notification, DS1500 forms for monetary benefits, anticipatory medication and LCP). Two clusters were selected from the data collected from fourteen GP practices. Hierarchical clustering was used, which involves factors being organised into a hierarchical structure as part of the procedure. This was done with a between groups linkage that clusters objects based on the distance between them.

Cluster Analyses I

The first cluster analysis completed showed two clusters when using four factors from 2011/12 data: patient death in their own home (MIQUEST), patient presumed preferred place of death including home, care home and palliative care unit/hospice (MIQUEST), ratio of interventions administered to total deaths (MIQUEST) and ratio of palliative care registered deaths to total deaths (MIQUEST). These four factors were selected as they are outcomes of the ICP and offer explanatory potential however they are not outcomes of intervention use in their primary form (as in Cluster Analyses II). The analysis identified two clusters, cluster 1: GP Practices A, B, C, F, G, H, J, K, L, M and N, and cluster 2: GP Practices D, E and I.

T-tests were performed to find out which factors significantly contributed to the clusters. Normality of data was checked for all outcomes the t-tests were performed on; normality pertained in all instances. There was a significant difference between clusters for the numbers of home deaths patients achieved ($t(12) = -3.07$, $p < .05$). Cluster 2 (practices D, E and I) had significantly more patients who died in their own homes ($M = 10.33$, $SD = 4.51$) than cluster 1 ($M = 4.36$, $SD = 2.58$). There was also a significant difference between clusters for presumed preferred place of death (MIQUEST) ($t(12) = -6.29$, $p < .001$). The presumed preferred place of death is a combination of home, care home and palliative care unit/hospice deaths. It is assumed that these are preferred places of death for patients as a considerable effort would be needed in order for a patient to die in this location, and hospital is reported as the least preferred place to die in both locality and regional data (Gomes, Calanzani et al. 2011). Significantly more patients died in the presumed preferred place of death in cluster 2 ($M = 29.33$, $SD = 6.81$) than in cluster 1 ($M = 8.45$, $SD = 4.68$). The ratio of interventions administered ($t(12) = -1.7$, $p > .05$) and the ratio of palliative care registrations to total deaths ($t(12) = -1.29$, $p > .05$) were both not significantly different between cluster 1 and cluster 2.

To summarise, cluster 2, which consisted of practices D, E and I helped patients to achieve a home or presumed preferred place of death significantly more than cluster 1 (all other practices from the locality).

Cluster Analyses II

The second cluster analyses focused on interventions and formal outcomes of the ICP. This cluster organised the GP practices in the same way as cluster I; cluster I

consisted of GP practices A, B, C, F, G, H, J, K, L, M and N, and cluster 2 consisted of GP Practices D, E and I. The factors entered into the cluster analysis were palliative care registration, locality advance care plan, OOH notification, DS1500 forms, anticipatory medication and LCP. All data was from 2011/12.

T-tests were performed to find out what significant differences contributed to the clusters. Normality of data was checked for all interventions t-tests were performed on; normality pertained in all instances. There was a significant difference between clusters for the number of palliative care registrations made ($t(12) = -4.63$, $p < .001$). Cluster 2 (practices D, E and I) registered significantly more patients on the palliative care register ($M = 36$, $SD = 12.12$) than cluster 1 ($M = 13.27$ $SD = 6.23$).

There was not a significant difference for use of the locality advance care plan between the two clusters, although the p value was near significance ($t(12) = -1.94$, $p = 0.76$) and the means indicated that cluster 2 ($M = 9.33$, $SD = 3.22$) completed more advance care plans than cluster 1 ($M = 4 .64$, $SD = 3.8$).

OOH notifications were significantly different between the two clusters ($t(12) = -3.3$, $p < .01$), with cluster 2 completing significantly more OOH notifications ($M = 15.33$, $SD = 5.77$) than cluster 1 ($M = 6.27$, $SD = 1.153$).

A t-test showed that cluster 1 and 2 had a significant difference for DS1500 forms completed ($t(12) = -2.45$, $p < .05$), with cluster 2 administering more DS1500 forms ($M = 8.33$, $SD = 6.66$) than cluster 1 ($M = 3.09$, $SD = 2.02$).

Clusters 1 and 2 showed a significant difference on the amount of anticipatory medication prescribed to patients ($t(12) = -4.76$, $p < .001$). Cluster 2 prescribed significantly more anticipatory medication ($M = 14.67$, $SD = 3.22$) than cluster 1 ($M = 5.18$, $SD = 3.03$).

There was a significant difference in the amount the LCP was used between cluster 1 and cluster 2 ($t(12) = -7.26$, $p < .001$). Cluster 2 used the LCP significantly more ($M = 26.67$, $SD = 6.51$) than cluster 1 ($M = 6.45$, $SD = 3.67$).

To summarise, cluster 2, consisting of practices D, E and I, administered or completed significantly more formal interventions from the ICP than cluster 1 on all formal interventions apart from use of the locality advance care plan, where the outcome was not significant, but it was extremely close to significance. They also had significantly more home or presumed preferred place of death (home, care home or palliative care unit). Since it has now been highlighted by this quantitative analysis that practices D, E and I can be considered as 'high performers' a comparison can be made; between the high performing practices and the other practices in the locality.

Mechanism: Opinion leaders and a champion

Peer support and leadership are both very important when implementing new initiatives (Greenhalgh, Robert et al. 2004) and contribute to embeddedness. Practice D, E and I all have peer support and leadership in the form of opinion leads or a champion. Practice I hosts the GP Locality Lead for Research who is very research active and a data active GP who ensures the recording, analysis and feedback of data to the practice is of a high standard. This GP and the GP Locality Lead for Research could be considered as peer opinion leaders (Greenhalgh, Robert et al. 2004). These two peer opinion leaders at practice I had a positive effect on ICP diffusion in their practice, they adopted the ICP promptly after sign up due to their active roles and their desire for constant progress through research, feedback, and innovation and this had an effect on others in the practice (I).

Practice D also has an opinion leader present (resource), but this opinion leader is an expert opinion leader, as opposed to a peer. An expert opinion leader exerts influence through their authority and status (Greenhalgh, Robert et al. 2004). The expert opinion leader is a GP at practice D and the Director of the Clinical Commissioning Group. He was a great supporter of the ICP, involved in its design and implementation; his support of the ICP influenced others in his practice (practice D) to also support it.

The literature on innovation diffusion highlights that the ICP's founder is a 'champion'. A champion (resource) can aid innovation diffusion as they exert influence on others. Before retiring in 2011, the founder was a GP at practice E. Thus, the presence of a champion may have resulted in the ICP becoming more embedded at practice E, hence their better outcomes in comparison to other practices. The founder of the ICP meets the criteria to be a champion, described in Chapter 2 (p.40) He hosts PCQV to provide a forum for the health care professionals who deliver the ICP to discuss their unique practice problems (organisational maverick). The founder then works collaboratively with them to formulate autonomous solutions. The PCQVs also allow the founder to feedback to the practices on their performance, thus providing a flexible monitoring system that gives information on resource use such as the commissioned palliative care unit or ACP (organisational buffer). This flexible monitoring system also ensures that innovators properly use the organisation's resources while still allowing them to act creatively (organisational buffer). He is also a well-respected, long standing GP from the locality (now retired), thus he inherently has organisational, clinical and local knowledge that is valued by others (transformational leader). Finally, he acts as a network facilitator, as he develops cross-functional coalitions within the

organisation by regularly hosting multidisciplinary workshops for the full locality including all fourteen practices (network facilitator). Specifically, coalitions have been made between social care and nursing care staff via workshops which addressed issues that affected practice (Greenhalgh, Robert et al. 2004). Furthermore, the ICP founder worked closely with the management support that was contracted to aid implementation of the ICP.

New systems that have a clear, explicit advantage in either effectiveness or cost-effectiveness are more easily accepted and implemented (Greenhalgh, Robert et al. 2004). Thus if health care professionals see no relative advantage (reasoning) in the ICP, they usually will not consider it any further and therefore will not use it (Greenhalgh, Robert et al. 2004). Therefore, seeing the relative advantage is an essential reasoning for ICP adoption. Opinion leaders and champions who provide peer support and advocate the ICP by pushing the palliative care agenda will help other members of their team to see its relative advantage. When asked about the relative advantage of the ICP, representatives from Practices D and E stated:

> Practice D representative: *"The ICP ensures good communication* around patient care and thus improves patient care. The palliative care pathway helps us provide high quality palliative care. It ensures all aspects of palliative care are addressed and also *communicated to Out of Hours care providers."*

> Practice E representative: *"It is a good* framework for us, based on *sound clinical evidence."*

Opinion leaders and champions were identified in high performing practices through field work prior to FG3. However, in this focus group, one of the GPs who works at a high performing practice (practice D) identified correctly that they had an expert opinion leader, confirming the field work theory.

GP4 (FG3): "I think from my point of view (founder) visits were very supportive and helpful but in addition to that, (expert opinion leader) here (at practice D), he was sort of pushing the (advance) care *planning agenda as well and motivated us as a practice as well.*"

The comments from GP4 confirmed that opinion leads played an important role in the embeddedness of the ICP.

Context: Shared nursing team on site which facilitates MDT meetings

Nursing care can be shared between practices in the locality. All of the high performing practices share a nursing team with a neighbouring practice. However, despite being shared with another practice, all of the high performing practices have their nursing team on site. This has an impact on the mechanism, as having the nursing team on site will make weekly MDT meetings more achievable. Furthermore, it increases the likelihood of informal contact and enhances professional relationships within the MDT. MDT meetings are important as they allow for discussions of palliative care and implementation of the ICP. Intra-organisational communication across departmental boundaries within a practice enhances the success of innovation diffusion and therefore enhances embeddedness (Greenhalgh, Robert et al. 2004). The presence of opinion leads will facilitate this by pushing the palliative care agenda at these meetings and helping other health care professionals see the relative advantage of the ICP. Although some of the practices that were not classified as high performing also have their nursing team on site, they do not have other facets of the CMOC such as opinion leaders or champions. Other practices in the locality also have fewer MDT meetings, either monthly or bimonthly.

Both the social care team lead and GP4 highlighted the importance of regular MDT meetings in FG3, confirming the important context of having a shared nursing team on site. GP4 was from one of the previously identified 'high performing' practices.

> Social care team lead (FG3): *"So you're talking about physical face to face, peer support, sharing information and sort of good practice and having a bit of reflection going on and that sort of pushes it forward and keeps up that enthusiasm around it really. You can see good outcomes for people."*

> GP4 (FG3): *"And I think also the regular MDT meetings, we talk about out palliative care meetings each week and possibly stuff gets highlighted then that wouldn't necessarily in the course of everyday surgery because it actually is a space to talk about these patients regularly and also I would say that the district nurses are our eyes on the ground really, they see a lot more of the patients on a daily basis than we do as GPs and its good for them to remind us exactly what's going on regularly regarding these patients."*

Discussions in FG3 also highlighted that having the nursing team on site is not only useful due to its facilitation of regular MDT meetings, but also because nurses often prompt GPs to carry out important tasks. This may be due to their more regular contact with patients in the community, as referred to in the quote above from GP4.

> GP3 (FG3): *"The thing with nurses being on site… (district nurse) was always prodding us (as GPs) to do things."*

In summary, health care professionals value regular MDT meetings highly and find these useful in addressing the needs of palliative care patients. Having the nursing team on site can aid regular MDT meetings and nurses can also prompt GPs regularly to carry out important actions. Effective communication across structural boundaries within the organisation enhances the success of implementation and the chances of ICP sustainability (Greenhalgh, Robert et al. 2004). Thus having the

nursing team on site is crucial as it facilitates MDT meetings and informal discussions in practice (meeting in the corridor).

Summary
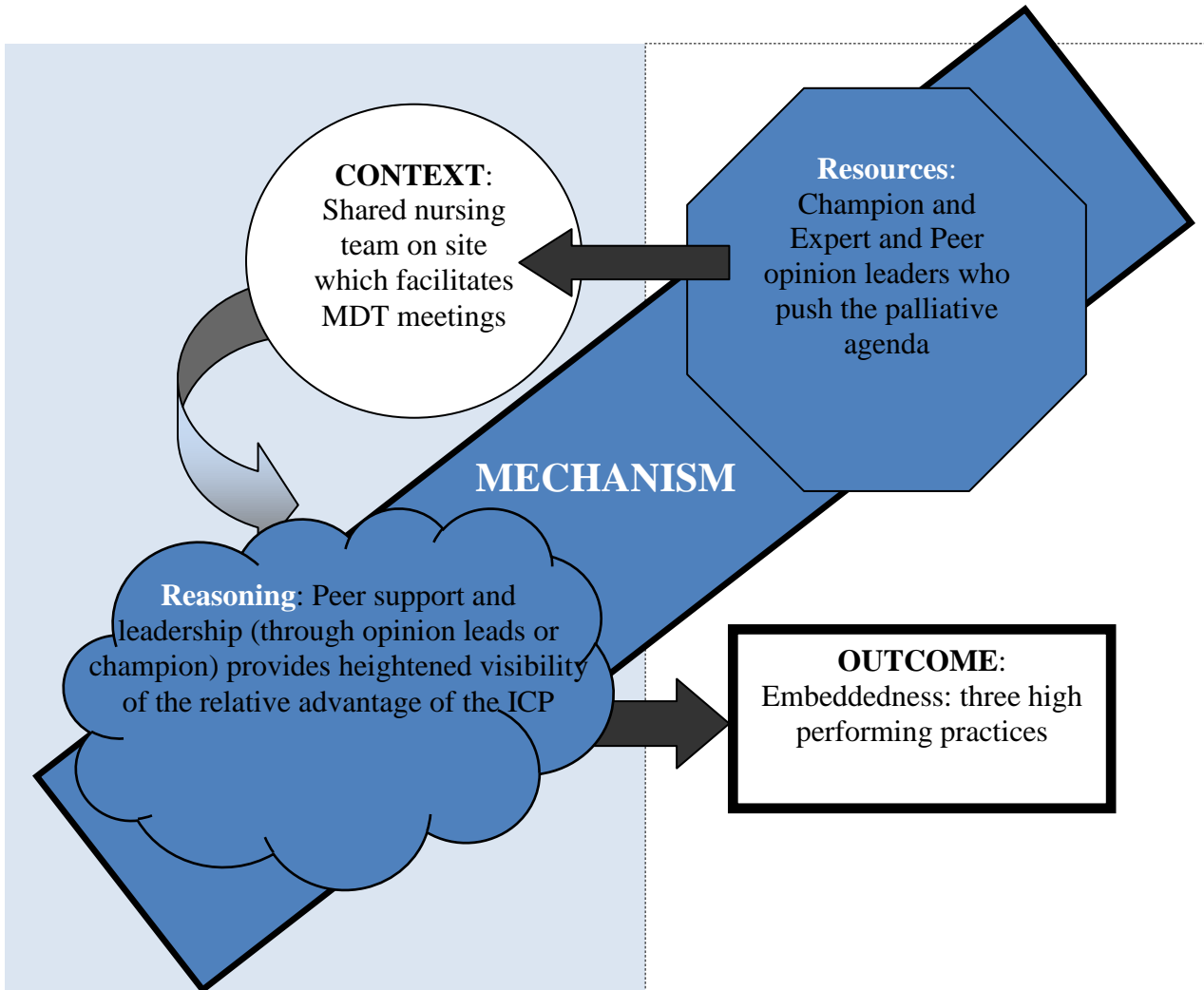
Figure 11: CMOC3 (I), peer support and embeddedness of the ICP.

The mechanism of leadership and peer support in a fertile context (nursing tem on site facilitating regular MDT meetings) has resulted in three practices becoming high performers in terms of intervention use and outcome (preferred place of death). This CMOC (Figure 11) explains how the ICP is working for the high performing

practices. The next CMOC will be its associate, describing how the ICP has not worked as well for one of the other practices in the locality.

CMOC4 (II) – Low peer support and perceived detachment

This CMOC is based on evidence from the PCQV with Practice C, a practice that was not performing as well as could be expected. The evaluation of the ICP began in 2011 whilst the ICP began in 2008. This meant that most PCQVs had already been undertaken by the time the evaluation began. However, the PCQVs attended provided crucial insight into some of the practices in the locality.

Outcome: Less use of the palliative care register and other interventions

Figure 12 shows that Practice C is increasing its use of the palliative care register. However, table 7, which displays the number of interventions given to patients, indicates that palliative care registration is still not meaningful to this practice; little further action comes from it.
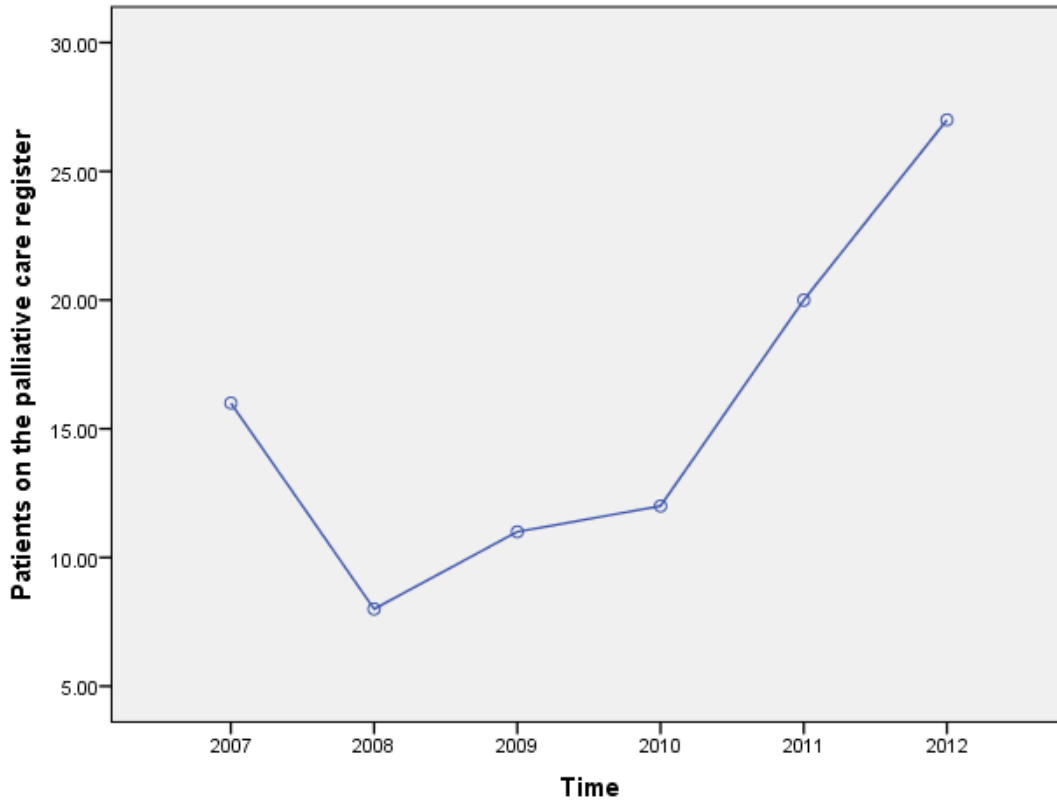
Figure 12: The number of palliative care registrations in Practice C from 2007 to 2012, using Death Audit data.

Table 7: The number of patients who had interventions in Practice C, using MIQUEST data.

	2009/10	2010/11	2011/12
Preference Discussions	3	3	10
ACP	2	2	5
Anticipatory medication	3	3	8
LCP	2	4	8

Despite recent (2011/12) increases in intervention use in practice C, intervention use is still low in comparison to the numbers of palliative care patients registered (see Table 7). This practice's data is reminiscent of the old palliative care registers that were used in the locality where patients were registered but few interventions were provided.

Mechanism: Lack of communication

The PCQVs revealed that Practice C did not have a cohesive team (lack of resource), with the lead palliative care GP having several issues with implementing the ICP. Other staff would not administer or record interventions using the system templates. CQI is based on the premise of a cohesive team who work well together under high quality leadership (Robbins and Finley 1995). Thus the CQI mechanism is unlikely to enhance engagement with the ICP in this circumstance. Practice C also has fewer MDT meetings (monthly) in comparison to the high performing practices (weekly). This gives them less time to provide peer support to one another, an aspect of the MDT meeting that was valued as very important to health care professionals in FG3.

> MacMillan Nurse (FG2): *"And experience as well you know, you've got so many different people with levels of experience and* things like that, that you can feed off each other and learn so much *from each other, and I think that gets lost doesn't it when you…* (Trails off). Especially in the community because you spend a lot *of time on your own, so it's nice to get together and have those* times when yo*u can discuss."*

> GP1 (FG3): *"A very big function of it (MDT meeting) is, is support* of members (inaudible) of that (working) family, because every palliative care is different, everyone, everyone is, is different in its *own way, it's unique and challenging. I think that's a really important output."*

> GP3 (FG2): *"I think support is vitally important to be giving each* other and I (inaudible), I can see that going in many different directions. And er, one of the last locums I did here (GP practice), there was a discussion, must have been just before (specialist) left, of a very difficult case which the nurses and the doctors, and most of the support went actually from the district nurses to the two GPs who felt incredibly exposed in the situation, but left the meeting feeling so much more supported, when everybody else had realised the difficult situation they had been in. So I think that the support, *seeing it as a whole team was so important."*

It was also apparent from the PCQV that practice C did not see the relative advantage of the ICP (reasoning) due to their lack of teamwork. Despite being asked to, they refused to display their palliative care register on a board where all members of the health care team could see it. This would mean that if one GP places a patient on the palliative care register, no other team members would be aware of this registration until the monthly MDT meeting, unless through informal communication. Furthermore, since the MDT meeting is only monthly and will have a large agenda, palliative care may not be discussed in depth due to time restrictions. This contributes to the low numbers of interventions patients receive once put on to the palliative care register. Nurses are often those who carry out preference discussions and ACP and suggest the need for anticipatory medication, whereas GPs are more likely to register patients. This lack of communication (resource) via a palliative care register that all health care professionals can see is having an effect on the interventions provided. To summarise, health care professionals' reasoning is not being changed to see the relative advantage of the ICP through weak team support and leadership, which leads to less intervention use due to crucial breaks in communication between team members.

Context: Detachment from the ICP and locality

At the PCQV the lead GP described feeling detached from the locality in general. This led to late adoption and slow implementation of templates and backup for administrative purposes. Furthermore, the nursing team are shared but are not on site at Practice C, a crucial context identified previously in CMOC4 (I). The nursing team are actually shared with Practice E (a high performing practice). Thus despite having the same nursing staff, one practice (E) is performing extremely well,

administering significantly more interventions and achieving better outcomes (place of death), and one GP practice is not (C).

Summary
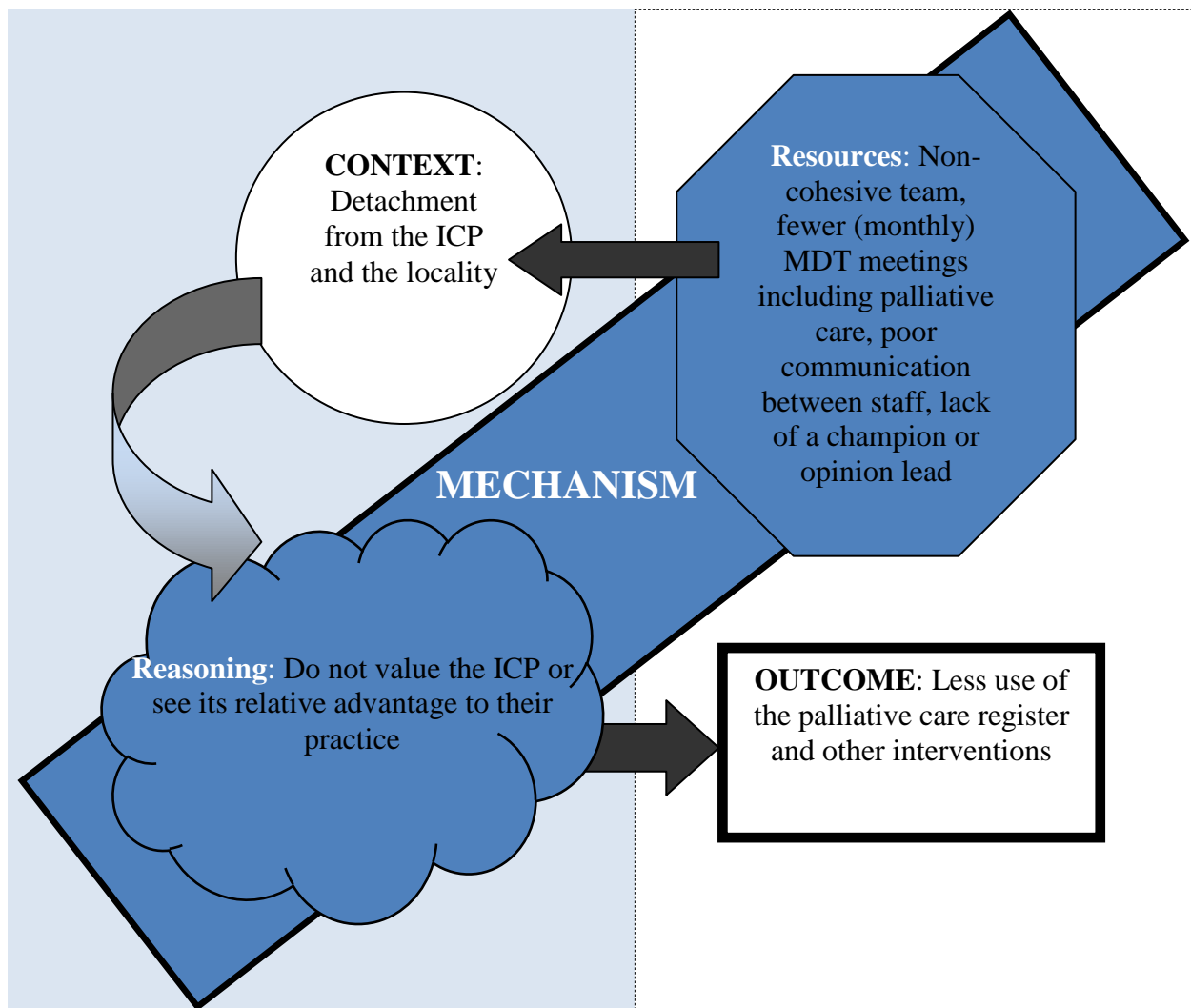
Figure 13: CMOC3 (II), low peer support and perceived detachment

Practice C is detached from the locality and the ICP (context). They share a nursing team with one of the high performing practices previously identified, but crucially this nursing team is not on site (context). Health care professionals' reasoning has not been changed to see the relative advantage of the ICP through peer support (resource) from those with significant involvement in palliative care or the ICP (less

frequent MDT meetings, no opinion leader or champion present). This has resulted in limited increase in use of ICP interventions such as palliative care registration, preference discussions and LCP use (outcome). Thus, the ICP is less embedded in this practice (outcome), as depicted in Figure 13.

Chapter Summary

The ICP has embedded into GP practices to varying degrees. Peer support and CQI are essential to ICP embeddedness, with those who have a strong peer support using more ICP interventions and getting better outcomes for patients in terms of place of death. CQI has contributed to practices significantly increasing their palliative care registrations, preference discussions and LCP use across the locality. Thus the ICP works as it is increasing intervention use (apart from ACP and anticipatory medication which will be discussed elsewhere in the thesis) and it works particularly well for those practices that have strong peer support mechanisms and CQI sessions. Furthermore, the ICP itself is a mechanism which provides interventions; intervention use predicts some of the variance in place of death, thus showing that the ICP works as a palliative care pathway. Finally, interviews highlighted that uptake of commissioned services was variable. This was attributed to personal circumstances and needs yet does not necessarily reflect lack of service value.

Programme theory 1 stated that some GP practices will have better outcomes in terms of place of death than others (context) due to use of interventions (mechanism). This programme theory has been expanded and refined. Some GP

practices (Practices D, E and I) do have better outcomes than others in terms of place of death, which is predicted by intervention use. However, there are also other essential mechanisms such as peer support and CQI.

The next chapter focuses on the first intervention in the ICP, palliative care registration. This intervention is crucial, as it allows health care professionals to identify appropriate patients and work within a palliative care framework and to administer further interventions from the ICP such as preference discussions, ACP and LCP.

Chapter 5: Identifying and registering palliative care patients

Palliative care registration is the first step in engaging with the ICP and allows access to further appropriate interventions; palliative care registrations can thus be considered as a measurable proxy for early identification and ICP use. In line with national policy (Department of Health 2008) one of the key aims of the ICP was to identify palliative care patients within 6 months of the end-of-life and place them on the practice palliative care register. This leads to the use of ICP interventions such as OOH notifications and ACP. It also allows health care professionals to use the traffic light system to identify when patients are declining and allows for more responsive, comprehensive and individualised care in the patient's preferred setting, where possible. In turn, this early identification can lead to a good death (Department of Health 2008). A second aim of the ICP was to identify and register all palliative care patients, regardless of diagnosis, with a specific focus on increasing the registration of non-cancer patients. This was due to the acknowledgement within the locality that non-cancer palliative care patients were rarely identified early. This is also particularly important as population based studies using random samples of deaths and bereaved carer reports indicate that there are more symptom issues in the last year of life in those suffering from progressive non-cancer diseases than those suffering from cancer (Higginson 1997). This is due to the more extended trajectory of decline in non-cancer illnesses

(Murray, Boyd et al. 2005). This suggests that non-cancer patients will rely heavily on palliative care symptom control; the palliative care register identifies these patients and highlights them to health care professionals who can meet their needs. This chapter will describe CMOCs focused on the registration of palliative care patients in order to address the research questions and programme theory below.

Initial questions asked of the data

The programme theory and subsidiary questions that this chapter focuses on were first stated in the methodology chapter and are reiterated below.

- **Programme theory 2**: Palliative care registrations should increase (outcome) due to a focus on identifying patients early using the palliative care register (mechanism) in a health care domain that appreciates the palliative care needs of patients (context).

    - Are palliative care registrations increasing in the locality and if so why?

    - Are both cancer and non-cancer patients appropriately put onto the palliative care register?

CMOC1 focuses on palliative care registrations for all palliative care patients regardless of disease type and explains how this is affected by the consensus of a palliative care definition in the locality. CMOC2 investigates the differences between cancer and non-cancer deaths on the palliative care register and the stress associated with non-cancer registrations. Supporting CMOC2, CMOC3 elucidates

the anxieties health care professionals have about over populating the palliative care register with elderly and frail care home residents who have non-cancer illnesses. CMOC4 explains the recent increase in non-cancer registrations from 2011 to 2012.

CMOC1 – Palliative care registrations

Outcome: Increase in all palliative care registrations from 2008 to 2012

As discussed in relation to the embeddedness of the ICP, palliative care registrations are significantly increasing over time; a one-way repeated measures ANOVA was conducted to compare numbers of palliative care registrations from 2008 to 2012, using Death Audit data. Mauchly's Test of Sphericity was significant ($p < .05$), meaning that sphericity was not assumed and Greenhouse-Geisser values are reported. There was a significant effect of time on palliative care registrations ($F(2.74, 30.17) = 9.93$, $p < .001$, $\eta_p^2 = 0.47$), indicating a large effect (Cohen 1988). The means showed an overall increase in palliative care registrations from 2008 to 2012, therefore it can be concluded that palliative care registrations have increased.

Mechanisms: The decision to register patients

Presented below are two mechanisms which work at different levels – the individual level, which contributes to the second mechanism which is at the team level.

Individual level

'Would you be surprised if this patient was to die in the next 6 months?' (The National Gold Standards Framework Centre 2009) (resource) is used by health care professionals in the locality to assess suitability of a patient for the palliative care register. This resource increases individual health care professionals' confidence to suggest palliative care patients for registration at the MDT meeting (reasoning).

> GP2 (FG2): *"I think it's one of the things that t*he palliative care pathway helped us with, in creating our palliative care registers we had to question, we had to ask ourselves, would you be surprised if this person died within six months? And that most certainly helped me define who I had previously would not have *defined as palliative care… so I think that the pathway has helped that definition but that's a local phenomenon I think."*

The surprise question is a resource that health care professionals can use in isolation to make decisions about individual patients. If a health care professional believes that the patient may die in the next 6 months then they should suggest them for registration at the next MDT meeting.

Team level

The surprise questions prompts individuals to make a decision about whether to suggest a patient for palliative care registration at the MDT meeting. The support that these meetings provide for health care professionals was evident in FG2. The social care lead in FG2 described how she felt that MDT meetings provided support by providing safety.

> Social care team lead (FG2): *"I think it's strength in numbers isn't it, with support for each other as well as safety. It, it's safer, it's a safer way to practice all round if you're making multidisciplinary decisions."*

In FG3 support in the palliative care MDT meetings was also described as non-hierarchical; with nurses sometimes providing support for GPs. Palliative care MDT meetings (resource) provide non-hierarchical support for health care professionals which they value highly. Decisions about palliative care registrations take place in these supportive MDT meetings, thus enhancing the confidence of health care professionals in deciding that the patient is appropriate for palliative care registration and removal from unhelpful life prolonging treatment (reasoning).

> GP1 (FG1): *"And what I think is you grow in confidence as a GP* with your team and if the whole teams saying the same thing you feel more empowered to take control and confidently disconnect them from unhelpful (life p*rolonging) hospital appointments"*

> Community matron (FG1): "I think it (MDT meeting) gives you *that permission to say, right where do we stop, you know? And it's about quality of life, not length of life and it's about having that* conversation with the patient to say, you know what do you want *out of this? You know, the chemotherapy isn't going to make you better? You know? It, it's going to make them feel rotten anyway, so what do they want out of it? ...But I think it allows you to, like* GP1 says, (MDT working and meetings) gives you that confidence *to have those conversations."*

> Community matron 2 (FG1): *"I think as a primary health* care team member, when we meet and discuss our patients who are on that register, it makes, makes you talk about them a bit more than you would have done without it. You know you, it allows you to, erm, you know, once a week or once a fortnight, depending on how often you hold your meetings, it allows you to bring those *patients and to, you know, and they're not forgot about,* and both *the GPs and the nurses and everybody that's involved with it can* share their views and concerns in a structured way, so I think in *that way its good."*

The GP and community matron felt that MDT meetings gave them confidence to operate within a palliative care framework where appropriate (reasoning). Thus, health care professionals' reasoning is being changed in response to the MDT

meetings that the ICP provides (resource), to have increased confidence that a patient is appropriate for palliative care (reasoning) and registration.

To summarise the mechanisms, at the individual level the surprise question (resource) increases health care professionals' confidence to suggest a palliative care patient for registration at the MDT meeting (reasoning). This mechanism triggers the next, which operates at the team level; MDT meetings (resource) then provide additional support and further enhanced confidence that a patient is appropriate for palliative care (reasoning). Health care professionals' reasoning is being changed to be confident that the patient is appropriate for palliative care in response to resources that the ICP provides, both for the health care professional working in isolation (surprise question) and then as part of a MDT (MDT meeting). Confidence can be related to self-efficacy, which is the perceived ability to perform a task (Bandura 1977). It has been shown to be an underlying mechanism in a wide range of behaviours (O'Leary 1985, Strecher, DeVellis et al. 1986, Yalow and Collins 1987, Bandura 1991) and can reasonably be linked to the increase in confidence seen in health care professionals in this CMOC.

The ICP offers many resources which can be used in different ways – for example in isolation (the surprise question) or collaboratively (the MDT). Thus it is sometimes impossible to disentangle the different elements of the ICP because they have a synergistic effect on one another. For example, in isolation, the surprise question or MDT meetings may not result in a sufficient increase in confidence to register a patient. Therefore either the surprise question or MDT meetings in isolation provide limited explanatory potential for the increase in all palliative care registrations.

Context: Consensual definitions

In 2008, the End of Life Care Strategy (Department of Health 2008) was published which made palliative and end-of-life care a priority. The locality absorbed this information and made it applicable through the design and use of the palliative care registers. The publication of this policy and implementation of the ICP prompted the need for enhanced understanding of the definitions of palliative and end-of-life care. Individuals living with progressive and complex illnesses eventually experience the transition from treatment focused on stabilisation, even remission of their disease, to treatment focused on palliation (Thompson, McClement et al. 2006). FG2 highlighted that some health care professionals are still not confident in identifying when curative care should become palliative care, resulting in less palliative care registrations.

> *GP2 (FG2): "Definition of what is palliative care,* I think that lots of us, (laughs) are not sure when people enter palliative care, *some people think it's the last 3 days of life and some people think it's the last 3 years of life. I think what we mean by it is a constraint to some practices."*

> Community Matron (FG1): *"It is a new term, it's a new term and we're all used to, you know, the palliative being end*-of-life and *now it's separated and it is confusing."*

Palliative care is described by the community matron as a new term that causes confusion, this is unexpected given that the recent political agendas focus on improving palliative care services (Department of Health 2008, The National Gold Standards Framework Centre 2009, NHS North East 2012). In order to appropriately register patients, health care professionals need to understand the definitions of curative care, palliative care and end-of-life care. However, as the

community matron highlights, this is difficult. In the locality, generally health care professionals refer to palliative care patients as those with palliative care needs (holistic, supportive care for those with a terminal diagnosis), and end-of-life care is referred to as the last 3 days of life when the LCP is implemented. The differences between these types of care (curative, palliative and end-of-life) can seem very distinct and therefore the cessation of curative treatment is often viewed as a discrete event. However, current guidelines suggest a palliative approach should be adopted gradually alongside disease progression (Schofield, Carey et al. 2006). Yet this is not an easy process, with modern advances in treatment illnesses which can last for many months, even several years and therefore this makes the sharp transition from curative to palliative care blurred and difficult to operationalise (Schofield, Carey et al. 2006), as described by GP1.

> GP1 (FG1): *"I think it's very difficult (definitions of palliative* care) and *it's something we've endlessly discussed in our practice,* and the nomenclature is very confusing, and I think cancer treatment makes it even more confusing, for example breast *cancer, is often palliative but it doesn't mean that, they may live a* long life*, it's like a chronic illness isn't it, the definition of palliative has to start to change, it's very difficult, you know, what* do you call people? I use the palliative care register and then people get confused that I mean the very end of life, the Liverpool *pathway, it is very confusing."*

Despite health care professionals' discussions about the difficulties they had encountered with nomenclature, consensus in FG2 was that curative care precedes palliative care which precedes end-of-life care, as demonstrated by the quotes below.

> GP1 (FG1): *"you may be able to surmise that you should turn this palliative because they've got dementia etc, but they might not be* the right person for full end-of-life care and all that, who needs hospital avoidance and all o*f that."*

GP3 (FG1): *"Once you have that label of palliative care, we're* meaning would you be surprised if this patient was to die in the *next 6 to 12 months, yes and therefore let's put them on the* palliative care register, to hospital teams that might be like right *ok, very different meaning."*

GP1 (FG2): *"Because yes they're palliative, but they might still* want specific active treatment, and to understand and give active *treatment and then discharge."*

GP1: *"Just to tell you the, mix, the kind of,* erm, confusion out there about what a palliative care register is, I put him on the palliative care register and there was merry hell on with the learning disability team. Merry hell. It was hilarious actually. It was a very good learning experience actually. They all thought I *had said he was about to die and that's the degree of confusion about what a palliative care register is."*

The traffic light system can be used to facilitate health care professionals' understanding of curative, palliative and end-of-life care. Green can relate to when a curative framework is in operation, but palliative care should begin to be considered. Amber relates to a decrease in functioning, suggesting illness progression; a palliative care framework should have been adopted by this point. Red refers to end-of-life, where the LCP would have been implemented (pre-phase out).

Community matron (FG1): "Are they green amber or red? Where do they sit?"

GP1 (FG1): "Yeah that's (traffic light system) quite well defined now and I th*ink it's nice that it is so well defined. And I think that* will encourage people to use the palliative care register better because I do think palliative gets connected with death and dying *and it's not and we need the palliative care register to be bigger* so we can then hone down and pick out the end-of-life care *pathway patients."*

Once health care professionals in the locality had formed an informal consensus about these definitions and had experienced using the traffic light system they could then use these concepts in practice to place patients on the palliative care register. The palliative care register can be considered as a tool to keep a track of patients with palliative care needs. FG3 discussions highlighted that health care professionals had become sensitised to the appropriate definitions over time, from 2008 to 2012.

> GP4 (FG3): *"I presume something's changed between 2008 and 2012 and I think presumably the health care professional knowledge of the patients and family hasn't changed very much i*n relative terms, so I guess obviously the end of life strategy and the agreed consensus of palliative care terms are where awareness *has been heightened over the past few years. And I guess that's* facilitated the registration of palliative care patients on to the list *and erm, you know use of the pathway I suppose."*

The GP in FG3 explains how health care professionals' understanding and awareness of palliative care has increased since the implementation of the ICP.
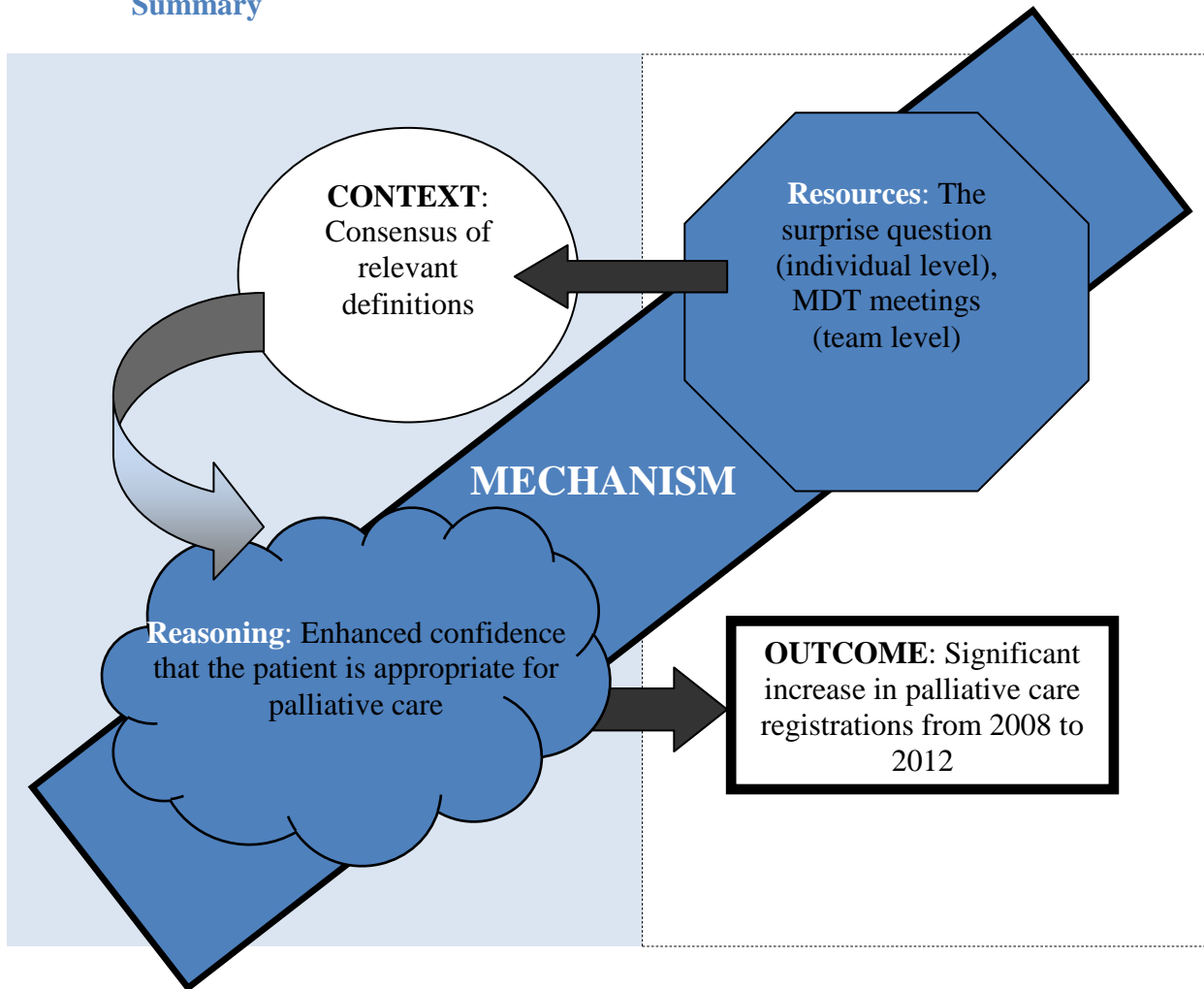
Figure 14: CMOC1, palliative care registrations

In summary, publication of essential policy in the form of the End of Life Care Strategy (Department of Health 2008) sensitised practices to the need to improve palliative and end-of-life care which the locality did through the development and use of palliative care registers. In order to do this they needed to become familiar with and form consensual definitions of active, palliative and end-of-life care (context). Despite on-going difficulties, discussions identified that this had been mostly achieved. The surprise question (individual resource) has increased health care professionals confidence (individual reasoning) to suggest the patient for

palliative care registration at MDT meetings (team resource) which further increases confidence of the health care professionals to operate within a palliative care framework where appropriate (reasoning). These two mechanisms (individual and team) have resulted in an increase in palliative care registrations from 2008 (ICP implementation) to 2012. This CMOC is displayed diagrammatically in Figure 14.

It is also important to note here the importance of MDT meetings. High performing practices identified in Chapter 4 (Embeddedness of the ICP as a new initiative, p.117) had more frequent MDT meetings, which were facilitated by having the shared nursing team on site. MDT meetings also have a key role in this CMOC, resulting in more palliative care registrations.

CMOC2 – Registering non-cancer patients

Outcome: Less non-cancer patients than cancer patients registered

Analyses were conducted to investigate whether there were fewer non-cancer registrations than cancer registrations using the most recent data available at the time, from 2011. The 2012 data was made available at a later date allowing extra comparative analyses to be conducted. All data includes sudden deaths, as removing these cases would result in biases; the definition of a sudden death is variably interpreted in some practices in the locality, one practice had recorded all non-cancer deaths as sudden. Removing these people would result in a greater bias than leaving them in the analyses.

Histograms were created in order to visualise the number of cancer and non-cancer patients registered in each practice (Figures, 15, 16 and 17).
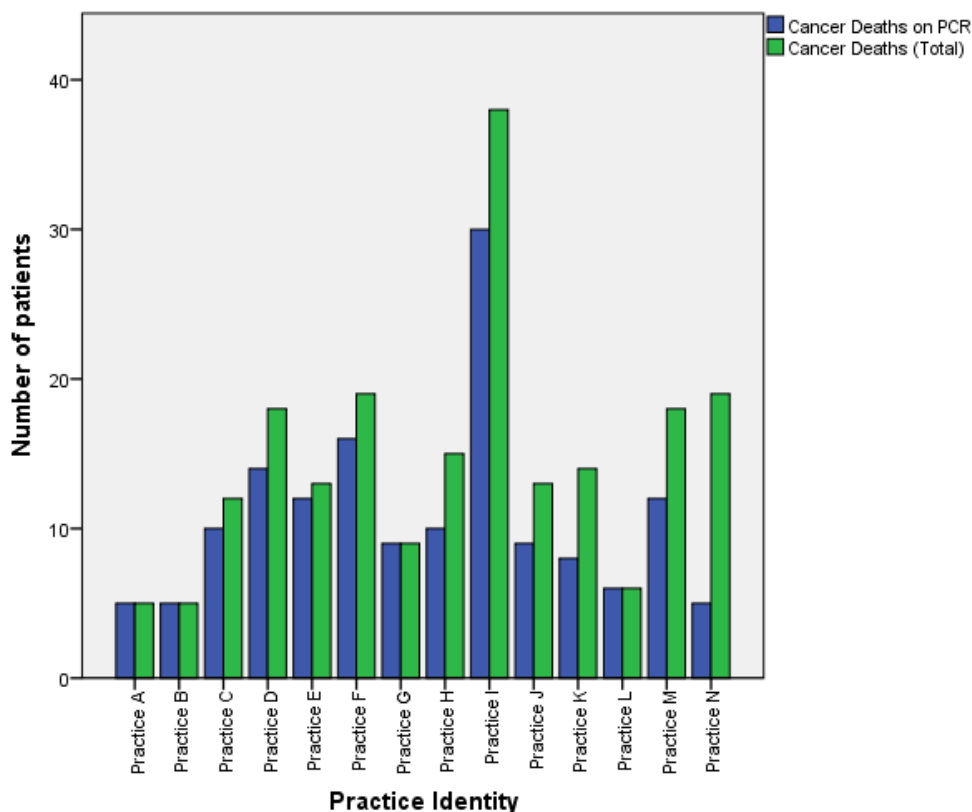
Figure 15: The number of cancer deaths in total compared to the number of cancer deaths that were on the palliative care register, for 2011, using Death Audit data.

Figure 15 indicates that a majority of cancer deaths in each practice are on the palliative care register, although there are wide variations. For example, four of the practices managed to register all of the cancer deaths in 2011, whereas practice N registered very few (the differences between practices was focused upon in more detail in the previous chapter on embeddedness, p.117).
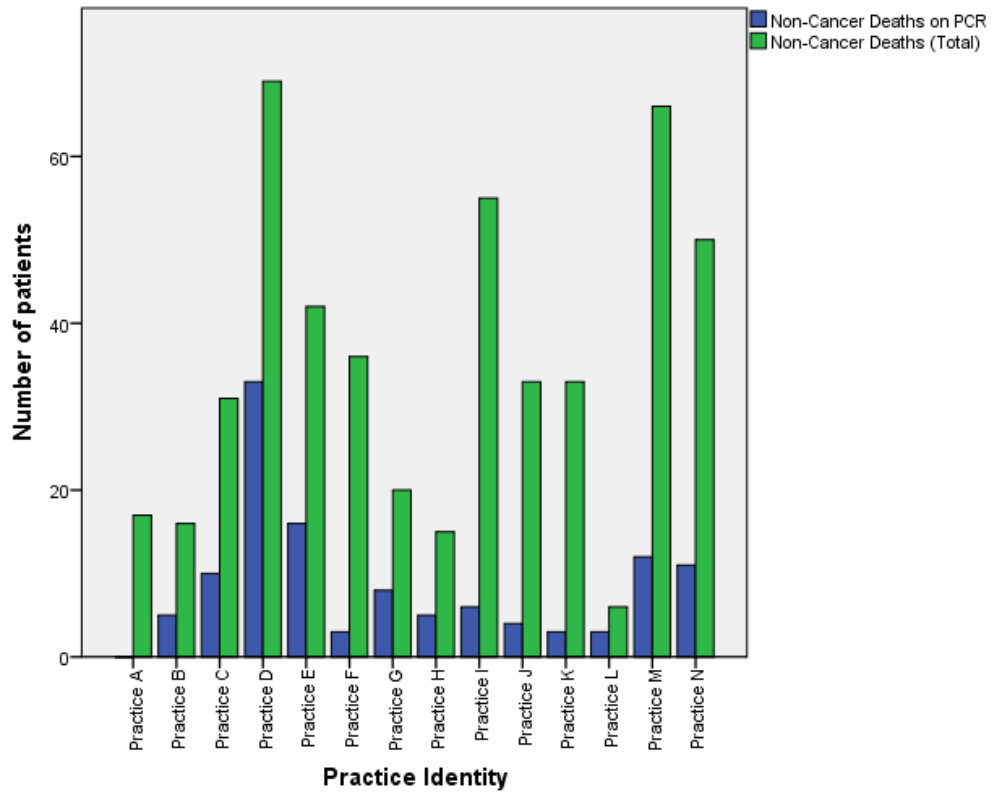
Figure 16: The number of non-cancer deaths in total compared to the number of non-cancer deaths that were on the palliative care register, for 2011, using Death Audit data.

Figure 16 shows that in every practice there are a substantial number of non-cancer deaths that occur that are not on the palliative care register. In comparison to Figure 15 a visual discrepancy becomes apparent; there are more cancer deaths registered than non-cancer deaths registered, even in practices that clearly use the palliative care register extensively for cancer patients.
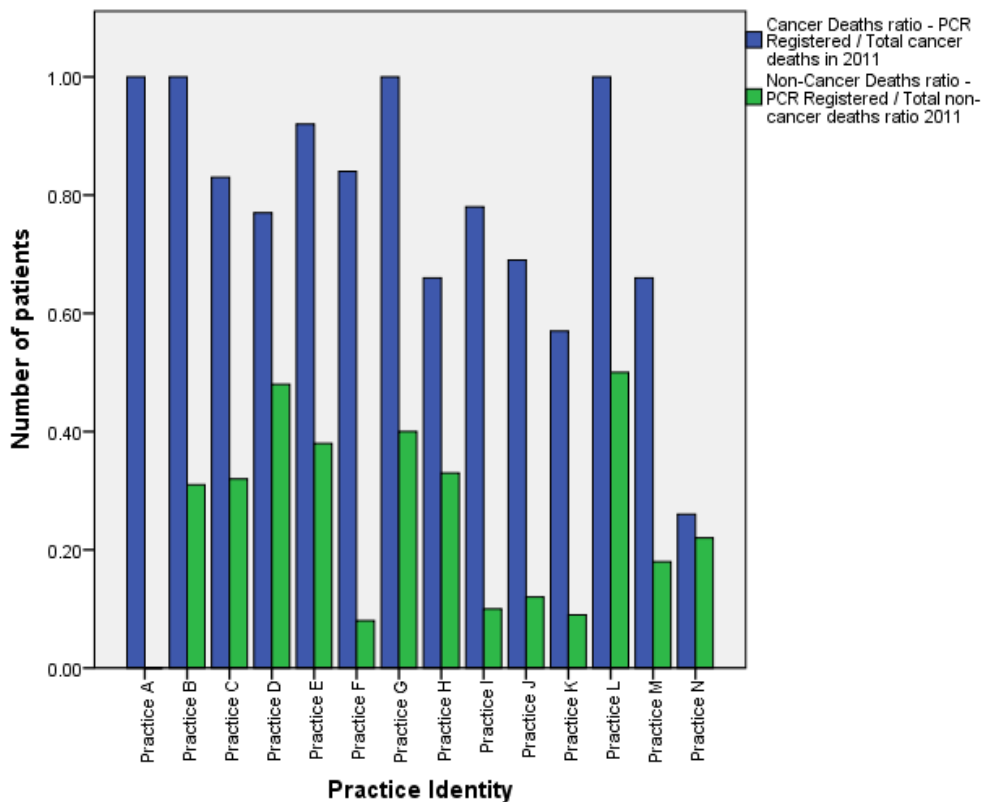
Figure 17: Ratios of palliative care registered to not palliative care registered deaths for those with cancer and non-cancer for each practice in 2011, using Death Audit data.

The use of ratios in Figure 17 allows for comparisons of cancer and non-cancer palliative care registrations irrespective of practice population size. Using ratios, a score of 1 would mean that all of the cancer or non-cancer patients who died in 2011 were on the register. A score of 0.5 would mean half of the patients were registered. Figure 16 shows that a lot more cancer patients are put on to the palliative care register than non-cancer patients, in all practices. However, there is significant variability, some practices do have better outcomes than others, for example, Practice A registered no non-cancer patients, whereas practice D registered around half of all non-cancer deaths.

A Pearson product moment correlation co-efficient showed that there was a weak non-significant correlation between cancer and non-cancer palliative care registrations (r = 0.26, n = 14, p > .05), suggesting that in each practice the number of non-cancer registrations does not increase as the number of cancer registrations does. This finding is unexpected as cancer deaths only account for around 30% of overall deaths (Office for National Statistics 2013).

A paired samples t-test was conducted to investigate this further and evaluate the impact of the ICP on cancer and non-cancer registrations in 2011, using the ratio of cancer deaths on the palliative care register to total cancer deaths and the ratio of non-cancer deaths on the palliative care register to total non-cancer deaths. A significant difference between cancer and non-cancer registrations was identified (t(13) = 8.78, p < .001). There were significantly more cancer palliative care registrations (M = 0.78, SD = 0.06) than non-cancer palliative care registrations (M = 0.25, SD = 0.16) in 2011 across all fourteen practices. This highlights that there are significantly more cancer patients than non-cancer patients being put onto the palliative care register.

Mechanism: Stress when registering a non-cancer patient

FG3 highlighted that health care professionals find registering non-cancer patients difficult. This is due to the non-predictable trajectory of non-cancer illnesses, the difficulty in considering non-cancer patients as appropriate for palliative care and the lack of health care professionals' involvement in treating progressive symptoms.

> GP4 (FG3): I think, erm the other things as well, historically with cancer patients rather than with non-*cancer patient's we've been* more actively involved in proactively managing symptoms as *they're reaching end*-of-life. Whereas in a lot of the non-cancer

deaths we might have been possibly, for example, more frequently treating infections but often i*t's a gradual slide with a lot more* intervention on our part necessarily, and I think the same goes for *the nurses as well."*

GP5 (FG3): *"You're acknowledging that they're declining but you're not necessarily actively doing a lot more for the symptomology… You don't necessarily understand the pain that they're feeling like you would with bone mets in the spine (in cancer)."*

GPs 4 and 5 explained how they felt that this lack of experience in treating the symptoms of non-cancer patients as they approach end-of-life, and the context of non-cancer patients' unpredictable illness trajectory led to stress when deciding whether to put non-cancer patients on the palliative care register.

GP5 (FG3): Err, so how do you make choices? So I make choices and then they c*ome off the board."*

GP4 (FG3): *"There is stress with non-*cancer registrations. With a cancer diagnosis you have a fixed underlying illness I think *haven't you? That the family are aware of and recognise that their* relatives generally going downhill. But with a non-cancer diagnosis you know they might have had heart failure for years *and years and years and yes they're getting a bit worse but they've* had this diagnosis for years whereas with cancer, quite often, *there's the downhill trend.*

A stressful decision like this would mean that health care professionals' confidence about the decision is low. Low confidence in a decision would mean that they are less likely to register a non-cancer patient.

GP5 (FG3): *"But I still find it difficult in my head because there's a blip, you're just not as confident in putting someone on the board when they're non cancer than you are if they're cancer. You're just not confident about where the end point is going to happen, how it's going to happen, what it's going to be l*ike, so *there is kind of a confidence thing about it."*

Self-efficacy is the perceived confidence to carry out desired tasks (Bandura 1977) and can be influenced by experience, persuasion, or physiological and psychological states such as distress. High self-efficacy correlates with low perceived stress in professional caregivers (Hulbert and Morrison 2006), thus suggesting that when health care professionals have more confidence (self-efficacy) then they have less stress about the decision they have to make. The results indicated that health care professionals were confident in registering cancer patients but less confident in registering non-cancer patients. This suggests they have a lower self-efficacy (reasoning) when registering non-cancer patients with unpredictable prognoses (context), giving them more perceived stress about the decision (reasoning) which results in less non-cancer registrations. Furthermore, effective co-worker communication and work place peer support have been identified as important variables for occupational stress management (Alexander and Ritchie 1990, Searle, Bright et al. 2001, Bradley and Cartwright 2002). The three practices which were identified as high performers (in Chapter 4: Embeddedness of the ICP as a new initiative, p.117) demonstrated strong peer support for palliative care. Therefore, peer support may have reduced occupational stress in these practices which may have subsequently facilitated their use of the ICP. Previous research which found high levels of occupational stress to be related to low levels of self-efficacy provides support for this relationship (Grau, Salanova et al. 2001). Self-efficacy is crucial in registering patients on the palliative care register, especially non-cancer palliative care patients. Thus the strong peer support in the three high performing practices may have some explanatory potential, as these three practices registered significantly more patients on the palliative care register than the others, in Cluster Analysis I.

In addition to low self-efficacy in dealing with non-cancer patients, the traffic light system (resource) is not as useful when dealing with non-cancer trajectories. Non-cancer patients often move between traffic light stages non-linearly meaning that if a patient is in 'green' they could very quickly deteriorate to 'red' and potentially be put on to the LCP, but their condition could improve and they can become 'green' again. This is unlikely to happen in cancer diagnoses. Thus, the traffic light system (resource) and the increased self-efficacy it gives health care professionals (reasoning) to register palliative care patients cannot be used as efficiently in the context of the unpredictable trajectory of non-cancer diagnoses.

To summarise this mechanism, health care professionals have little experience of treating the symptoms of non-cancer palliative illnesses and thus have low self-efficacy (reasoning) in registering this patient group. The traffic light system, that is one of the resources used to help register cancer patients, is not as useful in the context of unpredictable trajectories of those patients with non-cancer illnesses.

Context: Unpredictable illness trajectories

As discussed in the opening of this chapter, non-cancer diagnoses typically have an unpredictable trajectory. This makes decisions about when palliative care is appropriate particularly difficult and may help to explain why health care professionals' self-efficacy in treating this patient group is low. Therefore registering a non-cancer patient is challenging for health care professionals, as a period of significant decline can be followed by substantial improvement, despite a downward trend in wellness (Murtagh, Preston et al. 2004, Murray, Boyd et al. 2005). A GP in FG3 explained this.

GP5 (FG3): *"I think t*he, the definition of palliative care is still difficult, not so much with cancer deaths, but still with non-cancer. *I still put people on the board and then take them off it, they've rallied. I'm like "err, he was dying last week?" and now he's* rallied, you know (inaudible)."

The same GP went on to elaborate on the difficulty of the unpredictable prognosis in older people with non-cancer. He felt that all older people are at risk of entering end-of-life care rapidly and this is an unpredictable transition from palliative care. The care home population frequently have non-cancer illnesses which can exacerbate quickly and unpredictably. Health care professionals cannot predict this but also do not wish to over populate their palliative care registers by registering all non-cancer elderly patients. Once a decline in health begins in elderly people with non-cancer illnesses, it can be very rapid and thus end-of-life care is implemented. The GP felt that this left no time for putting people on to the palliative care register. Comparatively, this is not the case with cancer diagnoses as often there is a specific diagnosis and steady illness trajectory.

GP5 (FG3): *"I think the confidence comes from the potential for* flood gates, really, if you say well basically everyone in a care *home, I wouldn't be surprised if they all had an acute illness and* died from whatever frailty the suffer, COPD, dementia, whatever, you feel that you could then just open the flood gates to say that everyone could be on the palliative care register. You know, *they're all in their 80s and 90s, they're all getting to the end of their life, and so it's very difficult to kind of be selective about* them, and the illness that they get that ends their life is only a *matter of weeks which isn't a* lot of time to engage palliative care *in your brain and go to the board and write it down, you're chasing your tail really. At least in cancer you've got this progression and diagnosis and it'll end in one way, but with this you're chasing your tail, it's* just the timing and the... I could put basically everyone in care homes on that list.

The inequity between cancer and non-cancer palliative care registrations may also be exacerbated due to the emergence of the palliative care register from the cancer

register. In the past, practices were required to identify and register people with cancer and then undertake an annual review. Following this, a requirement to have a palliative care register emerged. However, these registers were under populated and those on the list were often cancer patients (identified from the aforementioned cancer register). Furthermore, typically no action was taken following registration. This history of palliative care registers being populated almost solely by cancer patients exacerbates the notion that palliative care only relates to terminal cancer illnesses and thus may cause health care professionals to refrain from registering non-cancer patients. The evidence highlights that a health care professional who has a palliative care definition inclusive of non-cancer will be more likely to register such a palliative care patient.
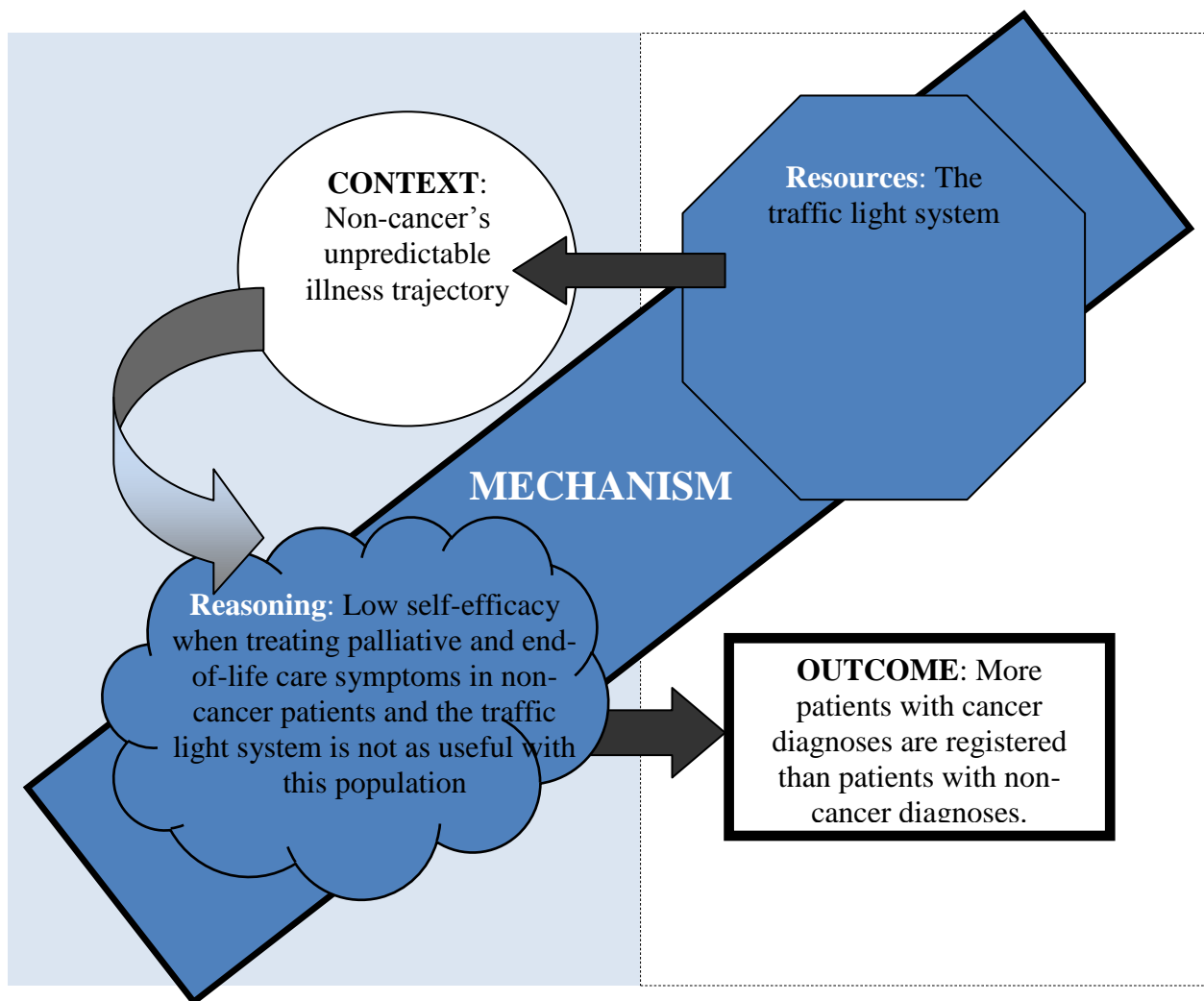
Figure 18: CMOC2, registering non-cancer patients

The unpredictable trajectory of non-cancer illnesses and difficulties in considering non-cancer patients as appropriate for palliative care (context), mean that health care professionals have less experience of treating palliative and end-of-life care symptoms in those with non-cancer (in comparison to cancer), meaning that health care professionals are less confident in registering non cancer patients (reasoning). This results in significantly less non-cancer patients than cancer patients being registered in 2011. This CMOC is displayed in Figure 18.

CMOC3 – Care home residents

Outcome: Less non-cancer patients than cancer patients registered

As described in CMOC2, in 2011 there were significantly more cancer palliative care registrations (M = 0.78, SD = 0.06) than non-cancer palliative care registrations (M = 0.25, SD = 0.16) across all fourteen practices.

Mechanism: Anxiety about registering care home residents

In FG3 health care professionals discussed the difficulties in the decision (reasoning) to put elderly patients who are in care homes and have a non-cancer diagnosis on the palliative care register (resource), due to their rapid declines and unexpected recoveries (context). This led to concerns regarding the over population of the palliative care register, as described by GP5.

> GP5 (FG3): *"T*here is the potential for flood gates, really, if you *say well basically everyone in a care home, I wouldn't be* surprised if they all had an acute illness and died from whatever frailty they suffer, COPD, dementia, whatever, you feel that you could then just open the flood gates to say that everyone could be *on the palliative care register. You know, they're all in their 80s and 90s, they're all getting to the end of their life, and so it's very* difficult to kind of be selective about them, and the illness that they *get that ends their life is only a matter of weeks which isn't a lot of* time to engage palliative care in your brain and go to the board *and write it down, you're chasing your tail really. At least in cancer you've got this progression and diagnosis and it'll end in one way, but with this you're chasing your tail, it's just the timing* and the... I could put basically everyone in care homes on that list. Err, so how do you make choices? So I make choices and then they *come off the board."*

Although the ICP and surprise question (The National Gold Standards Framework Centre 2009) premise would suggest that all patients who are likely to die in the

next 6 months should be registered, this can result in over population of the palliative care register. This can lead to a greater workload for health care professionals who already have stringent time constraints and laboured discussions about palliative care patients at MDT meetings. The social care team lead and a GP in FG3 described how it is unhelpful to over populate the register, especially with frail elderly people in care homes, as this results in those who need high care input not receiving it.

> Social care team lead (FG3)*: "You want to be giving care to those* who *most need it"*
>
> GP6 (FG3): *"And that's a burden administratively, the dangers* are that we take our eye of the ball because we have so little time *and focus on people who really need the medical input."*

GP5 suggested that the palliative care register is inappropriate for those with non-cancer palliative care needs and that another tool that is more flexible may be more useful. However, it seems that this would still result in the same issue of register over population.

> GP5 (FG3): I think defining it, fear of flooding the board, and erm, perhaps, perhaps we should be using the palliative care register less as a black and white thing in our mind and more of a kind of *flexible, ah here's someone getting a bit worse, put them on the* board. A palliative care, sort of declining, register (laughs). A bit softer, it kind of helps you to see it as some kind of, 'going through a blip register'. You know, may not recover register, I dunno. *Something that's a bit more flexible but palliative for non-*cancer is really the wrong word because they go through this dip and *you're not quite sure if they're going to recover. The definition doesn't quite fit; it's difficult to put them in th*at box. *It's difficult.*

The GP referred to 'palliative care' as inappropriate for those with non-cancer. Other health care professionals in the locality did not express the same belief but did agree that non-cancer patients are a difficult population to provide palliative care to.

Context: Elderly non-cancer patients' prognosis is difficult to predict

The literature highlighted that there is an ageing population in the UK (Forder and Fernandez 2011, Gomes, Calanzani et al. 2011) and the level of frailty, impairment and need of people admitted to care homes is now higher than it was 10-15 years ago (Forder and Fernandez 2011). Non-cancer elderly patients' health can decline rapidly, which makes palliative care registration difficult for health care professionals.

> *GP5 (FG3): They're insidious aren't they? The lethargy that* comes with being ninety kind of, you just kind of accept the fact that someone starts using a Zimmer frame because of their *arthritis"*

Accompanying this rapid decline can be an unexpected recovery.

> GP5 (FG3): *"They become Lazarus and rise from the dead and start having breakfast the next day."*

The unpredictable prognosis of elderly patients in care homes with non-cancer diagnoses poses particular issues for effective health care management. Elderly people in care homes form a key context within which the decision to register is difficult to trigger (reasoning) even with ICP resources (surprise question, traffic light system, MDT team meetings).
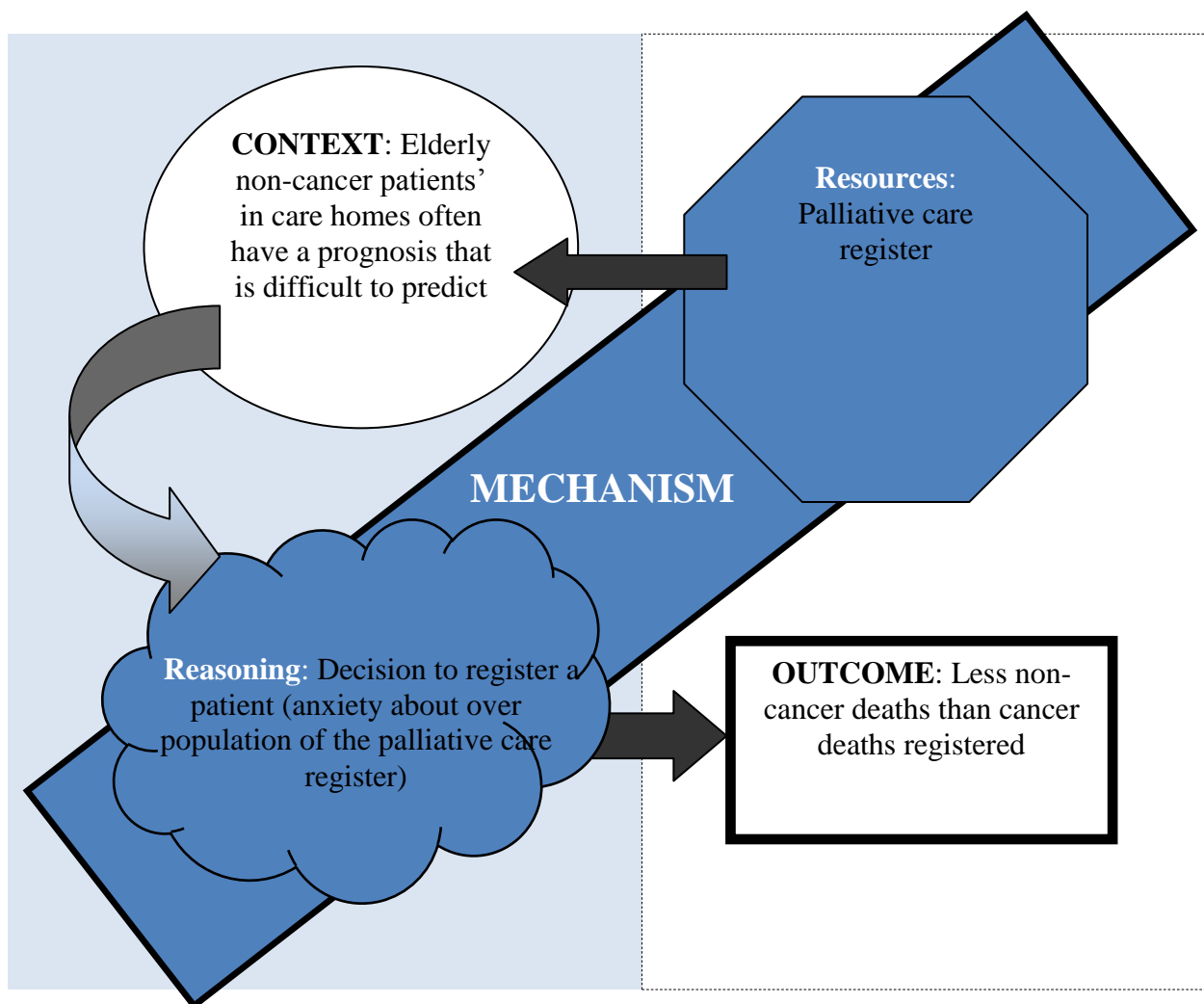
Figure 19: CMOC3, care home residents.

The literature has indicated for some time that failure of health care professionals to consider patients as palliative may contribute to the inappropriate care of patients (Graham and Livesley 1983), thus it is essential that appropriate patients are put on to the palliative care register, regardless of diagnosis. However, elderly people in care homes constitute a key context, in which the decision to register is difficult. In 2011, fewer non-cancer patients who died were on the palliative care register (outcome). This could be due to health care professionals' decisions not to register elderly care home residents with non-cancer diagnoses (reasoning) due to anxiety

about flooding the register and not providing needs based care to patients requiring palliative or end-of-life care (Figure 19). Contributing to this is CMOC2, in that most care home patients have non-cancer illnesses which can be very difficult to prognosticate.

CMOC4 – Recent increase in non-cancer registrations

Outcome: Significant increase in non-cancer registrations from 2011 to 2012

Although significantly less non-cancer patients than cancer patients were put on to the palliative care register in 2011, this does not indicate whether non-cancer palliative care registered deaths are increasing. To identify if practices using the ICP were increasing their registration of non-cancer patients 2011 data was compared to 2012 data.

Data from the 2011 and 2012 Death Audit allowed more refined questions to be answered by the data sets; allowing the number of people who died of cancer and non-cancer that were on the palliative care register to be identified. Two ratios were made for each year (2011 and 2012) and for each GP practice using their cancer deaths on the palliative care register divided by the total cancer deaths that year and the non-cancer deaths on the palliative care register divided by all non-cancer deaths that year. The mean and standard deviations for these ratios are presented in Table 8. The cancer ratios for 2011 and 2012 were then compared, and the non-cancer ratios were then compared with each other. Ratios were created in order to account for differences in practice population sizes.

A paired samples t-test was conducted to compare the ratios of cancer deaths on the palliative care register between 2011 and 2012. There was no significant effect of time on cancer death palliative care registrations (t(13)= -1.06, p > .05, two tailed). The means and standard deviations of the palliative care registered cancer deaths to all cancer deaths ratio are displayed in Table 8 and indicate an increase from 2011 to 2012.

Table 8: Ratio of registered cancer deaths to total cancer deaths in 2011 and 2012

Time	N	Mean	Standard Deviation
2011	14	0.78	0.21
2012	14	0.84	0.12

A paired samples t-test was conducted to allow a comparison of the ratios of non-cancer deaths on the palliative care register between 2011 and 2012. There was a significant effect of time on non-cancer death palliative care registrations (t(13) = -2.56, p < .05, two tailed). The means and standard deviations are presented in Table 9 and show an increase from 2011 to 2012, meaning that GP practices are significantly increasing the number of non-cancer palliative care registrations they make. Increases appear small due to the data being in ratio form, where 1 would mean that all patients who died of cancer were on the palliative care register. The eta^2 statistic (0.34) indicated a small effect size, according to Cohen (1988).

Table 9: The ratio of non-cancer deaths to total non-cancer deaths in 2011 and 2012.

Time	N	Mean	Standard Deviation
2011	14	0.25	0.16
2012	14	0.34	0.19

These two statistical tests indicate very important outcomes; between 2011 and 2012 practices did not significantly increase the number of cancer patients they registered but did increase the number of non-cancer patients they registered. The lack of increase in the number of cancer patients registered who died could be attributed to most practices being quite competent in registering them.

However, it is not possible to know whether non-cancer registrations have been increasing since ICP implementation (2008) or whether they have just started to increase from 2011 to 2012. This is due to data restrictions explained earlier; the tools that collect data only asked more refined questions about disease type from 2011.

Mechanism: Legitimation through education

Discussions in FG3 highlighted that health care professionals now had more informal education about non-cancer diagnoses and their relevance and need for appropriate palliative care. This was following the publication of national policy such as the End of Life Care Strategy (Department of Health 2008), educational events, PCQV and informal learning from the ICPs founder.

GP4 (FG3): *"I think it's more that we've been legitimised to put* palliative care patients on the register, you know, through educational events and people like (founder), the End-of-Life Care *Strategy and things such as that."*

GP3 (FG3): *"I think its education, really. We've been educated* that we can now think that non-cancer patients require palliative *care. And the permission, it's the permission that* you can consider non-*cancer patients as palliative."*

Health care professionals felt that these forms of education (resource) had legitimised their decision to put palliative care patients on the register (reasoning) which increased their self-efficacy to provide high quality palliative care to all. Health care professionals also felt that as their experience built in providing palliative care for cancer patients, so did their self-efficacy in providing palliative care for non-cancer patients.

GP6 (FG3): *"Experience wise, you start feeling, maybe there's a confidence thing there as well. We're starting to build more confidence in cancer deaths and as a result of that we're thinking this is quality (care), and actually why shouldn't that person there* have the same bit of me or the same pathway. I mean that is a *significant challenge due to prognostics, that's really difficult isn't* it. So maybe our reasoning is, why not? Why not this group of people, if cancer patients get it, but also as a confidence thing as well maybe. I feel happy I could manage these kind of dying *patients so why can't I manage all my dying patients rather than just a select few?"*

GP6 highlights how health care professionals in the locality have increased their self-efficacy to provide palliative care to non-cancer patients.

Context: Changes in cause of death and palliative care for all

The literature highlighted that non-cancer illnesses such as dementia are expected to increase, from 800,000 in 2012 to 1,000,000 in 2021 (Alzheimer's Society 2013). This evidence, alongside the knowledge that the population is aging (Caley and Sidhu 2011) and cancer treatment is advancing (Costanzo, Ryff et al. 2009), suggests that cancer deaths will continue to decrease and non-cancer deaths will increase in the future. The participants in FG3 commented upon the changes in cause of death in the UK.

> GP5 (FG3): *"Also, I think there's less, less, some cancers that people aren't dying from that much now. Breast cancer for example, we're just better at treating it. They're just not coming through the door quite so regularly."*

> GP4 (FG3): *"I think the other thing as well is that people, not just* cancer patients but patients with other terminal illnesses such as heart failure due to modern medicine are living longer than they ever did and this has kind of filtered down, as in days gone by hospices would only take cancer patients whereas now hospices will take people with end stage heart failure or end stage COPD *and things and that's because they've lived longer than they would have done historically."*

The increasing numbers of non-cancer deaths mean that the identification of non-cancer palliative care patients needs to be of the same standard as the identification of cancer patients (via palliative care registration) and non-cancer patients need to be considered as appropriate for palliative care. However, FG2 highlighted that some health care professionals still have uncertainties about palliative care and its applicability to all terminal illnesses.

> Community Matron (FG2): *"And I think that erm, maybe* sometimes we do tend to, when you say palliative care, you do think of cancer diagnoses whereas your COPD and heart failures *and things like that, and I think they're quite difficult from our*

perspective to know when, you know if they have an exacerbation *then yes they're really struggling but the next week they could be* fine so at what point do you think well, they might be ready for the *pathway (ICP)?"*

This nurse refers to an important context when registering a non-cancer palliative care patient, the inequality between cancer and non-cancer diagnoses due to the association cancer has with palliative care. The nurse explicitly states that palliative care still has strong associations with cancer. However, health care professionals are increasingly viewing non-cancer patients as appropriate for palliative care. In FG2 most health care professionals selected palliative care for those with non-cancer diagnoses as an important context for palliative care registrations. This suggests that they are aware of the difficulties associated with non-cancer diagnoses and the need for and importance of palliative care for non-cancer patients. In FG3 a GP referred to the increasing recognition of non-cancer patients requiring palliative care.

GP4 (FG3): *"That's why more non*-cancer patients are being *registered. And because historically we wouldn't have thought of it, palliative meant cancer patients. I think that's the biggest factor."*
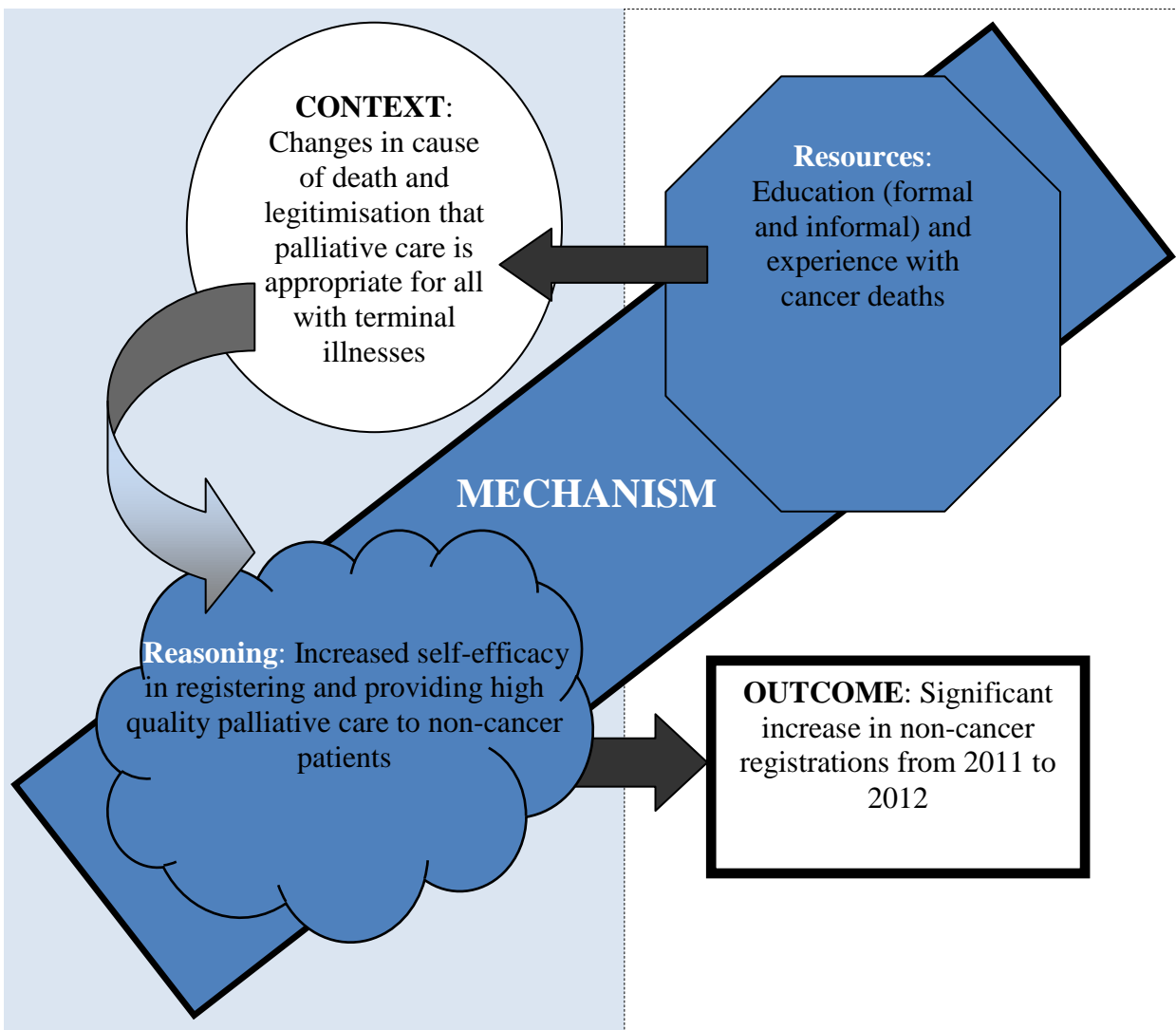
Figure 20: Recent increases in non-cancer registrations

Health care professionals have an increased recognition that causes of death are changing and that palliative care should be inclusive of non-cancer patients (context). The education the ICP has provided (resource) through several mediums has legitimised registering non-cancer patients and the experience with cancer patients has built self-efficacy in registering non-cancer patients (reasoning) and providing them with the same high quality palliative care. The outcome of this is

that more non-cancer registrations are increasing from 2011 to 2012, as displayed in Figure 20.

It is important to note the impact of CQI efforts in the ICP, in the form of PCQV. They not only impacted on the embeddedness of the ICP (Chapter 4, CMOC3, p.133) but have also aided in increasing the registrations of a difficult population (non-cancer patients).

Chapter Summary

Putting patients on to the register is an essential step when health care professionals assess a patient as requiring palliative care. It prompts the use of other ICP interventions and helps health care professionals to work within a palliative framework. Although all palliative care registrations are increasing (from 2008 to 2012) due to resources the ICP provides (the surprise question and MDT meetings – CMOC1) there are still significantly more people with cancer diagnoses registered than non-cancer diagnoses. This is because health care professionals feel the unpredictable prognosis of non-cancer illnesses makes registering patients a stressful process; they are unconfident with it (CMOC2). Providing palliative care in care homes to frail elderly people with non-cancer illnesses can also be particularly difficult (CMOC3). However, from 2011 to 2012 registrations of non-cancer patients have increased. This is due to the increased recognition of change in cause of death and of non-cancer patients requiring palliative care (context) formal and informal education provided by the ICP and experience from providing high quality palliative care to cancer patients (resource) (CMOC4). These factors are slowly building confidence in health care professionals to place more non-cancer

patients on the register. Throughout all of the CMOCs reasoning is related to confidence or self-efficacy (the perceived ability to carry out a task) which is related to confidence. Health care professionals need to have confidence to provide palliative care for non-cancer patients. This can come from a variety of sources: MDT meetings (peer support), ICP tools (the surprise question, the traffic light system), education (formal and informal), experience from providing palliative care to cancer patients.

Programme theory 2 stated that palliative care registrations should increase (outcome) due to a focus on identifying patients early using the palliative care register (mechanism) in a health care domain that appreciates the palliative care needs of patients (context). The registration of all palliative care patients is increasing (outcome) due to the use of ICP tools such as the surprise question, the traffic light system and MDT meeting (resources) and a consensus of the definition of palliative care. However, data has shown that there are difficulties in providing palliative care for all patients who need it, due to the difficulties of prognostication with non-cancer illnesses (context), which causes stress in decisions about registering patients; this results in less people with non-cancer illnesses being registered (outcome). Elderly people who live in care homes with non-cancer illnesses (context) also posed a difficulty for health care professionals in terms of palliative care registrations. However, the health care professionals in the locality are increasing their use of palliative care registrations for non-cancer patients (outcome). They felt that this was because they were building confidence in registering non-cancer patients (reasoning) from education and experience of registering cancer patients (resources) and a legitimisation of non-cancer patients as appropriate for palliative care. Thus the programme theory (2) described is

generally supported, as all palliative care registrations are increasing from 2008 to 2012. However, there are underlying facets to this general CMOC that are extremely important to equality of care.

Once patients have been identified as requiring palliative care and registered as such, health care professionals may wish to broach preference discussions and offer the use of the locality advance care plan to the patient. The next chapter focuses on these difficult conversations and their documentation.

Chapter 6: Preference discussions and the locality advance care plan

One of the crucial roles health care professionals have throughout a patient's palliative care is to try to assess preferences for end-of-life care, specifically regarding the type of care they would wish to receive and where they wished to be cared for (Department of Health 2008). These preferences are important for patient centred care and planning, but also in case a patient loses capacity and therefore is unable to express a preference in the future. Even though preference discussions are of high importance they need to be entered into mutually by health care professional and patient. Thus they require skill and sensitivity, and the health care professional may have to approach the subject several times before the patient is willing to engage; but providing the opportunity to engage as early as possible is crucial, to avoid loss of capacity issues. The outcomes of preference discussions should be documented, regularly reviewed and communicated to other relevant people involved in the patient's care: family members, carers and other health care professionals (Department of Health 2008). This process is referred to as ACP. Until April 2012, a locality advance care plan was in use to document patient preferences. This was then replaced with the introduction of Deciding Right (NHS North East 2012), which explained ACP as an umbrella term, with several potential formal outcomes: the advance statement, the DNACPR form, the ADRT, EHCP or PW-LPA including health (all of which were described fully in the introduction chapter).

Initial questions asked of the data

The programme theory and subsidiary questions that this chapter focuses on were first stated in the methodology chapter and are restated below.

- **Programme theory 3**: There will be an increase in the use of preference discussions and use of the locality advance care plan (outcome), as health care professionals become more confident with broaching the subject of death and dying with patients (mechanism) and aware of the importance of having and documenting preference discussions, which has been highlighted by recent policy (context).

  - Are preference discussions increasing and if so why?

  - Are preference discussions occurring earlier in a patient's illness trajectory (green traffic light phase)?

  - Are the number of locality advance care plans carried out with patients increasing and if so why?

  - Do preference discussions predict the use of advance care plans?

CMOC1 explains the increases in informal preference discussions between health care professionals and patients, prompted by changes in condition or need. CMOC2 identifies why these preference discussions may sometimes occur late in a patient's illness, even when their illness trajectory is predictable. The time constraints in primary care are discussed in relation to the use of the locality advance care plan in CMOC4 and the change to the advance statement from the locality advance care plan is detailed in CMOC5.

CMOC1 – Markers for initiating preference discussions

Outcome: Increase in preference discussions

A one-way repeated measures ANOVA was conducted to compare numbers of preference discussions that occurred and were recorded on MIQUEST in 2009/10, 2010/11 and 2011/12. The means and standard deviations are presented in Table 10; the means show an increase in preference discussions over time. Mauchly's Test of Sphericity was not significant so sphericity was assumed. There was a significant effect for time on preference discussions ($F(2, 22) = 15.95$, $p < .001$, $\eta_p^2 = 0.59$). Using the guidelines proposed by Cohen (1988) for the η_p^2 (0.01 = small, 0.06 = moderate, 0.14 = large effect), this result suggests a large effect size. Post hoc tests revealed a significant difference between 2009/10 and 2011/12 ($p < .001$) and a significant difference between 2010/11 and 2011/12 ($p < .005$) in preference discussions. There was no significant difference between 2009/10 and 2010/11 ($p > .05$), although it was close to significance ($p = .08$). Therefore it can be concluded that the GP practices are significantly increasing their use of preference discussions since the introduction of the ICP, with these increases being significant from 2009/10 to 2011/12 and 2010/11 to 2011/12. It may have been that in the first year (2009/10 – 2010/11) the ICP had not become embedded enough yet to yield a significant increase. The increases over time in preference discussions are represented in Figure 21.

Table 10: Preference discussions over time, using MIQUEST data.

Time Period	N	Mean	Standard Deviation
2009/10	12	2.58	4.06
2010/11	12	5.58	8.2
2011/12	12	10.75	7.61

The number of practices involved in the analysis (N) is twelve instead of fourteen as SPSS accounts for there being no data for two of the practices in 2009/10 as they joined the ICP at a later date. These missing values are not regarded as an issue as the reason they are missing is not related to the data or intervention.
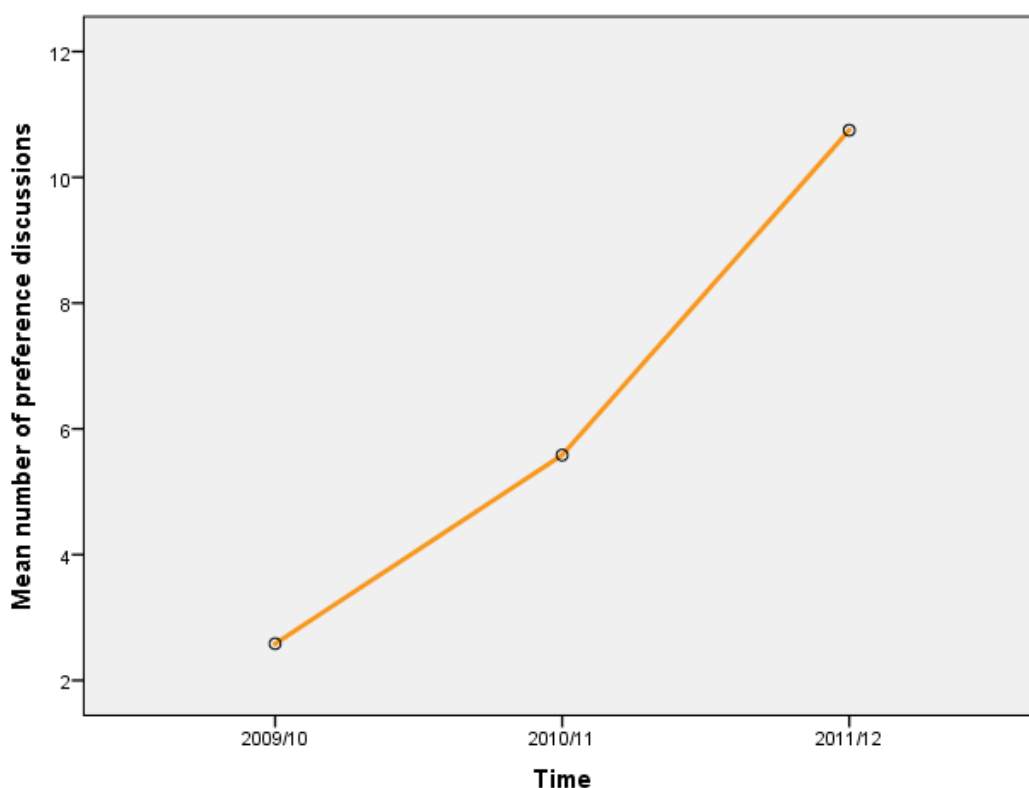
Figure 21: Mean number of preference discussions between 2009/10 and 2011/12, using MIQUEST data.

In addition to the statistical outcomes, the QDDM identified that preference discussions that are taking place are holistic. Planning for a funeral can be a very important aspect of preference discussions, and all GPs and bereaved relatives who answered the question relating to funeral planning scored it very highly, suggesting that the GP did broach funeral plans within preference discussions with the patient and their family.

Mechanism: Health care professionals' desire to be patient centred

Through using the ICP framework, health care professionals know that they have a responsibility to document patients' preferences (resource). Following from this they need to ensure that these preferences will be adhered to, to ensure a preference based, patient centred, death. The ICP framework (resource) has always promoted the use of preference discussions through educational events, PCP meetings, PCQV and its underlying principle of proactive care and early intervention. Preference discussions provide patients with the opportunity to discuss concerns that may not otherwise be addressed. These discussions help patients to express where they would wish to be cared for and die if their condition worsens. Although preference discussions can sometimes be difficult to broach, they help patients to plan holistically for a good death, assessing spiritual, emotional and physical needs, and they are therefore a necessity. The increase in preference discussions is a combination of factors: the ICP's framework (resource) which is enhancing health care professionals patient centred practice (reasoning).

> Social care team lead: *"I think it's about empathy as well, I think gosh if that was me, what would I want? You can, you know, if you've got lots of management and skills around that area you want that person to have the best because that's what you would want. Erm, and I think that we can't underestimate the value of*

> planning and if you can plan that pathway for that person and so *they have a you know smooth and… that's being kind and* empathetic and person centr*ed isn't it."*

Health care professionals have increased their use of preference discussions due to the ICP framework (resource), which focuses on proactivity and patient centred care, thus resulting in health care professionals' drive to be patient centred and proactive (reasoning). Supporting this, all participants who answered the QDDM question referring to the opportunity to discuss funeral plans scored this as a 9 or 10 meaning that they felt this experience was almost perfect. This suggests that preference discussions are holistic, proactive and patient centred, including conversations about the patient's funeral and not just assessing physical aspects of palliative care.

Context: A change in condition or increased needs

Some patients have very clear end-of-life care preferences but they often rely on health care professionals to initiate discussions about this (Hanson, Danis et al. 1997). However, few health care professionals agree on a clinical marker as to when preference discussions should be initiated (Quill 2000, Thoonsen, Groot et al. 2011). A national questionnaire answered by multiple health care professionals identified the lack of prognostic indicators and clinical triggers for initiating palliative care, which appeared to be the main missing link in applying palliative care in primary care (Shipman, Gysels et al. 2008). Thus, if a palliative care framework is adopted at a late stage then preference discussions can often occur late or in crises (Quill 2000). However, in FG3 health care professionals stated that a change in a patient's condition often resulted in them broaching preference

discussions. This included a deterioration of condition, a formal terminal diagnosis or inappropriate hospital admission.

> GP4 (FG3): *"A deterioration in their condition (would prompt* preference discussions), no possibility of further treatment, so end *of the line… It's sometimes a hospital admission that you consider* to be inappropriate as well. *You think, they probably shouldn't* have gone in, can we prevent this happening again, should we *have a chat with the patient"*

Consensus has evolved among health care professionals that meaningful end-of-life discussions often occur too late. Quill (2000) suggests that if a patient has recently had an admission to hospital then a preference discussion can be prompted, but that this is too late. This is especially the case if the patient has had repeated admissions to hospital for severe progressive illness. This may be why most preference discussions in the locality are occurring at the amber stage of the traffic light system, as opposed to the green stage (verified by health care professionals in the locality and the founder of the ICP). However, this is an improvement from preference discussions occurring only in the red stage (end-of-life care being implemented and use of the LCP).

Another GP went on to elaborate that not only deterioration in condition but also an increase in needs could prompt him to broach preference discussions with a patient. This included increased use of service such as social care and district nurses.

> GP6 (FG3): *"I think also, when someone's needs are, what can* we, *what can we provide for someone'*s needs and (inaudible) from the community, so carers are going in, the DNs are going in, their *nursing needs are escalating… they'd been in hospital severa*l times and you think, hang on here, do we need to wrap this up and *start to put a pathway in?"*

GP6 highlights how an increase in a patient's needs can trigger a change to palliative care from a previously curative framework.

Summary
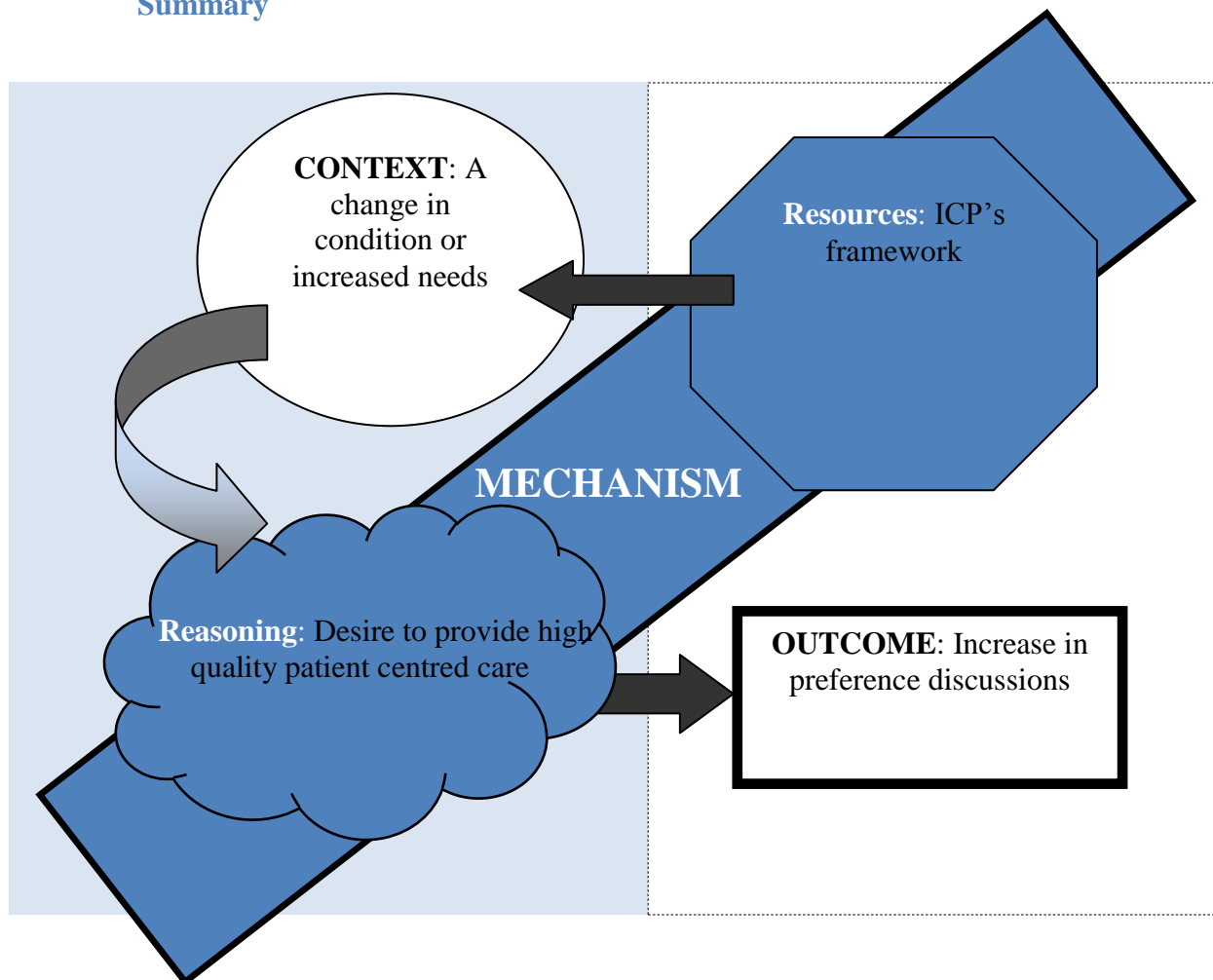
Figure 22: CMOC1, markers for initiating preference discussions

Deterioration of a condition, increase in need (due to deterioration), or inappropriate hospital admission(s) are hospitable contexts for the ICP framework (resource) to be used which results in an enhancement in health care professionals' proactive and patient centred care (reasoning) through preference discussions (outcome). CMOC1 is displayed diagrammatically in Figure 22. This CMOC does not infer that health care professionals were previously not operating within a patient centred

framework; it explains that the ICP's framework enhanced their patient centeredness.

CMOC2 – False hope can prevent preference discussions

Outcome: Preference discussions can occur late

Interviews identified that preference discussions often occurred late, even with patients who had cancer and a predictable disease trajectory. All of the palliative care patients interviewed had engaged in preference discussions with their GP but this was at a very late stage, when they were very unwell and bed bound.

> Richard (Doris's son): "Dr. (name) did ask when you were really poorly."
>
> Doris (palliative care patient): "*Yeah, yes he did, yeah.*"
>
> Richard (Doris's son): "And, and you said home. Yeah*"*

> Janet (palliative care patient): "*It was a particular, that doctor,* because I remember her standing at my bedside looking directly at *me and she didn't exactly say you know, what would you like to* end, happen at the end. But I think that the way she used her words*, I think I realised what she was getting at.*"

> Michael (palliative care patient): "*Yes, Dr. (Name) asked (where he'd like to be cared for), erm, it'd be last week, last Tuesday. We had Dr. (name) and 2 student doctors here… And he did ask, and* we said at *home.*"

All of these patients were cancer patients, which suggest that the prognosis of their condition would have been quite clear. Despite this, these quotes suggest that GPs have initiated preference discussions when patients become very unwell and bed bound, as opposed to in advance of a significant deterioration in health due to their terminal illness.

None of the palliative care participants interviewed had a locality advance care plan (the predominant form at the time, before it was replaced with the advanced statement from Deciding Right (NHS North East 2012) or any other associated care planning forms (DNACPR form, EHCP) and only one of the bereaved relatives recalled their loved one having a formal document (Caroline). The others just had informal preference discussions with their GPs.

> Richard (Doris's son): "No it was just general conversation I *wasn't there at the time, he did come and mention it to me."*
>
> Doris (palliative are patient): "Yes he did, he came and had a word with you.*"*

> Barbara (Michael's wife): "*We've had it (*preference discussion*) yeah."*
>
> Interviewer: "*But you just haven't got it written down?"*
>
> Barbara (Michael's wife): "*No, that's right.*"

The quotes above indicate that these palliative care patients and their relatives had not been asked to engage in the formal ACP process, thus meaning that late preferences discussions (discussed above) were the only form of eliciting preferences for these patients. This was despite one of the patients, Janet, specifically stating to a health care professional that she did not want to be resuscitated, which should have prompted the use of a DNACPR form but did not.

> Janet (palliative care patient): *"I do remember people asking me, erm, I don't know the way she put it, she didn't put it to me directly* you know, do you want to carry on, but you know I made it quite *sure and quite certain, hoped I had, have, but you know I don't want resuscitation, I don't want anything, I just want to go."*

> Jill (Janet's daughter): *"You haven't filled one (DNACPR) in. It's just been, it's, it's been said but you haven't put anything into writing or filled… no."*

Janet (palliative care patient): *"No I haven't signed anything or… I don't want, I don't want to be resuscitated."*

The QDDM (Curtis, Patrick et al. 2002) results support this outcome in that some GPs and bereaved relatives had markedly different perceptions on preference discussions. Three out of four of the matched GP and bereaved relatives had very different scores; GPs scored 8-10 indicating an 'almost perfect experience' of preference discussions and bereaved relatives scored zero to three, indicating a 'terrible experience'. This could be due to preference discussions occurring late. However, this questionnaire asks bereaved relatives to answer on behalf of their loved ones, thus it may be that preference discussions occurred when relatives were not present, or relatives could feel that their own needs in terms of end-of-life preference discussions were not met. Again, this could be because they were not involved in preference discussions or because their loved one did not wish to engage in them, potentially due to their false hope for recovery.

To conclude, preference discussions with palliative care patients can still occur very late in the palliative care process, often when a GP believes that the patient is nearing end-of-life. This is evident by the participants' statements about when they were asked about their preferences; all of the patients were bed bound at the time. DNACPR forms had not been filled in despite one patient specifically telling a GP that she did not wish to be resuscitated. The qualitative data analysis supports the quantitative GP practice data; preference discussions are increasing; however the quantitative data alone did not highlight that preference discussions are still occurring very late in the illness trajectory.

Mechanism: Preference discussions can dash patients' hopes for recovery

GPs 4 and 5 stated that they felt patients often had false hope from secondary care treatment options.

> GP4 (FG3): *"I think sometimes with cancer patients* there is an element of possibly being given false hope by the cancer specialists in terms of what treatment is available and continuing treatment *till quite late in an illness. And I think it's quite hard as a GP to come in and dash those hopes."*

> GP3 (FG3): *"I think (GP4*'s) point about conflicting advice is one of the difficulties, be it oncologists or surgeons or haematologists. Then how can you have a conversation with somebody when *somebody else is saying we're going to add in drug y to drug x and* Z th*at you've already got. It makes it a very difficult conversation to have."*

GPs 4 and 5 stated in FG3 that they found it difficult to broach preference discussions when patients were being given false hope from secondary care and pursuing aggressive treatment. They felt that if they broached preference discussions (resource) it might affect patients' hopes that had been raised in secondary care consultations (reasoning).

Context: False hope from secondary care

Receiving realistic information about the different treatment options and the likelihood of successful treatment or adverse effects and symptoms is difficult for palliative care patients (Matsuyama, Reddy et al. 2006). The literature indicates that patients would have chemotherapy for much smaller improvements in outcome than would health care professionals (Matsuyama, Reddy et al. 2006). However, patient autonomy and choice should always be valued and thus patients' options should

always be presented in a balanced manner (Earle 2006). However, there is a subjective discrepancy in how aggressive palliative treatment is viewed by patients, bereaved relatives and health care professionals. Both bereaved relatives and health care professionals who have experienced aggressive treatment for palliative care patients would avoid it, giving more time to plan hospice and end-of-life care (Earle 2006). However, in focus groups, terminally ill cancer patients who by virtue of still being alive had not experienced the whole course of their illness were more inclined to consider aggressive palliative treatment (Earle 2006). This discrepancy suggests that there is a gap between the informed opinions of bereaved relatives and health care professionals, and the decisions of patients. Slevin, Stubbs et al. (1990) make this more explicit, stating that 53% of cancer patients are willing to contemplate aggressive chemotherapy if chances of a cure were increased by as little as 1%. Furthermore, patients have stated that they would accept chemotherapy or radiotherapy despite being aware that it would have no clinical benefit and no gain in survival chances (Palda, Llewellyn et al. 1997, Jansen, Kievit et al. 2001). This could be due to explanations from those providing the treatment being unclear. A quote from de Haes and Koedoot (2003) suggests that oncologists prefer to give treatment as opposed to deny it, despite doubtful expectations about a positive result.

> "Giving chemotherapy, rather than watchful waiting, is what I
> have been educated to do; *that's* what I have to sell in my shop."
> (de Haes and Koedoot 2003, p. 45).

Another explanation of preference discussions not being broached with those who are receiving aggressive palliative treatment is that primary care professionals do not feel comfortable in communicating this information. This could be attributed to: a lack of tools in conveying pros and cons; the subject being too emotionally

distressing to discuss; patients being unable to comprehend the realistic outcomes; an attempt to not be totally honest in order to preserve hope (Earle 2006). Although aggressive treatment can sometimes be inappropriately offered to non-cancer patients experiencing exacerbations, it is more often offered to those with cancer in the form of chemotherapy, especially those in the later stages where it could be considered to be inappropriate (Mayor 2008). Furthermore, when health care professionals were discussing false hope it was in reference to those patients who have cancer. The CMOC is therefore more relevant to cancer patients, as is the literature discussed surrounding the pursuit of aggressive treatment.

Summary
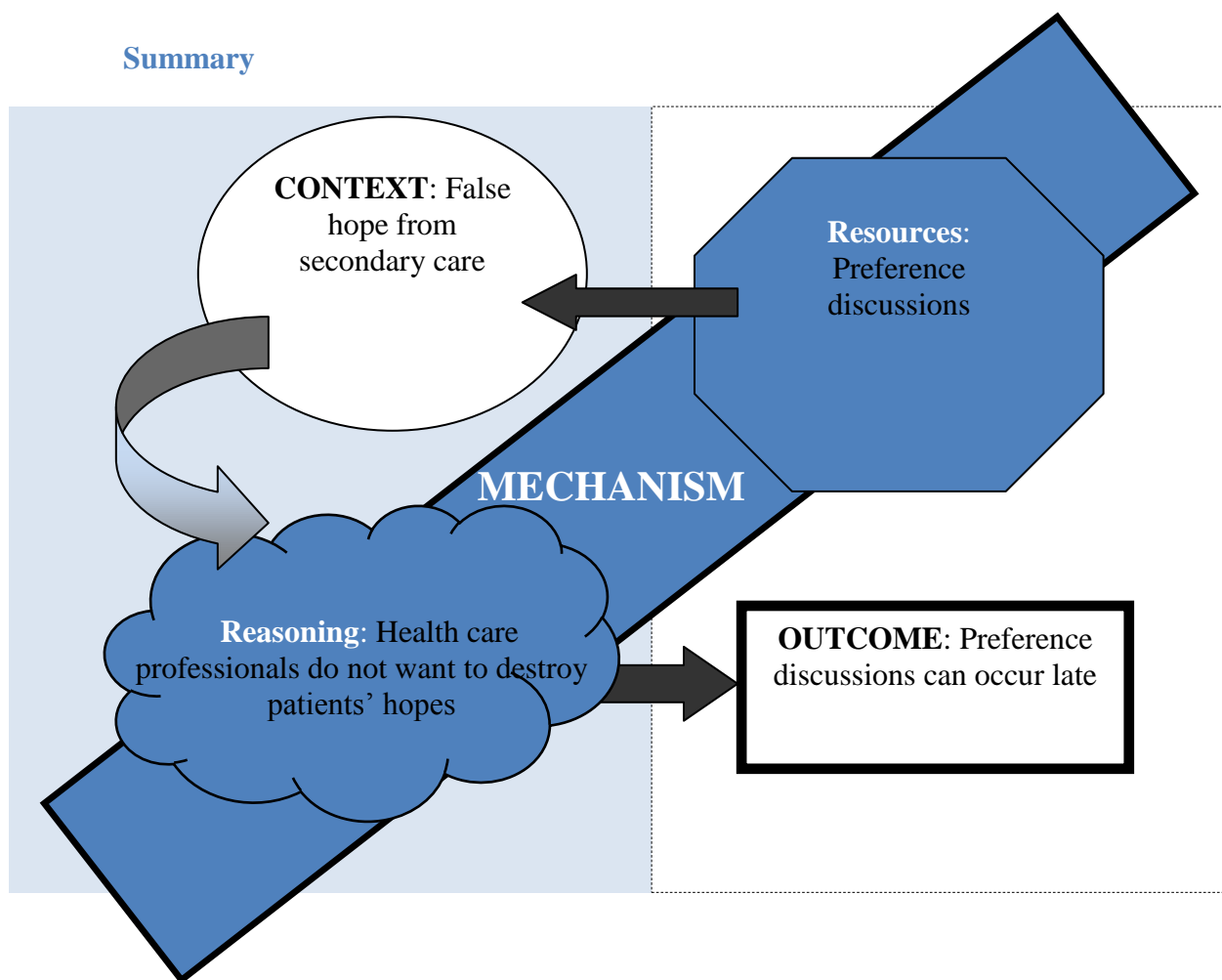
Figure 23: CMOC2, false hope can prevent preference discussions

As displayed in Figure 23, patients are often given false hope from secondary care and offered aggressive treatment when they are approaching end-of-life (context). This makes it difficult for health care professionals to broach preference discussions (resource) due to a fear of affecting their hope about prognosis (reasoning). This has resulted in preference discussions sometimes occurring late in the locality. CMOC2 can be construed in a positive way. If patients remove themselves from aggressive treatment from secondary care or if it is not offered (change in context), then health care professionals might be able to be open about illness progression and broach preference discussions (resource) without the fear of destroying patients' hope (reasoning). This would result in preference discussions being viable earlier in the patient's palliative care journey.

CMOC3 – Time constraints in primary care

Outcome: Preference discussions do not predict use of the locality advance care plan

Preference discussions and the locality advance care plan are both part of the ACP process. It is assumed that if a locality advance care plan has been completed with a patient then they have engaged in the ACP process. This is more of a robust process than preference discussions alone. A Spearman's rank correlation co-efficient was used to see whether there was a relationship between preference discussions and the locality advance care plan (documentation) as the data was not linear. The correlation showed that preference discussions and the locality advance care plan (documentation) have a significant positive relationship ($r = 0.55$, $n = 14$, $p < .05$),

the least squares regression line (line of best fit) in Figure 24 displays a large strength positive trend (Cohen 1988). This suggests that practices that do more preference discussions also use the locality advance care plan documentation more often.
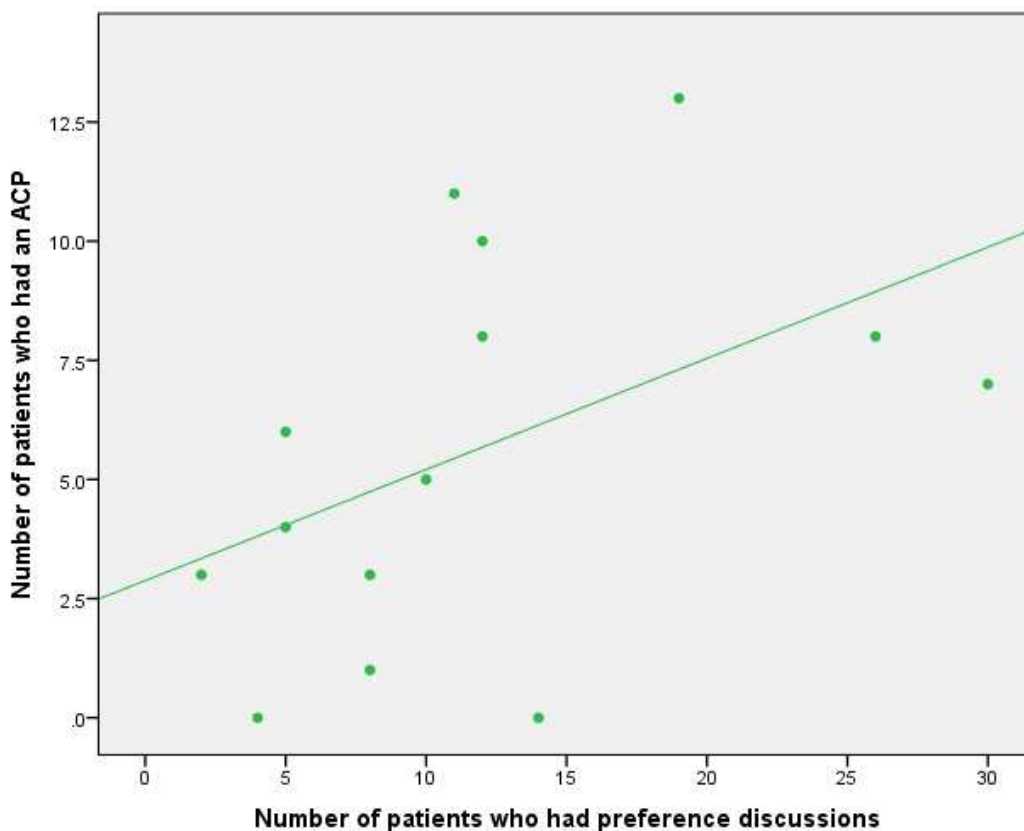
Figure 24: A correlation between preference discussions and locality advance care plans.

The correlation prompted a multiple regression, a stronger statistical test that identifies not only a relationship, as a correlation does, but whether one factor predicts another. Thus it was used to assess the ability of preference discussions to predict the use of the locality advance care plan (document). Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. The model was not significant ($F(1,12) =$

3.35, p > .05) thus meaning that preference discussions do not predict the use of the locality advance care plan.

In summary, the statistical tests indicated that there was a significant strong positive correlation between preference discussions and the use of the locality advance care plan, using 2011 data; however preference discussions do not predict the use of the locality advance care plan.

Mechanism: Additional paper work generated from the locality advance care plan

In FG1 the community matron stated that she felt the locality advance care plan was difficult to use.

> Community Matron (FG1): *"The prin, the principle of the* document is great and very, very sound. But it really needs to be *made more, erm, more user friendly."*

If a document is difficult to use then it is likely to be time consuming, which in the time constrained environment of primary care (context) makes the document less likely to be completed. Three of the GPs in FG3 commented on how much paper work the advance care plan generates.

> GP4 (FG3): *"It comes down to communication skills and time. That's* one of the biggest constraints, not having the time to do advance care planning. You know, the days are just getting more *and more hectic so there's less and less time to effectively do things like this."*

> GP6 (FG3): *"I mean undoubtedly there a huge* work load there, in *paper work… So it's an issue over, as a format it's a good thing, but it has to be built on communication and that's a timely thing.*

And maybe that's the issue. With care planning and with end-of-life advance care planning. Maybe that's the issue… It's resource, and the biggest resource we don't have is time."

GP3 (FG3): *"Certainly when I was in practice it was the time consuming paper work that was the problem".*

The GPs may have opted to not use the locality advance care plan due to the extensive amount of paper work it generated (reasoning), especially due to the time constraints in primary care (context). The social care team lead described how time constraints became stressful for health care professionals in primary care.

Social care team lead (FG3): *"And that's stressful, because you know what you should be doing but it's, and how you should be doing it, but it's just so difficult when you're stretching yourself ever so thinly."*

Context: Time constraints in primary care

The literature in the introduction highlighted that health care professionals in the UK have time constraints with patients (Elwyn, Edwards et al. 1999). Both the social care team lead and a GP commented on how time pressured they felt in practice.

Social care team lead: *"We need more hours in the day"*

GP6 (FG3): *"An 8 day week would just about cover it (tasks to be completed)"*

The quotes above highlight that health care professionals using the ICP feel pressured to complete all the necessary tasks they have to do in the short time they are given.

Summary
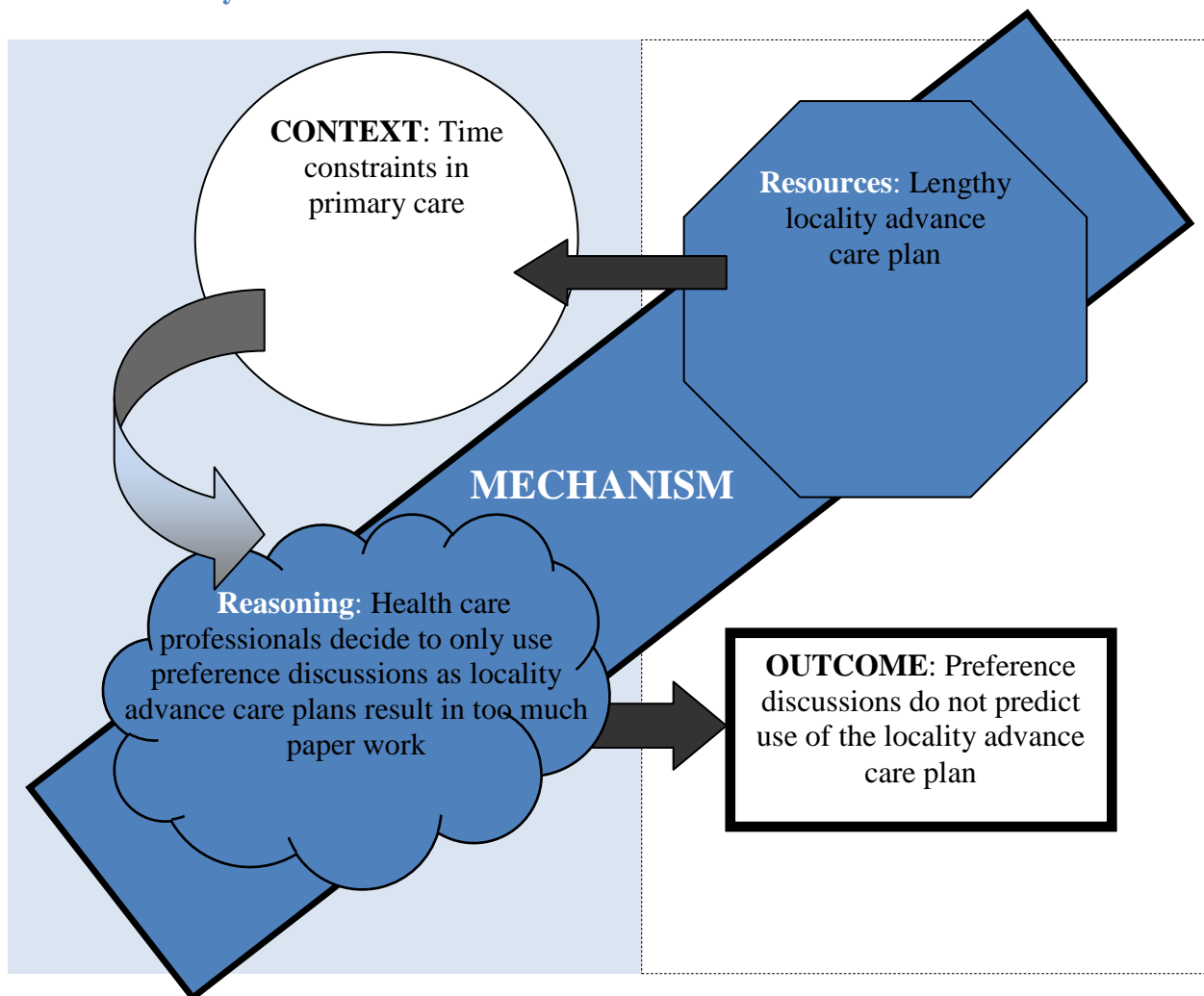
Figure 25: CMOC3, time constraints in primary care

The decision not to use the locality advance care plan (resource) may be due to the time consuming paper work it generates (reasoning), which is not feasible in a time constrained primary care setting (context), as shown in Figure 25. This has resulted in preference discussions not predicting the use of the locality advance care plan. However, engaging in preference discussions can make the use of a locality advance

care plan more likely, as demonstrated by the correlation showing a positive relationship between the two tools.

CMOC4 – The Mental Capacity Act and the locality advance care plan

Outcome: No significant increase in locality advance care plans from 2009 to 2012

A one-way repeated measures ANOVA was conducted to compare numbers of advance care plans completed in 2009/10, 2010/11 and 2011/12. There was no significant effect for time on locality advance care plans completed ($F_{(2, 22)} = 0.21$, $p > .05$, $\eta^2_p = 0.2$). This means that the number of locality advance care plans being carried out since the introduction of the ICP has not significantly increased. Figure 26 depicts this.
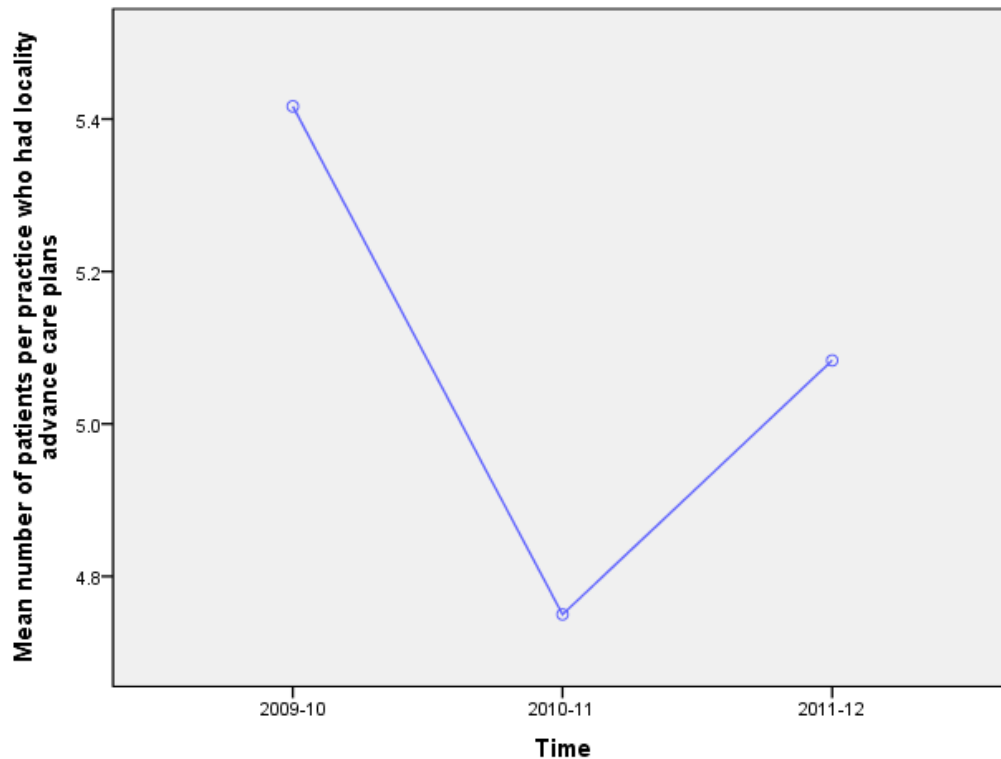
Figure 26: The mean number of patients who had locality advance care plans from 2009 to 2012, using Death Audit data.

Mechanism: The mental capacity act and instability of capacity

The impairment that causes a lack of capacity can be temporary or permanent. A person must be assumed to have capacity unless it is established that they do not have capacity to make a certain decision about a certain matter (NHS North East 2012). This means that a lack of capacity does not apply to all decisions but only the one in question at that current time. Thus, capacity is unstable, as it relates to the decision that is being made and the functionality of the person at the time of the decision. This instability of capacity (resource) was commented upon in FG3.

GP4 (FG3): *"It's (capacity) is individual and it's time specific."*

GP3 elaborated on GP4's comments, stating that capacity is very difficult to decipher and with is comes a fear of litigation from families (reasoning), suggesting that health care professionals have low confidence in their capability to efficiently assess capacity.

> GP3 (FG3): *"It's* the variability of capacity, erm, and in certain ways that can point to litigation. You see somebody you thought on this day seemed to understand and have capacity but then in three days time they may not even remember that they had the conversation and th*en if you're certain you've got their* preferences for do not resuscitate etc. and then the family say well *they clearly couldn't make that decision… Society believes that you never die. And that if you do then it's someone's fault."*

GP3 also felt that the lengthy locality advance care plan made completing it with someone who's capacity was questionable even more difficult.

> GP3 (FG1): "I would welcome it (a shorter advance care plan). I am put off by the amount of detail present (in the locality advance care plan). The locality advance care planning document makes a difficulty of assessing mental capacity. For example, does this person have mental capacity for all of this document or just bits of *it? I think a shorter document would be more defined."*

Health care professionals have a fear of repercussions (reasoning) from assessing patients' capacity which can be unstable (resource). This results in less use of the locality advance care plan.

Context: The locality advance care plan is to be used with those who have capacity to engage

Most patients on the palliative care register have cancer diagnoses. However, some have non-cancer diagnoses which can result in cognitive impairment. A large proportion of patients with non-cancer diagnoses in the locality are in care homes and some do not have capacity to make decisions about their health care. However,

in an increasingly patient-centred health service, individuals wish to make independent judgements about their care (Kon 2012), which can cause issues. The MCA (Justice 2007) provides a legal and clinical framework that health care professionals should adhere to when assisting patients in making treatment decision. GP3 highlighted the MCA as an important context (using SSM) in FG2.

> GP3: *"A factor in the worldwide view is the mental capacity act,* because I think that that is agonised over most and trying to do them (advance care plans), does this patient have the mental capacity to make these, these questions I was trying to ask them, *so, but I mean, I would agree patient's and carers, but the mental* cap*acity act most certainly has an impact."*

The quote above identifies that health care professionals are aware that the locality advance care plan (and all ACP) must be carried out with those who have capacity, and the MCA therefore has an impact on how they manage their use of locality advance care plans in practice. GP1 explains how this affects her use of ACP.

> GP1 (FG1): *"I go to the same care home* every week and see little old ladies and not one of them recognises me, because they have dementia and therefore advance care planning *is not feasible"*

The quote above highlights how GP1 feels that ACP is not appropriate for a proportion of the palliative care population.
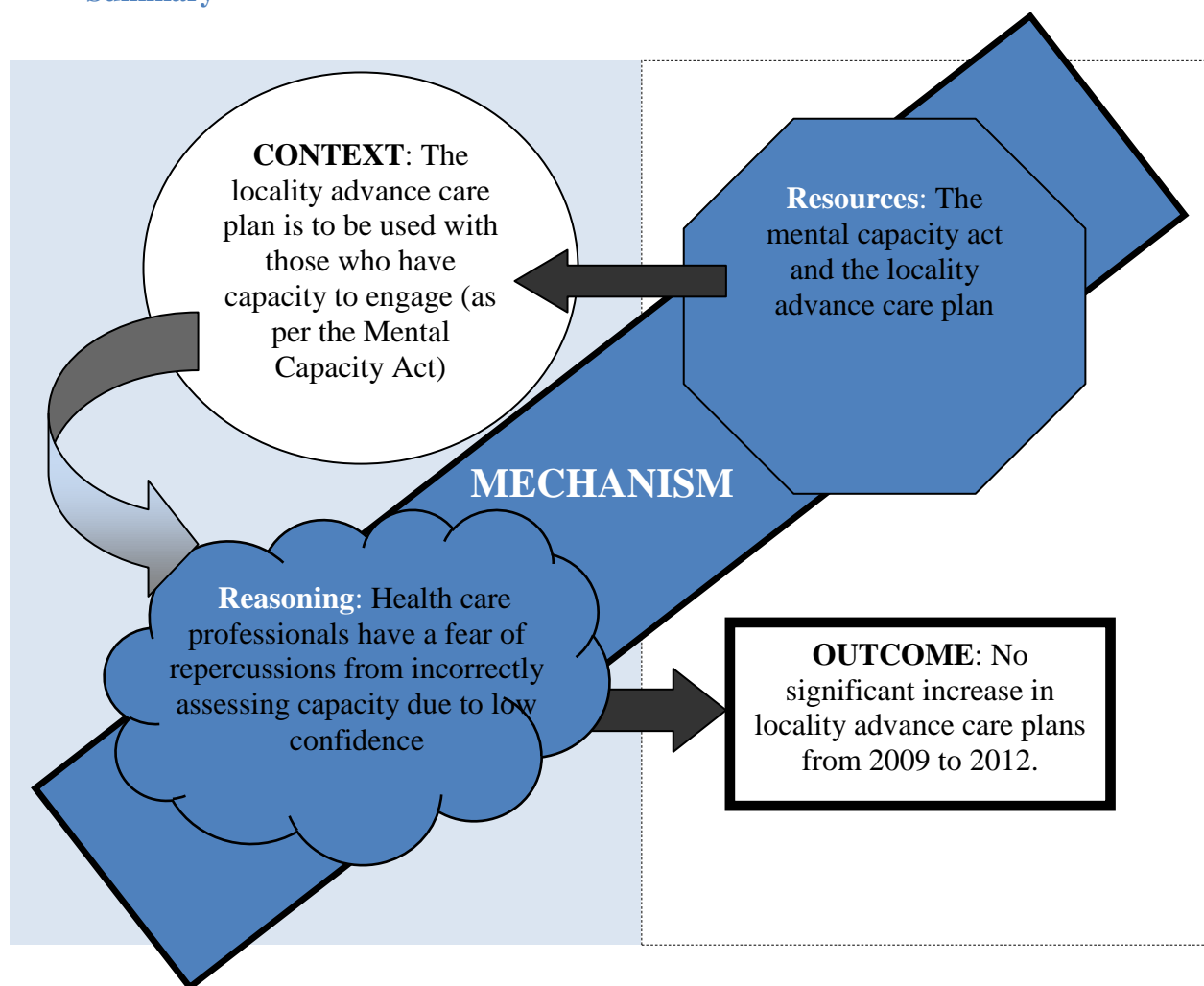
Figure 27: CMOC4, the MCA and the locality advance care plan

A diagrammatic explanation of CMOC3 is provided (Figure 27). The underlying principles of MCA (Justice 2007) mean that individuals must have capacity for the decisions they make (context). This makes it difficult for health care professionals to carry out locality advance care plans or ACP in general (resource), as capacity can be unstable. This gives health care professionals a fear of repercussions (reasoning) suggesting that they have low confidence in assessing mental capacity. This has resulted in no significant increase in the use of locality advance care plans from 2009 to 2012 (outcome).

CMOC5 – A change to the advance statement from Deciding Right

CMOC 5 describes a change that occurred within the locality, partly as a result of the focus group discussions that took place as part of this PhD, and provided information on health care professionals' perceptions of the locality advance care plan.

Outcome: The locality changed to the use of the advance statement

The discussions with the Palliative Care Partnership and the focus groups prompted the change to the advance statement and the use of other tools from Deciding Right (NHS North East 2012). The use of the advance statement may potentially result in an increase in advance statements (previously the locality advance care plan) in the future.

Mechanism: The advance statement

The focus groups identified that health care professionals were not comfortable using the locality advance care plan. Participants felt that it was time consuming; they were confused about where to write and thought that a lot of the questions were unnecessary.

> GP3 (FG1): *"I would definitely vote for that because I was* definitely put off by the amount of detail in the present (locality) advance care plan. I look at it and think where should I write? I mean the difficulty of mental capacity, the present document makes it even more difficult. Does this person have mental capacity for *all of this document or for bits of it?"*

> GP3 (FG2): *"Our staff didn't know w*here to write, and as a GP I would include myself in that, I used to write on any page I could *find to write on."*

A tailored, shorter version was required. This resource was offered in the form of the advance statement, one of the tools provided in the Deciding Right documentation (NHS North East 2012). Both myself and the PCP thought that the advance statement would be more user friendly and may encourage health care professionals to complete advance statements (reasoning).

Context: The locality advance care plan is not user friendly

The locality advance care plan was not being used by focus group participants (health care professionals) as it was time consuming and not user friendly.
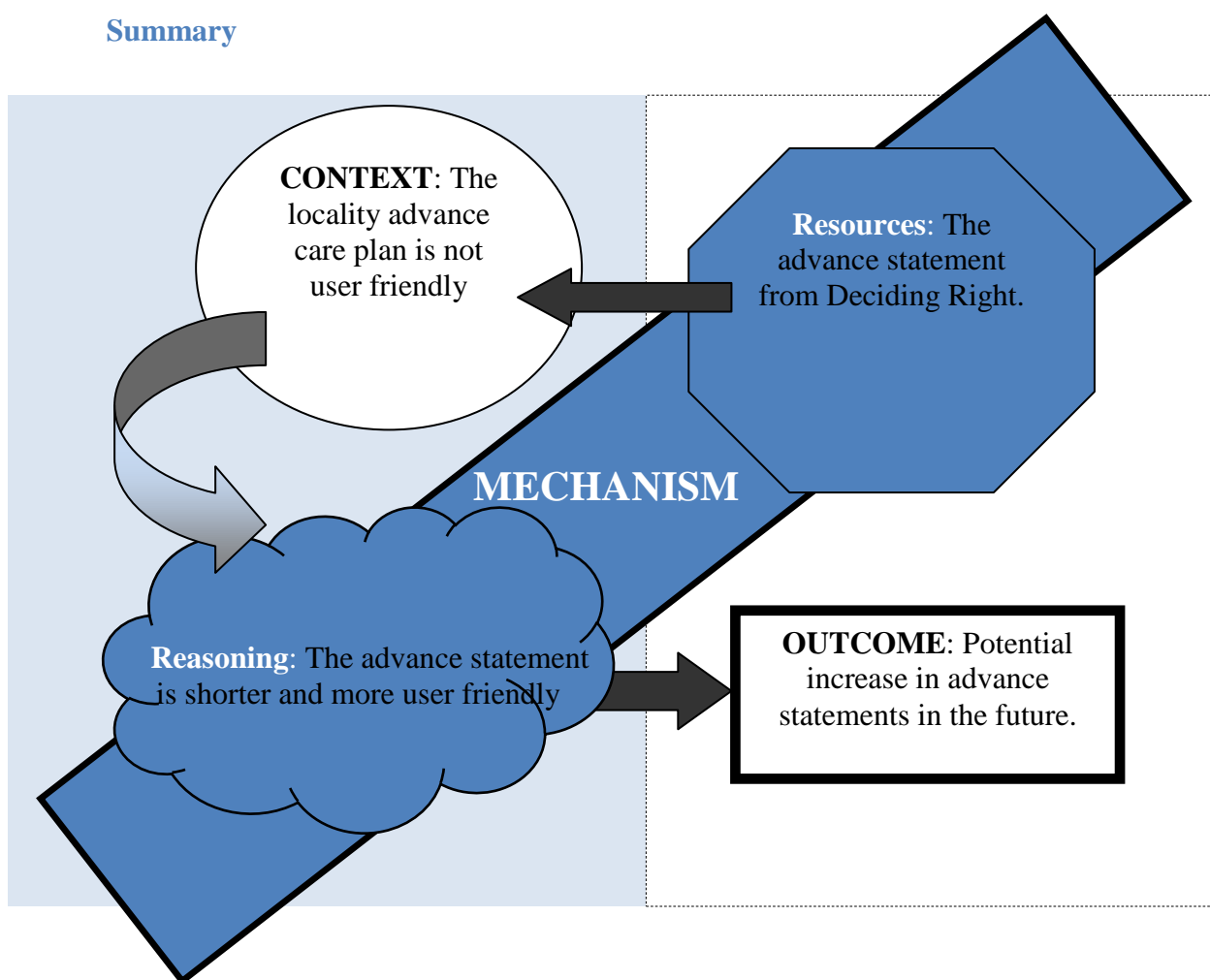
Figure 28: CMOC5, a change to the advance statement from deciding right

The advance statement is a shorter document which may mean that less paper work is generated for health care professionals. They may therefore be more likely to engage with it and use it as a tool to help patient plan their care, as opposed to relying on preference discussions. However, the change does not affect health care professionals' fear of repercussions from assessing unstable capacity. Although, Deciding Right, the documentation that provides the advance statement, does offer clear instructions on assessing mental capacity and the health care professionals in the locality have now (post data collection) had workshops on using Deciding Right, including assessing mental capacity. Thus, CMOC5 (displayed

diagrammatically in Figure 28) indicates that the locality advance care plan was not user friendly (context). The advance statement (resource) was a more concise document that may encourage health care professionals to engage with it (reasoning). This resulted in a change to the advance statement (outcome). This CMOC is also presented to demonstrate how the ICP is not a static intervention, but in itself responds to evolving contexts and new mechanisms. Therefore, whilst this PhD is an evaluation of the ICP, it also contributed to its development over time.

Chapter Summary

It has been highlighted that preference discussions are increasing (outcome) and often happen when patients' condition or needs change (context). The increase in preference discussions may be due to the ICP framework (resource) which encourages health care professionals to engage in preference discussions, to be proactive and patient centred. Health care professionals have a desire to be patient centred and provide high quality palliative care to facilitate the patient's good death (reasoning). However, preference discussions can happen late in the patient's illness trajectory (outcome), as they approach end-of-life; this can happen when health care professionals feel that patients have false hope about their prognosis (context), which will often come from secondary care treatment providers. Preference discussions do not predict the use of the locality advance care plan (outcome). The decision by health care professionals not to use the locality advance care plan (resource) may be due to the amount of paper work it generates, which is not feasible to complete (reasoning) in a time constrained environment such as primary care (context). This is supported by no significant increase in use of the locality advance care plan from 2009 to 2012 (outcome). This could be partly explained by

the need to complete the locality advance care plan with those who have capacity (context), when capacity can be unstable, as assessed by the MCA (Justice 2007) (resource). This results in health care professionals having fear of repercussions from inaccurately assessing the patient as having capacity and engaging in (documented) care planning with them. However, now the study and Palliative Care Partnership have prompted the change to the advance statement, and the locality has had workshops focusing on mental capacity and the use of Deciding Right (NHS North East 2012), there may be an increase in the advance statements (that replaced the locality advance care plan) completed.

From the analysis it appears that health care professionals engage in preference discussions more readily than they use the locality advance care plan. This may be due to issues surrounding the implementation of the locality advance care plan. Health care professionals felt that using the locality advance care plan was difficult, due to capacity issues and time constraints. Time to complete advance care plans has previously been highlighted as an issue in the literature (Seymour, Almack et al. 2010). In a study on advance directives it was found that nursing staff had very low rates of advance directive completion despite most nurses feeling that advance directives were valuable to the patient (Duke and Thompson 2007). This was attributed to the need for more resources including administrative support and time to engage in the process. Similar results were found in this study, with health care professionals seeing the need and value of the locality advance care plan, but not having the time or administrative support to carry it out. Without the resources to implement documented care plans, despite the potential of the tool to empower patients, health care professionals will not feel able to use it and therefore will have no ownership of it.

Programme theory 3 stated that there would be an increase in the use of preference discussions and the locality advance care plan (outcome), as health care professionals become more confident with broaching the subject of death and dying with patients (mechanism), and aware of the importance of having and documenting preference discussions, which has been highlighted by recent policy (context). This programme theory is not wholly supported by the findings. Preference discussions are increasing (outcome) but can sometimes occur late in a patient's illness (outcome), when they are approaching end-of-life. A change in the patient's condition or need (context) would prompt health care professionals to broach preference discussions with the desire to be patient centred (mechanism). When preference discussions occurred late it was due to patients having false hope (context). Thus, in order for preference discussions to occur (outcome), health care professionals seem to need some reassurance that they initiate this delicate conversation at the appropriate time: a change in condition or need, or the patient's acceptance that they are in their final illness (refusing aggressive palliative treatment from secondary care). This allows the health care professional to then work within a palliative care framework, being patient centred and broaching preference discussions. Thus, a refined programme theory can be created for preference discussions. A change in the patient's illness progression, in terms of condition deterioration, increased need or psychological acceptance (context), allows health care professionals to be patient centred and address sensitive issues at an appropriate time for the patient (reasoning), using preference discussions (resource). This has resulted in an increase in preference discussions from 2008 to 2012. Health care professionals also noted that often patients themselves would broach conversations about their preferences and wishes for end-of-life , but data was insufficient to support a CMOC for this. However, the programme theory (3)

does not support the findings for use of the locality advance care plan. Use of the locality advance care plan has not increased from 2008 to 2012 (outcome), and preference discussions do not predict the use of the locality advance care plan (outcome). The explanation for this is related to the pragmatic issue of the time consuming paper work the locality advance care plan generates (mechanism), and difficulties in assessing capacity (which can be unstable) using the MCA (mechanism).

This chapter has identified that documenting patients' preferences can be difficult. The next chapter will explore the potential of an information seeking and avoiding explanatory framework (monitoring and blunting) in facilitating consultations about palliative and end-of-life care, which often include preference discussions and ACP.

Chapter 7: Facilitating difficult conversations in palliative care

Clinicians need to create several opportunities for patients to engage in discussions about their future and end-of-life care (Barclay 2010). These discussions need to be guided by the patient as to timing, pace, and content. However, GPs must also be respectful of the wishes of those who do not want to discuss such matters but continue to give opportunities at different consultations to engage in discussions about end-of-life care (Barclay 2010). Thus, health care professionals must be respectful of those who both seek and avoid chances to engage in information sharing about end-of-life care.

Initial questions asked of the data

The programme theory and subsidiary questions that this chapter focuses on were first stated in the methodology chapter as:

- **Programme theory 4:** Innate coping style of the GP and patient (context) will facilitate a consultation if matched (mechanism), making a preference discussion and use of the locality advance care plan more likely to occur (outcome).

-       Are matched coping style consultations more successful (in terms of producing outcomes such as preference discussions and advance care plans).

-       Can matched coping styles facilitate practice?

This chapter focuses on the micro, concentrating on interactions between one patient and one GP in each CMOC to unpack the effects of coping style. From the programme theory and knowledge about monitoring and blunting styles a CMOC matrix was devised (Table 11).

Table 11: CMOC matrix, matched monitoring and blunting health care professional-patient interactions and the outcomes they can result in.

Context		Mechanism		Outcome
Patient	**Health care professional**	**Resource**	**Reasoning**	
High Monitor	Low Monitor	Health care professional's knowledge of preference discussions and their benefit to patients	Communication between patient and health care professional determined by monitor blunter combination, perseverance of health care professional and receptiveness of the patient.	No preference discussion broached
Low Monitor	High Monitor			Health care professional makes repeated attempts at preference discussions until successful
High Monitor	High Monitor			Preference discussion broached
Low Monitor	Low Monitor			No preference discussion broached

Consultations were recorded between three patients and their GPS. MBSS scores are out of 16 for both monitoring and blunting and are displayed in the table below (Table 12). A score of 10 or above for monitoring is considered a high monitor, thus two of the GP and patient pairs were high monitors (GP-A and Mary, GP-B and

John) and one of the pairs were low monitors (GP-B and Susan). However, the same low monitor pair also had low blunter scores, as did GP-A and Mary. GP-B and John who had high monitor scores also had high blunter scores. The MBSS creators do not provide a score to define high and low blunters but in comparison to the other patients, GP-B and John have much higher blunting scores (8/16 and 9/16, respectively).

Table 12: Monitoring and blunting scores out of 16 for GPs and patients.

	GP-A	Patient 1 (Mary)	GP-B	Patient 2 (John)	GP-C	Patient 3 (Susan)
Monitor Score	10	11	10	10	7	6
Blunter Score	2	5	8	9	3	2

Table 12 indicates that the patients and health care professionals are quite well matched in terms of their monitoring and blunting scores. Thus if the programme theory is correct, it would be predicted that GP-A and Mary are most likely to have a consultation that includes ACP (preference discussions and use of the locality advance care plan), as they both have a high monitoring score and low blunting score. GP-B and John have high monitoring scores but also have high blunting scores. GP-C and Susan have slightly lower monitoring scores than the other two GP-patient partnerships but also have low blunting scores.

This chapter will describe CMOC in a different order to the other chapters in the thesis. The CMOC will begin with an explanation of the context and end with

exploration of the outcome as this is how they were formulated. The chapter uses consultation recordings to test the impact of different combinations of contexts on the mechanism of ACP.

CMOC1 - High monitor and low blunter

Context: Information seekers: GP-A and patient 1 (Mary)

GP-A and Mary were both classified as high monitors and low blunters. High monitors are information seekers, those individuals who are likely to cognitively scan for, attend to and magnify threatening cues (Miller 1987). They have increased risk-related perceptions and higher levels of distress, regardless of their objective risk (Muris, de Jong et al. 1995, Schwartz, Lerman et al. 1995). Additionally, high monitors have increased anxiety about health risks and ruminate about information they perceive as threatening (Miller, Roussi et al. 1994, Muris, de Jongh et al. 1994, Miller, Rodoletz et al. 1996). Thus, it is likely that high monitors will wish to engage in preference discussions (seek information) and the ACP process in general.

Mechanism: Advance Care Planning

Over a course of two consultation recordings GP-A and Mary review Mary's locality advance care plan, which was completed prior to the recording. The GP begins by seeking information on general well-being and function:

> GP: *"So are you having to get them (social care) to do any more for you?"*
>
> Mary: *"No. Empty the dishwasher and make the bed (laugh)"*

The conversation develops with Mary talking about her locality advance care plan. The GP seeks information about who Mary feels is involved in her advance care plan. This is a way of ensuring that Mary understands the locality advance care plan and what has been stated on it. It also helps her to refine and develop it if and when her preferences change. Thus the GP is demonstrating their understanding that preferences and the locality advance care plan need to be reviewed regularly as patient's preferences and needs are not static (resource). Mary explains that she prefers to stay at home and has all the support she needs.

> Mary: *"I feel safe here, I feel I know who I can call upon. And not* just one person, two or three people I feel I could call upon. It gives me a great sense of security knowing all of the people who *are involved in the, in the (advance) care plan really."*

> GP: *"Sure ok. So who would you say is involved at the moment? If you were sort of to make a list."*

> Mary: *"Well obviously you probably. Erm, the nurses.* The *community nurses, erm, the, Macmillan nurses, err…"*

Mary was very open to the notion of ACP when she found out about her terminal illness. This may have been due to her information seeking disposition (high monitoring score) and low information avoidance (low blunting score). Mary wished to know her options, discuss them and then have them formalised (reasoning).

> GP: "So what difference do you think having that care plan or *talking though the care plan actually makes, do you think it's, do* you think it*'s a situation that you people knew about anyway, I think when we'd talked about it you'd already discussed it with your family."*

Mary: *"Yes I did. I did, as soon as I knew what the diagnosis was. I felt, I don't know how long I've got, I mean I might have a longer time or a shorter time but I just wanted something down in black and white."*

Mary then states that she thinks the advance statement will need to be updated as time progresses and the GP reassures her that this can be completed as and when needed, indicating that the GP has a good knowledge of the ACP process (resource). In this instance Mary is seeking information without asking questions.

Mary: *"I mean obviously you don't know what's the future but you don't know how much nursing care I might need (referring to hospice care), but I think I've got, yes. I'm very happy with (advance statement)…"*

GP: *"And we can update it as things change, if things change."*

Mary: *"Yes, yes."*

Discussions about the advance care plan between Mary and the GP then lead Mary to discuss other end-of-life issues, related to symptom management. She does this explicitly and implicitly, using questioning techniques and statements which seek confirming reassurance from the GP, respectively.

Mary: *"Yes, as long as I've got a reasonably comfortable end, I'm sure I won't be allowed to suffer unnecessarily will I?"*

GP: *"Not if any of us have anything to do with it."*

Mary: *"Yes"*

GP: *"Which we will."*

***

Mary: *"Well as you know I feel extremely calm about all that (death and dying)."*

GP: *"Always been very calm."*

Mary: *"Because, erm, well I feel all the family, fortunately I've got a very loving family who know what my future's going to be."*

GP: *"Sure."*

Mary: *"And what's wrong with me. And also I have some good friends and neighbours and erm I don't feel. I'm not afraid of dying. I'm just not afraid of it at all."*

GP: "Mmm."

Mary: *"As long as I'm not writhing in pain and they said oh well I don't think I'll be doing that."*

GP: *"No"*

***

Mary: "And as I say*, I say I'm so lucky because I don't have any pain and that's the thing, I never have had and I still haven't so. But you don't know do you? When it's? what that's? (laughs nervously)."*

GP: *"Nobody knows."*

Mary: *"They don't."*

The GP then seeks information from Mary about how palliative and end-of-life care and her terminal illness affect her psychologically, in her thoughts and her decision making.

GP: *"Have you been doing much thinking about what's going to happen or what might happen?"*

Mary: *"Erm, not, not a lot. Erm, I mean not so, not every day, particularly, sometimes, well sometimes when I'm awake in the night but no I don't really worry about it if that's, I've not got an anxiety about it."*

In the quote above the GP seeks information to understand Mary's psychological position in attending to her approaching end-of-life. This may help the GP to provide more sensitive or appropriate care (reasoning).   The GP also seeks information about Mary's decision making in relation to palliative care and investigative treatment. This demonstrates that the GP wishes to support Mary in her palliative care journey by avoiding aggressive treatment (resource).

GP: *"So if he was to say to you at the clinic you know, we could do an endoscopy, we could… check this, what would you say?"*

Mary: *"No thank you. I'll be very grateful for what you've done, already to relieve the symptoms but no I don't want any."*

In summary, throughout the consultation recordings GP-A demonstrates that they have a good understanding of the ACP process (resource). Mary wished to know her options and have them formalised (reasoning) which was done through use of the

locality advance care plan. Mary and GP-A have a good relationship, both seeking information from one another to aid understanding and facilitate conversations. This may be due to their matched high monitor and low blunter disposition (context).

Outcome: Locality advance care plan reviewed

Mary demonstrates a strong ownership of her locality advance care plan throughout the consultation recording which may have resulted in her determined attitude towards palliative care, rejecting hypothetical investigative treatment. Mary and GP-A successfully review Mary's locality ACP – a crucial step in the ACP process in order to ensure that preferences are current.
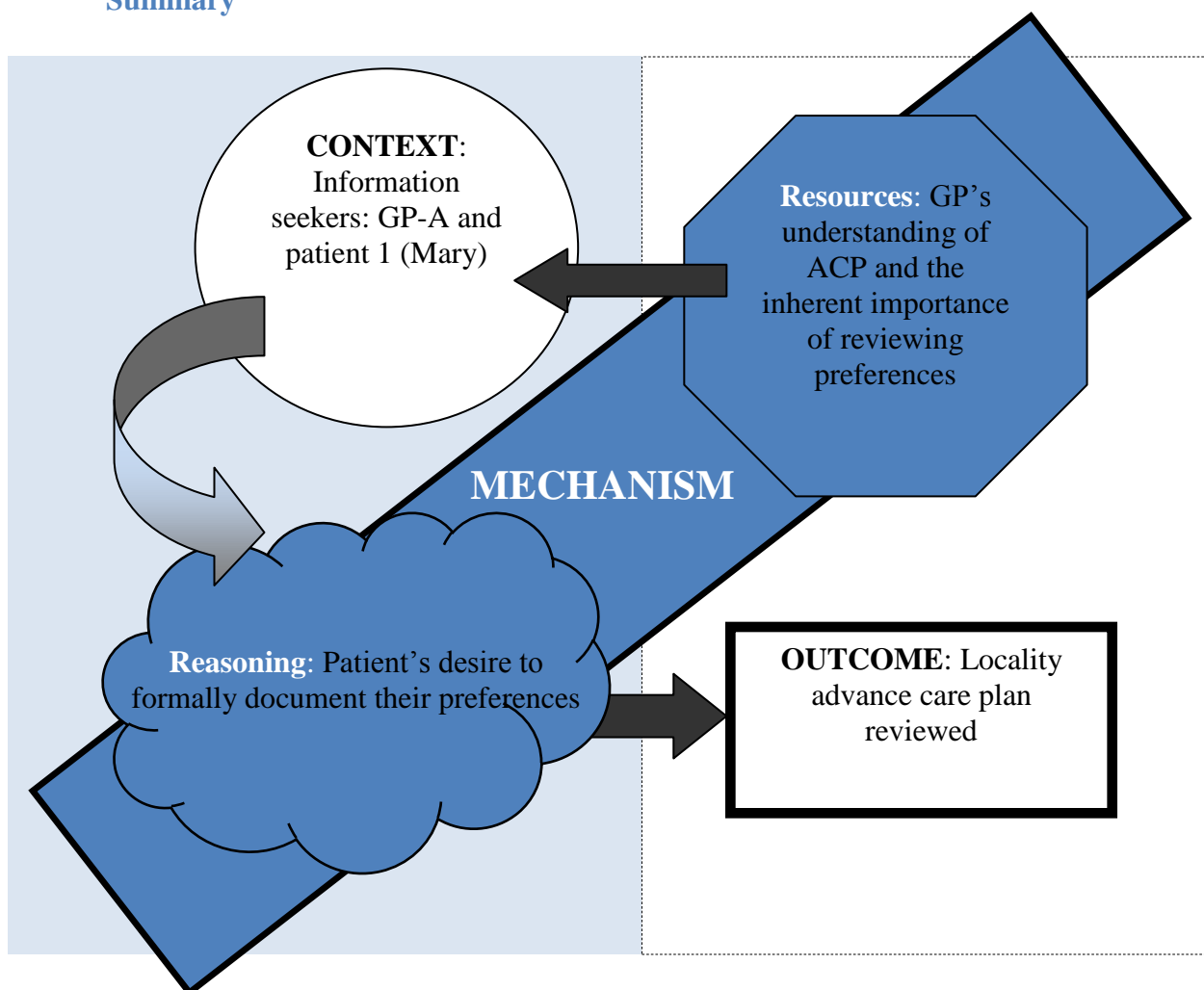
Figure 29: CMOC1, high monitor and low blunter.

Mary's locality advance care plan was reviewed throughout this consultation recording (outcome) leaving Mary feeling in control of her care (outcome). It is reasonable to assume that this was due to the matched coping style, resulting in an inherent desire for information (context), the GPs efficient ACP skills (resource), and Mary's desire to have her preferences formalised (reasoning). CMOC1 is displayed diagrammatically in Figure 29.

CMOC2 – High monitors and high blunters

Context: Information seeker or avoider? GP-B and patient 2 (John)

GP-B and John scored quite highly on the monitor and blunter scale. Blunters (also known in the literature as low monitors) are information avoiders and cognitively distract themselves from threatening cues. They tend to have low adherence to health behaviour regimes and therefore may underestimate their personal vulnerability for disease (Steptoe and O'Sullivan 1986). Individuals with a blunting coping style (low monitors) also use strategies such as distraction and denial when under stress (Miller 1980, Miller 1987, Bonk, France et al. 2001). Having a high score on the monitoring and blunting scales is unusual in that it means that GP-B and John both seek and avoid information. This makes it difficult to predict whether they will seek or avoid information. It could be that in different situations GP-B and John's monitoring or blunting trait is prevalent.

Mechanism: Advance Care Planning

In the two consultation recordings the GP does not broach ACP or discuss end-of-life issues (resource). Both John and the GP sought information from one another, but this was always related to generic care or social care rather than palliative or end-of-life care. For example, in the quote below John implicitly seeks information from the GP about a specific symptom he is experiencing when eating food.

> John: *"Well it's funny because this (inaudible) mentioned about erm not being able to control me temperature when, when I'm eating food."*

> GP: *"Yeah"*

John: *"I'll be sitting there, I'll be eating a meal and, just little* meals you know, by normal standards and me temperature goes through the roof. And I suddenly get this, you know this sort of, this dark area around me vision. Like I was getting when I had low *blood pressure, we've checked the blood pressure once or twice and it aint, it aint that."*

GP: *"Mmm."*

John: *"And then, then just as soon as you get back on the air again* its five minutes and *you're fixed. So it's psychological ish but I'm not really convinced."*

***

John: *"No, exactly. There was something, I seem to just pass water* (urine) or some kind of mucus-*y stuff."*

GP: *"Mmm"*

John: *"I dunno if that's worthy of worrying about or if it'*s just the *fact that there's just nothing to come out."*

GP: *"Clear or?"*

John: *"Clear, yeah."*

GP: "I suspect its ok, just one of those things*".*

The GP also seeks information from John in order to provide individualised care that is most appropriate. An example of this is in reference to contact with the Motor Neurones Disease (MND) team.

> GP: "I mean, do you feel you want to be in contact with the (MND *team) again or do you feel really, they're not really going to add* much more?"

> John: *"It's hard to say after, after this time. I mean I wouldn't be (inaudible) because she was very good. But she's come, she's hiding very low isn't she (asking wife to confirm)?"*

At one point in the first consultation John seems to attempt to discuss end-of-life issues, or certainly the deterioration of his condition. However, the GP gives him the opportunity to not discuss this any further (resource). Unfortunately a section of the transcript is inaudible and the GP cannot recall what John said. However, both John and his wife clearly do not wish to engage in discussions about end-of-life care (reasoning).

> John: *"That's what the, really, what you've really gotta ask. I* mean has a, has there been a deterioration, yes there has *obviously. That's what it (MND) does. (Inaudible)."*

> GP: *"We don't need to talk about that today if you don't want to."*

> John: *"No"*

> John's wife: *"No"*

It may be that the MND team have addressed palliative and end-of-life care issues with John and thus the GP feels that this aspect of care has already been addressed. However, it would be presumed that end-of -life care would be provided by the GP and community nursing team, if a home death was desired. Thus, communication about end-of-life care with primary care is essential. GP-B does not attempt to

engage John in preference discussions (resource) and John and his wife do not wish to discuss death and dying (reasoning). This may be due to their blunting scores (despite their equally high monitoring scores) and the associated tendency to avoid stressful information. Therefore, in this case, combined high monitoring and high blunting styles did not provide a favourable context for ACP to be initiated or reviewed.

Outcome: Advance care planning does not occur

No preference discussions occurred and the locality advance care plan was not used. John and GP-B have a good relationship and discuss general health care, but neither approach end-of-life care discussions, and both avoid this topic when it comes up spontaneously in the consultation.
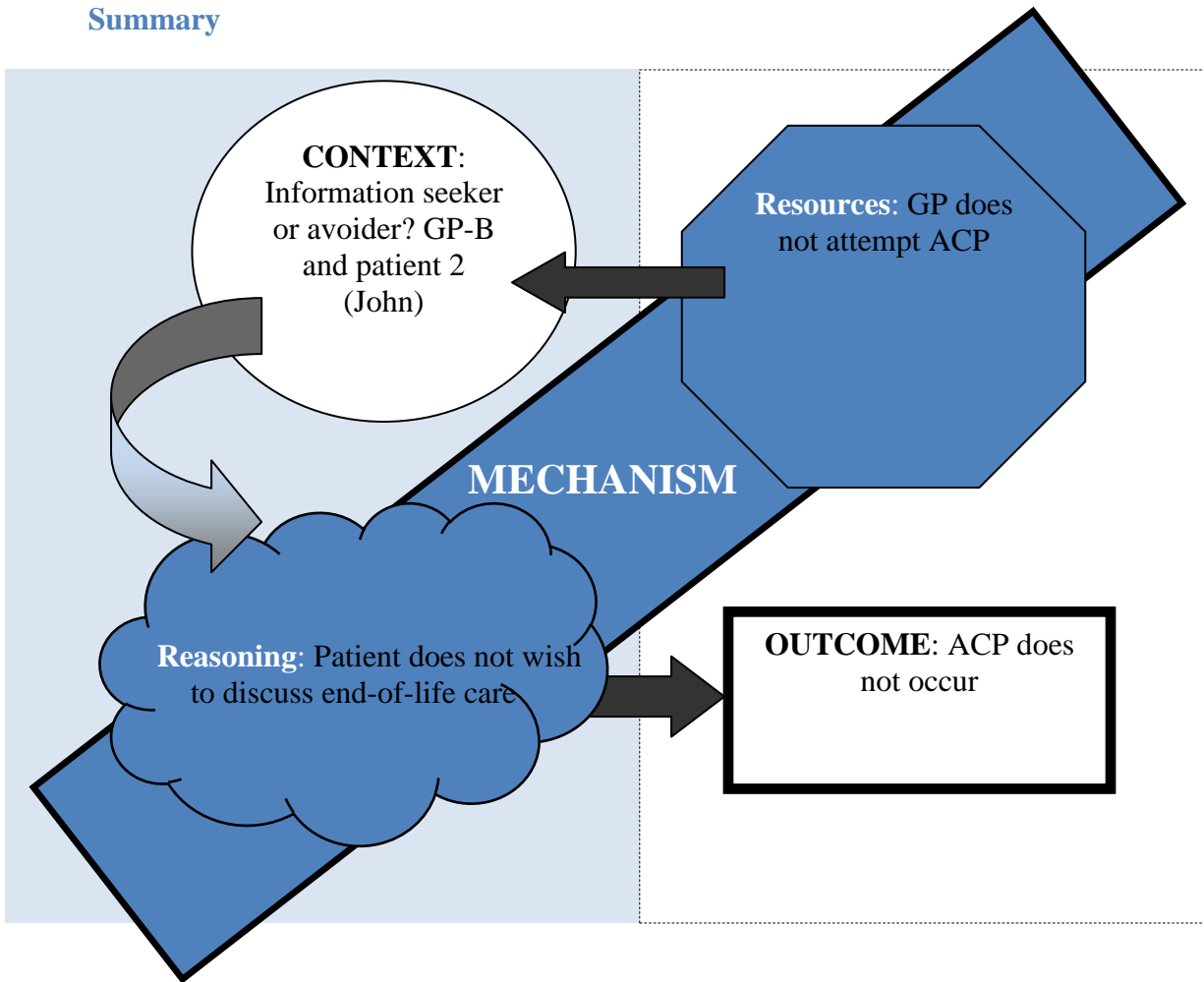
Figure 30: CMOC2, high monitor and high blunter.

As displayed in Figure 30, neither preference discussions nor use of the locality advance care plan has occurred as the context was not as fertile for these important conversations to take place. Furthermore, the GP did not broach preference discussions when they occurred spontaneously in the consultation (resource) thus questioning his understanding of repeated attempts to engage patients in ACP. Finally, the GP and the patient did not wish to discuss end-of-life care issues (reasoning), actually preferring to avoid these conversations.

CMOC3 - Low monitor and low blunter

Context: Low monitoring and blunting scores: GP-C and patient 3 (Susan)

Susan and GP-C were both classed as low monitor and low blunter. Therefore it is difficult to predict whether they will seek or avoid information about end-of-life care.

Mechanism: Advance Care Planning (not firing)

Throughout the consultation the GP broaches preference discussions and the locality advance care plan several times (resource), where he sees appropriate opportunities to do so. Susan distracts herself from this as she wishes to avoid information about palliative and end-of-life care (reasoning).

Susan: *"Listen, I've had friends ring me up or come and say "You've got your funeral arranged?"*

GP: (laughs)

Susan: *"Have you decided what you're having? I says I'm not going anywhere (laughs). I thought they were friends?"*

GP: *"Yeah but it's interesting because people deal with things in different ways."*

Susan: *"Course they do."*

GP: *"Yeah. So have you, have you had any thoughts like that at all?"*

Susan: *"Oh well we've got enough to cover a funeral."*

GP: *"Yeah."*

In the above quote Susan avoids focusing on preference discussions in relation to health care by turning the conversation to an unemotionally charged issue, finances. The GP recognises this and doesn't persist with this line of inquiry (resource). This is important as preference discussions must be entered into mutually. In the quote below Susan refers to the locality advance care plan which the GP had given her to look at (uncompleted) in a previous consultation. Susan avoids approaching information about the plan by changing the focus of the conversation to generic physical symptoms (reasoning). The GP persists in pursuing Susan's preferences on this occasion by asking how her husband would feel about the locality advance care plan (resource). It is highlighted that Susan's husband may also have a low monitoring style or a high blunting style.

Susan: *"But never mind I'm still here."*

GP: *"You are still here."*

Susan: *"I'm still here and that's the main thing."*

GP: *"And your positive thinking has been a real feature in how you've dealt with it you know, it's the…"*

Susan: *"You've got to be. As I say I was on a bit of a downer yesterday after I sat and read that and I'd been busy and err, but today I'm fine. I just put it away out of my mind."*

GP: *"Yeah."*

Susan: *"So, but I've got no other problems apart from me tongue and my fingers, that's all."*

GP: *"Yeah. What would, what would (husband) think about a conversation along those lines? Would he be the same as you, would he not want to get involved or?"*

Susan: *"I don't know. I know he gets anxious. And he gets angry, with me."*

GP: *"Yeah."*

Susan: *"Very impatient. But he doesn't talk about it."*

The consultation also reveals that Susan's daughter may have a low monitoring or high blunting style, as she too does not wish to discuss palliative and end-of-life care with her mother.

GP: *"Right. And what, what, conversations you've had with your daughter, have you had conversations about what happens if?"*

Susan: *"No."*

GP: *"No."*

Susan: *"No. She'll just say I don't want to know mam."*

GP: *"So you're all doing the I don't want to know bit? (laughs)."*

Susan: *"Yes (laughs)."*

The consultation indicates that Susan has had few opportunities to discuss her palliative and end-of-life care preferences with her family, but she also does not currently wish to engage in these discussions with the GP (reasoning). The GP attempts to explain the concept of ACP to Susan, as an attempt to allow her to engage with it and discuss her preferences (resource).

> GP: *"So just thinking about that, one of the, one of the thi*ngs that *we don't want to do is cause you any more distress in any way, in* any point in the future. And, and sort of, one of the ways that we can help with that is sort of through this advance care planning idea, thinking about how we want things to go for you and work if *and when."*

> Susan: *"If and when. Might get knocked over."*

> GP: *"So, it's more, it's more about that and just ensuring things and I, I don't necessarily want to talk about that in detail today…"*

> Susan: *"No, course not."*

> GP: *"But if you, it's just a few things to, to think about and so that we know what you want."*

> GP: *"Erm, because I think it's sort of, it's awful if you get there too late and there's a panic situation, something happens that somebody wouldn't have wanted, and again, this isn't going to happen to you, but they become demented and they can't make a, make a decision…"*

> Susan: *"A decision."*

> GP: *"…at that point. So we're just trying to get in there and find out what people's views are. What they feel. So that we can look* af*ter that and make sure that it's written down. And the different aspects of that to think about are, sort of where you'd like to be at the end of your life, whether it's at home..."*

Susan: *"Mmm."*

GP: *"...In a hospice, or in a hospital, or in a nursing home*, where would you like to be? Err in the understanding that we can make *any of those things happen quite easily."*

Susan: *"Mhm."*

Susan seems to display characteristics of denial (reasoning) when the GP tries to explain ACP, stating that she may not die of cancer but in an accident. Throughout the interview Susan makes many statements that could suggest that she is experiencing denial about her terminal illness and approaching end-of-life.

Susan: *"And I've never shed a tear."*

GP: *"No I know you haven't, and that's quite unusual. Are you proud of that or is that sort of something you feel?"*

Susan: *"No. I just don't feel like it."*

GP: *"Just don't feel like it."*

Susan: *"No."*

GP: *"Yeah. OK."*

Susan: *"She would have been in floods of tears this frien*d of *mine."*

GP: *"Do you feel like it's (upset) there waiting or do you just not feel like it's there?"*

Susan: *"Once or twice I've thought, oh, you know, I could sit down and cry but I don't."*

GP: *"Yeah"*

Susan states that she has never become upset about her condition or prognosis. It may be that Susan avoids information due to her denial or a fear that information may upset her (reasoning). Susan also shows denial when discussing the type of tumour she has, indicating that she still believes there is a chance that her cancer is not terminal (reasoning).

Susan: *"You just, as I say, you've just got to take what comes. And then send it back."*

GP: *"No, you can't."*

Susan: (Laughs) *"Well they are doing experiments on me tumours so."*

GP: *"Yeah they ke*ep them for a while. Especially, tumours like *yours that are quite rare and quite unusual."*

Susan: *"I'm different."*

GP: *"And present in a different way and have them puzzled for a bit. Yeah, those, those, they'll want to do a bit of that."*

Susan: *"Yeah she said, she says that I'm unique."*

GP: *"Yeah. That's good (laughs)."*

Susan: *"Course it is, one off (laughs). I'll surprise them all yet. I hope."*

GP: *"Well yeah. And there's no reason why, why you, why you shouldn't. And sort of talking about things doesn't make things happen, you know."*

Susan: *"Course it doesn't."*

GP: *"And I know you know that. But it's all that kind of, sometimes there's that kind of block."*

(Susan changes the topic of conversation)

This relates to CMOC2 in chapter 6 (Preference discussions and the locality advance care plan, p.199), which identified that health care professionals often find it difficult to broach preference discussions as this may destroy patients hopes that can often come from secondary care. In Susan's situation it seems that secondary care have told her that her tumour is unique, rather than being explicitly over optimistic about prognosis. Yet Susan has construed this information as good news about her illness, that it may potentially be treatable. The transcript highlights how difficult it is for health care professionals to engage patients in ACP when they have false hope. Despite this the GP gives Susan several opportunities to engage in preference discussions and enter the ACP process (resource). Feeling at peace with dying was scored variably by GPs and bereaved relatives who answered the related question in the QDDM (Curtis, Patrick et al. 2002). Palliative care, preference

discussions and ACP are difficult frameworks to operate within due to the sensitive nature of death and dying. However, if patients and their family members are able to express their holistic hopes and fears about death and dying through palliative preference discussions and use of the locality advance care plan this may start a process of acceptance. However, Susan is currently not ready to engage in this process. The GP therefore cannot currently help Susan in accepting her terminal diagnosis. Yet it is important that the GP continues to give Susan opportunities to engage in preference discussions (resource), as he does throughout the consultation. Susan does not seek information about her palliative or end-of-life care (reasoning), which is stereotypical of the blunting trait, as opposed to monitoring. Thus since Susan scored low for both monitoring and blunting it may be that her blunting trait is more predominant in this situation. As aforementioned, individuals with a blunting coping style use strategies such as distraction and denial when under stress (Miller 1980, Miller 1987, Bonk, France et al. 2001), thus Susan's denial may be related to her predominant blunting trait (context). Susan may be worried that information will upset her or may not wish to be given information as she will not accept it due to the denial she is experiencing about her prognosis (reasoning).

Outcome: Advance care planning does not occur

Susan does not engage in preference discussions or the ACP process in general and therefore makes no plans for her end-of-life care.
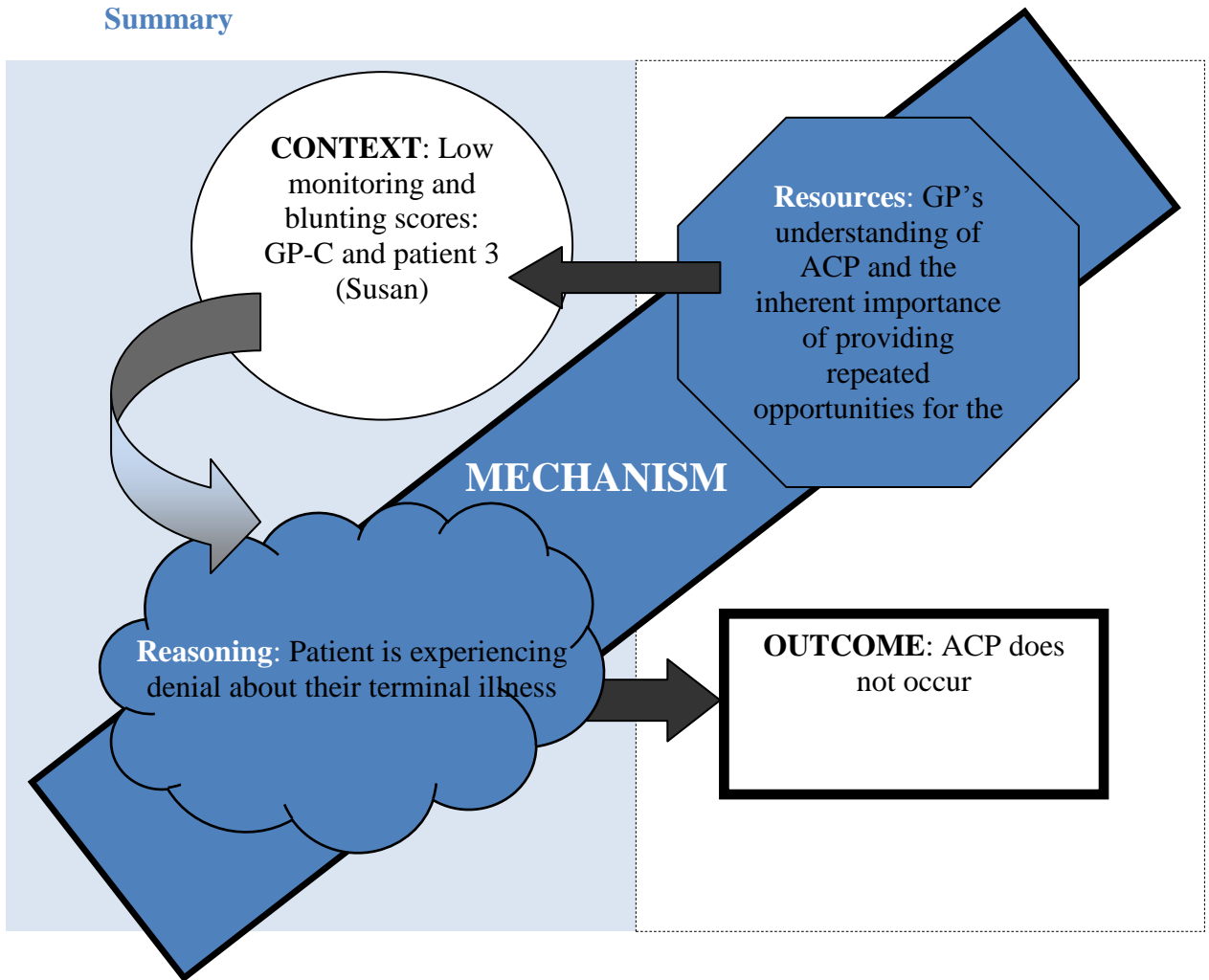
Figure 31: CMOC3, low monitor and low blunter

Susan's blunting trait seems predominant in this consultation (context). The GP
makes repeated and varied efforts to broach important preference discussions
(resource) but Susan avoids the information (reasoning). This may be due to her
denial. Therefore, in this context no ACP occurs (outcome). This CMOC is
displayed diagrammatically in Figure 31.

Formulation of a new CMOC

The data offers a valuable and rare insight into difficult conversations surrounding palliative and end-of-life care but is still very limited. However, from the data discussed the CMOC matrix can be revised (Table 13). This table takes into account that some of the patients and GPs scored high on both the monitoring and blunting scale (GP-B and John), or low on both the monitoring and blunting scale (GP-C and Susan). It would seem that this shouldn't be possible, as high monitors would seek information and high blunters would avoid information. However, it may be that classifying people as either high or low is unhelpful, it may be that one trait is stronger in some circumstances than others, as in Susan's case. Furthermore, it must be noted that the blunting score is not validated but the monitoring score is. This would suggest that participants' monitoring scores are a more valid and robust representation of their disposition due to the scores predictive validity (Petersson, Nordin et al. 2002). Susan still scored low on the monitoring score so it may be that she would still avoid information.

Table 13: CMOC for monitoring and blunting based on data from the study.

Context	Mechanism		Outcomes		Data Examples
GP-patient are both:	Resource	Reasoning			
High monitor	Health care professionals knowledge of preference discussions and ACP and their importance to patient care	Patient is ready to engage with ACP and GP is willing to broach	ACP broached	ACP carried out	GP-A and Mary
Low monitor					
High monitor (but also a high score on the blunting scale)		Patient does not wish to engage in ACP	ACP not broached	ACP not carried out	GP-B and John
Low Monitor (but also a low score on the blunting scale)		Patient is experiencing denial and therefore does not wish to engage in ACP	ACP broached	ACP not carried out	GP-C and Susan

Chapter Summary

This analysis indicates that GPs and patients who are both low blunters and high monitors may be more successful in partnership at engaging with preference discussions and using the locality advance care plan. Although a CMOC can be

formed based on monitoring and blunting scores and consultation outcomes, they offer little final explanatory potential. This is because patients are individual and their reasoning behind whether they wish to engage in ACP may change as their illness progresses. Alternatively, they may be open to ACP when it is first broached. Classifying patients as monitors or blunters does not allow for changes in context. Dr. Miller stated that monitoring and blunting are traits but that patients can be affected by situational factors (p.107). It may be that blunters are not willing to engage in ACP early in their terminal diagnosis but will become more open to information as their illness progresses. Thus classifying patients as monitors or blunters masks how context can change and impact on reasoning and thus patients' behaviour changes over time. Furthermore, classifying patients poses the inherent risk of ignoring the individuality of patients; although information seeking and avoidance is important, the context of the person's illness, their background and their general personality are also all important. GPs must react to the patient's reasoning (which can change over time) and use this as a trigger for their own reasoning in order to ensure that ACP is entered into mutually. Monitoring and blunting scores may provide a framework to inform whether patients and GPs are likely to engage with or broach ACP when they are first presented with it, but they are not informative past this point due to interactive factors between the GP and patient and individual differences of both parties. Furthermore, it is unknown how many times these patients had been approached with ACP before the consultation recordings. It may be that the recording was taken when preference discussions were first broached, thus some patients (John and Susan) may not have been ready to engage; alternatively Mary may have had ACP attempted several times before she engaged and then reviewed them in her consultation recordings. Also, as discussed in a previous chapter (Chapter 6: Preference discussions and the locality

Advance Care Plan, p.199), health care professionals do not have a strong ownership of the locality advance care plan due to issues surrounding time constraints and capacity. Therefore the outcomes of consultations may also be affected by this lack of ownership.

The findings do highlight the difficulties in being proactive and in engaging patients in shared decision making. Although shared decision making is promoted by the NHS there are difficulties in implementing this in practice that are not only attributable to professionals' willingness to do so. Patients are sometimes not willing to engage and this may be due to their monitoring or blunting characteristics. However, repeated opportunities for patients to engage in ACP are crucial, as despite personal characteristics, desire for information is not static.

The MBSS scale is subject to several different interpretations. If the MBSS creators' standard approach is used, that of only using the monitoring scale and classifying participants as either high or low monitors, then the study results are extremely difficult to interpret given the literature base about information seeking and avoiding related to the disposition. For example, John is classified as a high monitor but avoids information.

The initial programme theory (4) stated that innate coping style of the GP and patient (context) facilitates a consultation if matched (mechanism), making preference discussions and use of the locality advance care plan more likely to occur (outcome). The findings did not fully support the programme theory. Matched coping style may facilitate consultations including ACP when both the GP and patient are high monitors and low blunters. However, as discussed, patients are individual and their reasoning changes; as does health care professionals' (as described in relation to preference discussions in the previous chapter) in response

to a change in context, when the patient's condition, needs or psychological acceptance of their illness changes. This can affect whether they broach preference discussions and their monitoring and blunting can offer little facilitation to preference discussions and ACP in practice. Furthermore, the previous chapter suggests that health care professionals struggle to implement the locality advance care plan, thus this may not be the most effective tool to evaluate consultations with.

In conclusion, the analysis offers interesting insights into attempts at and reviews of an advance care plan. The results of this analysis are limited by the low participant numbers. However, although the study suggests that the MBSS does not provide any coherent framework to improve consultation recordings, it does offer information on how we can understand communication issues better in a society that struggles to discuss death and dying, even in the health care domain. Palliative care consultation recordings are also rare in the literature. This chapter offers key insights into how flexible tools such as ACP need to be and how difficult they are to implement in practice, where each and every patient is unique and varies over time.

Difficult conversations must take place in order to plan for a good death that is patient centred. ACP can help patients to identify where they wish to be cared for if their condition is to deteriorate and where they wish to die. Gomes, Calanzani et al. (2011) have identified that in the North of England and across England as a whole the most preferred place of death is in the person's own home. The next chapter focuses on facilitating home deaths for patients in the community and in care homes (which are considered as their own home).

Chapter 8: Facilitating a home death

This chapter describes CMOCs in relation to home deaths and avoidance of emergency admissions. In order to avoid unplanned admissions, a lot of responsibility is placed on those around the patient in their home environment, whether this is care home staff, carers or family members. This chapter will focus on facilitating a home death due to it being a preferable location of death. It will consider a home death as a quantifiable measure of the effectiveness of palliative care services in primary care, as others in the literature have done (Agar, Currow et al. 2008, Bower, Roderick et al. 2010).

Initial question asked of the data

The programme theory and subsidiary questions that this chapter focuses on were first stated in the methodology chapter as:

- **Programme theory 5:** The ICP can facilitate preferred place of death (outcome) and prevent emergency admissions (outcomes) through identifying patient preferences (context) and using the locality advance care plan (mechanism).

  - Are home deaths increasing?

  - Are care home deaths increasing?

The CMOCs in this chapter focus on open communication strategies. CMOC1 explains the increase in home deaths in the locality in reference to easily accessible palliative care expertise. CMOC2 explains the increase in both home and care home deaths using a multi component communication strategy, whereas CMOC3 elucidates why care home deaths may not have increased significantly until 2011.

CMOC1 – Caring for a loved one who is dying

Outcome: Increase in home deaths

A one-way repeated measures ANOVA was conducted to compare numbers of home deaths from 2007 to 2012, using Death Audit data. Mauchly's Test of Sphericity was not significant ($p > .05$), meaning that sphericity was assumed and the relevant values are reported. There was a significant effect of time on home deaths ($F(5, 55) = 2.47$, $p < .05$, $\eta_p^2 = 0.18$). Using the guidelines proposed by Cohen (1988) for the η_p^2 ($0.01 = $ small, $0.06 = $ moderate, $0.14 = $ large effect), this result indicates a large effect size. The means and standard deviations for home deaths from 2007 to 2012 are presented in Table 14; the means show an overall increase in home deaths from 2007 to 2012, however there is not a steady increase in home deaths over time.

Table 14: Descriptive statistics for home deaths in the participating GP practices

Time Period	N	Mean	Standard Deviation
2007	12	12.17	6.82
2008	12	10.83	7.35
2009	12	11.75	5.72
2010	12	11.75	7.23
2011	12	9.83	4.24
2012	12	15.17	6.53
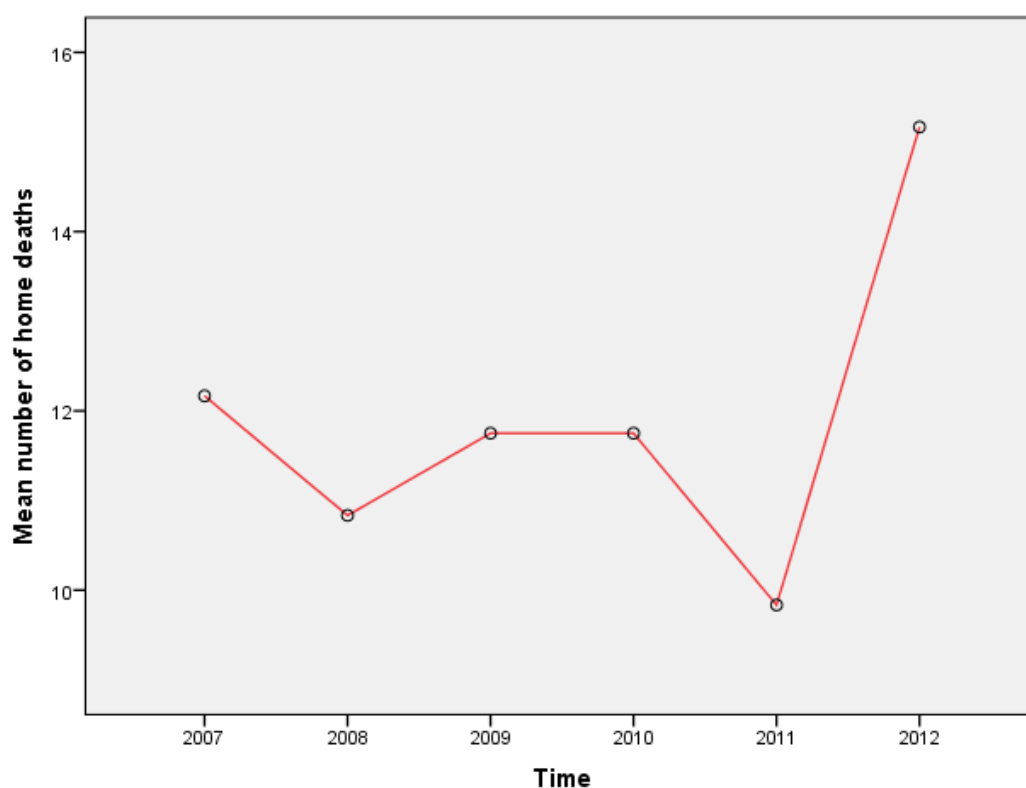
Figure 32: Mean number of home deaths in the fourteen GP practices between 2007 and 2012, using Death Audit data.

Figure 32 shows increases in home deaths in the year that the palliative care pathway was introduced (2008); this then plateaued from 2009 to 2010, followed by

a substantial drop from 2010 to 2011. Home deaths then increased from 2011 to 2012.

Mechanism: Easily accessible palliative expertise

Rachel (bereaved relative) was provided with an OOH district nursing service immediate contact telephone number (resource) after she expressed her anxieties to health care professionals. This telephone number provided her with quick access to palliative and end-of-life expertise and eased her anxieties. She needed to know that she could telephone someone who knew about the process of dying, who could reassure her that the symptoms her husband had were normal, or do something about them by coming to her house and providing treatment (reasoning). Similarly, during the day she explained that her anxiety was eased by the knowledge that she could go to her local GP practice for immediate help (resource) if she were to need it, in the village where she lived.

> Rachel (bereaved relative): *"And that was better because then I* knew I could ring them at any time, through the night, because *everything's always worse through the night. And it was, you felt,* alone, you know, on your own. Well when you had this number (OOH immediate contact) at least you knew you could ring somebody and you could speak to s*omebody straight away [...]* Erm, as I say it was mainly through the night the support, there was nothing till the last week, or until the Thursday. And that was when as I say I got a mobile number and that was when you felt *better, I didn't need to ring it on* the Thursday night but definitely *on the Friday night when he was pulling the drip out."*

> Rachel (bereaved relative): *"Because at least you knew you could just go up (to the GP surgery) and, and I didn't do that even. It* was just knowing that you could, y*es."*

> Rachel (bereaved relative): *"You know, so. So there's just nothing from the surgery closing to the next morning, it's just gone completely."*

Rachel highlights that it was not just loneliness at night and weekends that caused her fear and anxiety by stating that contacting her family did not ease her negative emotions. It was the knowledge of easy access to palliative and end-of-life advice (resource) she craved, the knowledge that she had it if and when she needed it was sufficient to ease her anxieties (reasoning).

> Rachel (bereaved relative): *"You were just left as I say with this person that was dying and you didn't know symptoms to look for, or, ahhh, I cannot explain it. Alone. That's the feeling that you got. Alone. You know I had me family I could ring but they couldn't diagnose anything or tell us what to do."*

The family member's reasoning was changed, as her anxieties were eased in response to the knowledge of easily accessible palliative and end-of-life advice: the GP surgery during the day and the OOH nursing telephone number (resources). This helped Rachel to keep her husband at home and not call the emergency services. This is supported by the literature; carers and patients take reassurance from knowing that they will receive skilled support quickly if they need help OOH (Ellershaw and Ward 2003, Eyre 2010).

Context: Death is hidden

Several of the participants discussed death and dying in their interviews and its relation to society, in terms of how death is often hidden away from the public. They also offered reasons as to why this might be and demonstrated that they

themselves had difficulty in discussing death and dying, which may be related to this taboo.

> Caroline (bereaved relative): *"And, but there is, people don't,* because we hide *the old away, urm, people don't understand that people aren't just alive and then die, you know there is this period of deterioration, and we're not very good at it."*

In the quote above Caroline describes how death is hidden from the public. She then states how she feels that the past has had an influence on how society deals with death and dying. She felt that prior to World War I death and dying was not as much of a taboo in British society, especially because death was experienced more often at younger ages and in the home.

> Caroline (bereaved relative): *"The first World War resulted in us* all not wanting to think about death. And there are lots of poetry *about death, but the Victorians were very into death. I've got some* wonderful mourning jewellery th*at (my husband's) mother has* given me that was her grandmothers, and people would wear specific types of of jewellery and, and there was a much, you know, because life was much, you know, life was hard and life was *earnest. What is it, 'Nasty, British and short'. Who was that? [...]* And so, families were always experiencing the loss of life, and the loss of life amongst lots of different ages and so death was very *much a part of life. And death has become something that doesn't* happen at home, it happens in a hospital, it happens somewhere *away, we don't see it, we're protected from it. And we need to* debunk that somehow, without going back to the point of, you know, what was she called? Miss Havisham, who, you know. The *rooms don't change because somebody's d*ied, and, no body would *move and we don't need to go back to that but we do need to erm, accept that most of us don't want to have that stroke and then* shuffle round an old peoples home for the next 5 years, 10 years, 15 years, whatever it is, not able to *live our life to the full."*

In the above quote Caroline provides an explanation as to why death may have become hidden, referring to World War I.

Caroline explains how death is hidden, which means that people are not used to providing care for dying relatives. However, the achievement of a home death heavily depends on a carer's ability and willingness to provide home care (Gomes and Higginson 2006, Grande and Ewing 2008). Informal carers are essential to the achievement of end-of-life care and death at home, and to policy aims of facilitating patient choice towards end-of-life (Department of Health 2008, Grande, Stajduhar et al. 2009). However, since death has been removed from the community and hospitalised, the general public can be anxious about death and often have no experience of caring for a person whose care is being shaped by an understanding that they are dying. A GP in FG3 commented on how family carers assume a lot of responsibility for which they have no training when caring for a dying loved one.

> GP5 (FG3): *When you're talking about proactive-ness, you're* talking about giving someone some confidence which you cannot *put on a tick box, you're trying to give someone confidence to* manage someone close to them dying, which is a huge achievement when they actually achieve it, if you think about it, dying in their own home, especially with difficult symptoms. So and to do it *successfully and feel like they've been supported and dignity and* you know, Macmillan nurses train for years to be able to do that a*nd we're expecting someone to do it in the space of a few months with all the emotions going on. So I think there's this huge amount* of subtlety about how you empower someone, how you get them *confident."*

Although health care professionals try to empower carers to look after their loved ones at home, anxiety and fear can increase as end-of-life approaches and symptoms worsen.

> Rachel (bereaved relative): *"So you're sent home with this person that's dying and you don't know what to do, at the weekend. So* th*at's another thing that you know that, there could be a little bit* more help there. Erm, cos I said to the nurse in the hospital well what do I do if anything happens and she says well what do you *mean if anything happens?"*

Weekends were referred to by both Rachel (above) and Linda (below) as particularly fear and anxiety-provoking times. In both cases this was due to reduced health care professional contact.

> Linda (bereaved relative): *"I'd say that's the only time I felt vulnerable. Weekends."*

> Linda (bereaved relative): *"That (weekends) was the only thing that rocked the boat a bit. At the end."*

> Linda (bereaved relative): *"Yeah you feel vulnerable and I, during the week they came in three times a day, weekends it's down to two."*

> Linda (bereaved relative): *"But, erm, I would say the only thing in this whole, this… looking after someone at home, as the only* breakthrough in that is weekends. Because weekends, obviously *people are off, and they have err, a backup, or somebody who's on call at week… or it's* the weekend nurse, or whoever and they *don't come in as often. And I had to call out at the end somebody* in the middle of the night and they had to come from (name of *place far away)."*

In the quote above Linda refers to the difficulties of not having easily accessible palliative expertise at the weekend and throughout the night. Rachel also felt vulnerable through the night.

> Rachel (bereaved relative): *"You just felt by, it got dark and that* was it. It was the weirdest feeling you could ever have, you were *alone with this person that was gunna die and you didn't know,* quite know when, or what was gunna happen. And if he was gunna take bad what was gunna happen when he took bad, you know no*body explained that, what could happen, if he did take bad."*

The literature identifies death and dying as a social taboo that is still prominent, despite its diminishing presence in comparison to the past (1980s). Interviewees discussed how death and dying was often hidden away from the public view, supporting the literatures' claims. These societal factors create anxieties for those providing home care for relatives (context). These anxieties are heightened when access to palliative expertise is not available, in OOH times such as weekends or overnight. In order to facilitate home deaths, the ICP must provide patients with reassurance and confidence to provide palliative care at home.

Summary

CONTEXT: Death is hidden from the general public

Resources: Easily accessible palliative expertise (access to the GP practice or an OOH district nursing telephone number)

MECHANISM

Reasoning: Reduced anxiety when caring for a loved one with end-of-life care needs

OUTCOME: Increase in home deaths
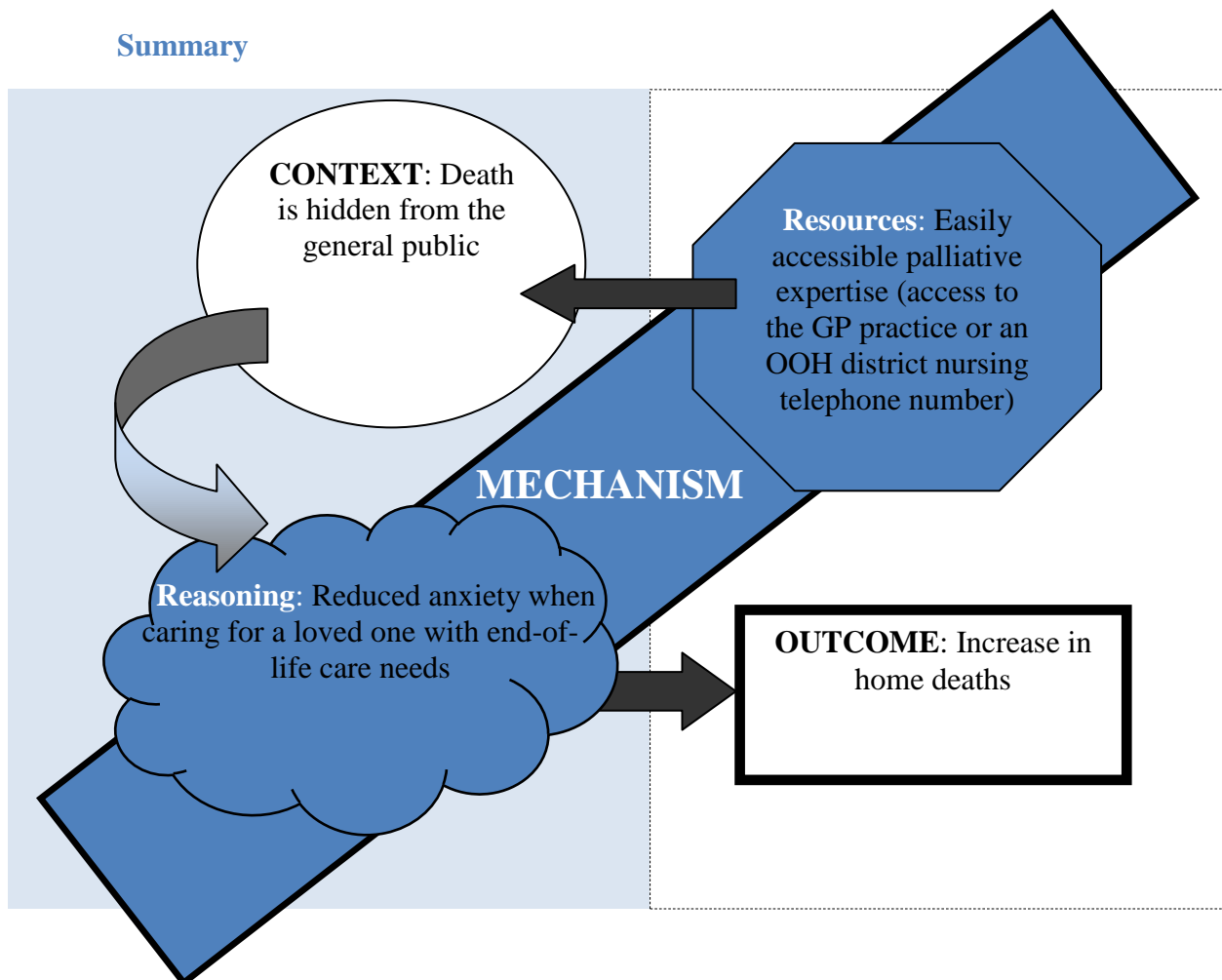
Figure 33: CMOC1, caring for a loved one who is dying

As displayed in Figure 33, CMOC1 identifies that the context of the social taboo of death and dying does make family members anxious about managing death at home. However, the data suggests that easily accessible palliative and end-of-life expertise (resource) which eased anxiety (reasoning) may have contributed to the increased numbers of home deaths. Thus it is important when preparing for a home death that carers are assured of where they can find easily accessible palliative and end-of-life help and expertise in order to reduce inappropriate hospital admissions. Although carers' needs have been identified in the literature (National Cancer Research Institute (NCRI) 2004), there is a lack of good evidence on how these should best be addressed (Grande, Stajduhar et al. 2009). CMOC1 identifies that providing a telephone number for easily accessible palliative advice could address carers' needs and reduce hospital admissions.

CMOC2 – Open communication strategies to increase 'home' deaths

Outcome: Increase in 'home' deaths

Chapter 6 (Preference discussions and the locality advance care plan, p.199) identified that the patient's own home or their care home can be considered as settings that are hospitable to open communication strategies (as opposed to hospital, where communication strategies can often break down). Therefore, it is important to include care homes in the outcome analysis. Thus, assessing how many 'home' deaths, where 'home' refers to care home and own home deaths, is essential in this section of outcome analysis. Furthermore, death in the usual place of

residence has been highlighted as an important proxy marker for quality (National End of Life Care Intelligence Network 2013).

A one-way repeated measures ANOVA was conducted to compare numbers of 'home' (own home and care home) deaths from 2007 to 2012, using Death Audit data. Mauchly's Test of Sphericity was not significant (p > .05), meaning that sphericity was assumed and relevant values are reported. There was a significant effect of time on 'home' deaths ($F(5, 60) = 3.64$, $p > .05$, $\eta_p^2 = 0.23$). Using the guidelines proposed by (Cohen 1988) for the η_p^2 (0.01 = small, 0.06 = moderate, 0.14 = large effect), this result suggests a large effect size. The means and standard deviations for 'home' deaths from 2007 to 2012 are presented in Table 15 and show a distinct increase in 'home' deaths from 2011 to 2012, which is expected from the previous analyses. Figure 34 also indicates that increases in home deaths each year have not been consecutive.

Table 15: Descriptive statistics for 'home' deaths in the participating GP practices.

Time Period	N	Mean	Standard Deviation
2007	12	19.31	15.45
2008	12	21.78	15.74
2009	12	20.92	12.35
2010	12	22.92	18.39
2011	12	19.54	13.66
2012	12	28.31	16.94
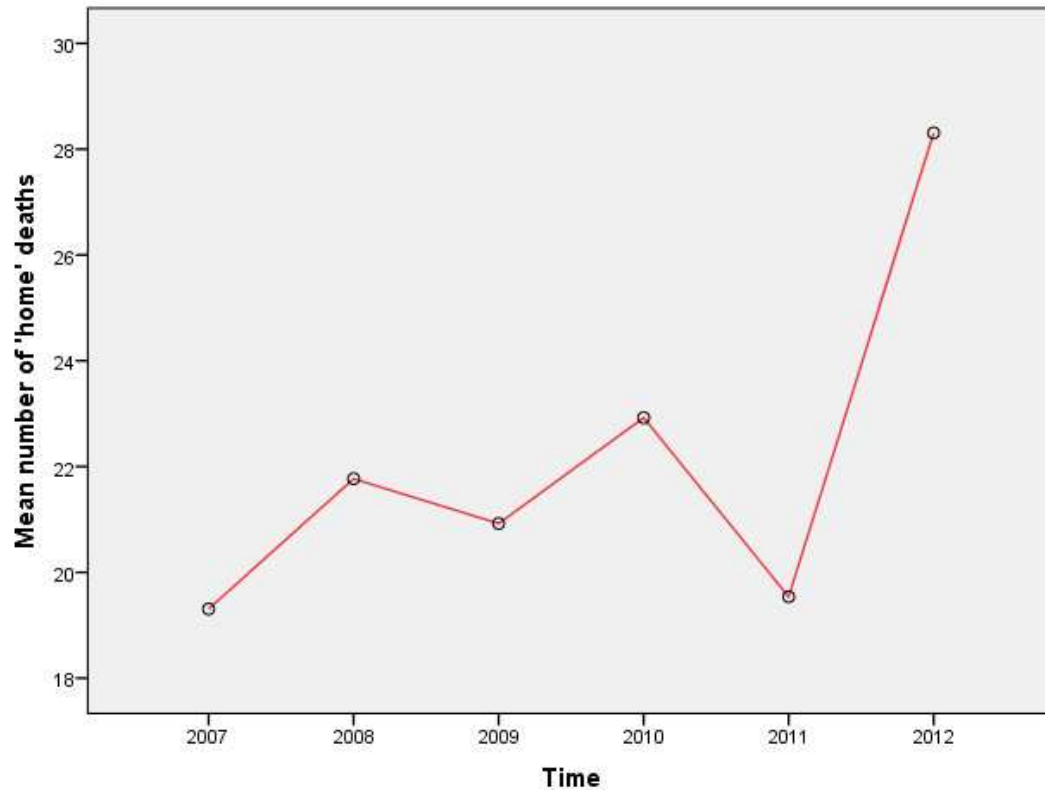
Figure 34: Mean number of 'home' deaths in the fourteen GP practices between 2007 and 2012, using Death Audit data.

Figure 34 shows a sharp decrease in the number of 'home' deaths from 2010 to 2011 and a sharp increase from 2011 to 2012. Hospital deaths have not significantly increased or decreased (F(2.63, 31.6) = 0.49, p > .05, η^2_p = 0.2) between 2007 and 2012; Figure 35 highlights this steady trend. Thus hospice deaths (including the commissioned local palliative care unit and other local facilities) were investigated. Overall, from 2007 to 2012 hospice deaths have decreased significantly (F(5, 60) = 2.57, p < .05, η^2_p = 0.18). However, there was a nearly significant increase in hospice deaths from 2010 to 2011 (F(1, 13) = 3.78, p = .074, η^2_p = 0.26), and a significant decrease in hospice deaths from 2011 to 2012 (F(1, 13) = 5.02, p > .05, η^2_p = 0.28). Thus the newly commissioned option available through the ICP (the

palliative care unit) may be giving patients extended choice and affecting the numbers of people who died at 'home' in 2011 and 2012; as when 'home' deaths decrease from 2010 to 2011, hospice deaths increase, and as 'home' deaths increase in 2011 to 2012, hospice deaths significantly decrease. The nearly significant increase in hospice deaths from 2010 to 2011 and the significant decrease in hospice deaths from 2011 to 2012 are displayed in Figure 36.
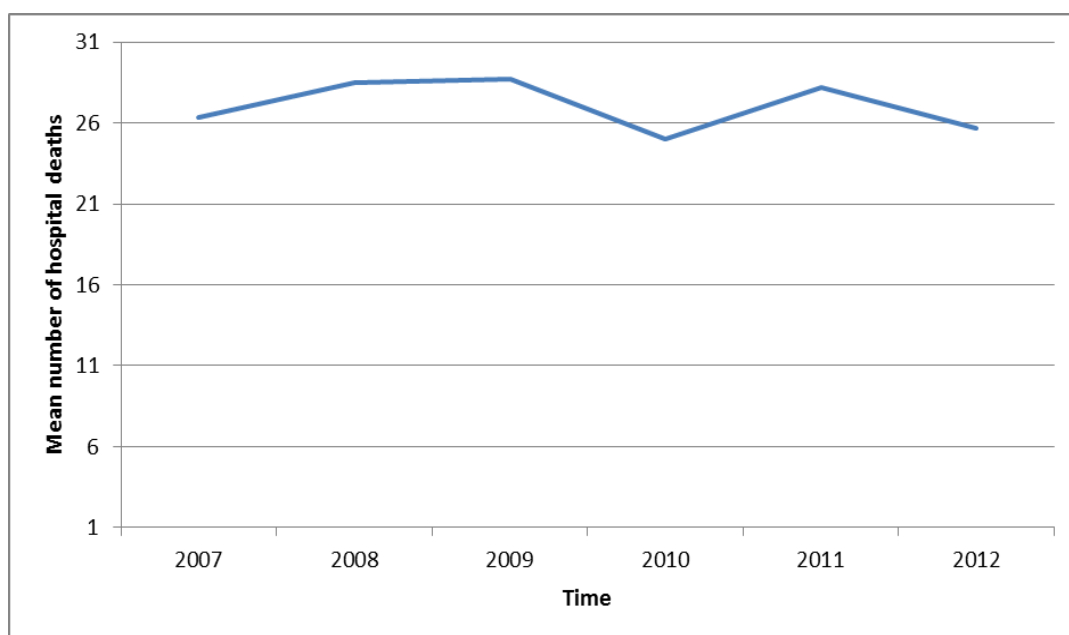
Figure 35: Mean number of hospital deaths between 2007 and 2012, using Death Audit data.
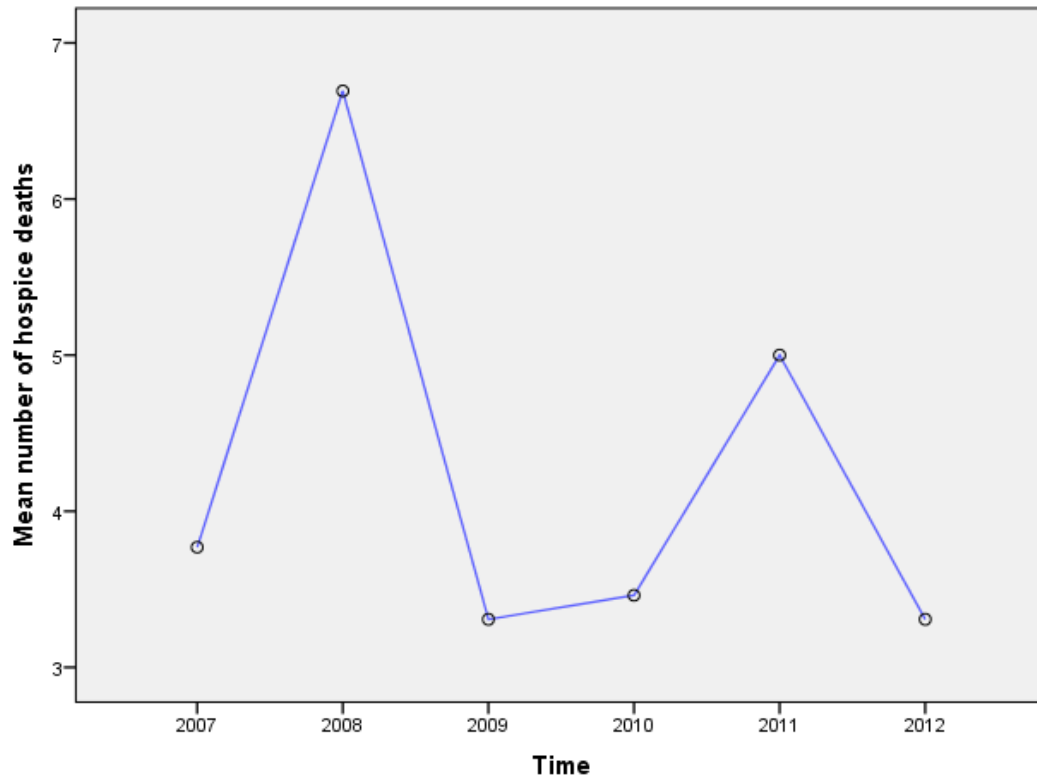
Figure 36: Mean number of hospice deaths between 2007 and 2012, using Death Audit data.

Data from the QDDM indicated that all GPs and bereaved relatives were very pleased with the location of their patient's or loved one's death. All patients' deaths were at home, suggesting that this had been their desired place to die and this had been planned and executed well. This may be due to the GP's knowledge of the patients' preferences.

To conclude, hospital deaths are not increasing or decreasing, but 'home' (own home and care home) deaths are increasing overall since ICP implementation. Hospice deaths including the locality palliative care unit may account for significant changes in the years 2011 and 2012. Location of death (home) was considered as extremely good by both GPs and bereaved relatives in the QDDM.

Mechanism: Open communication strategies (preference discussions and ACP)

ACP (including preference discussions, the advance statement, DNACPR, EHCP, LPA-HW) is based on shared decision making. All the component parts of ACP can be considered as open communication strategies (resources) and are part of the ICP. They promote discussions about care with patients, such as what care they would like to receive and where they would like to be cared for. Discussions are open and comprehensive and can include the patient, their family and health care professionals. These discussions empower patients and their family members (reasoning) to have ownership of their palliative care plan. A ward staff nurse asked why people from nursing homes are admitted to hospital in FG2 and was answered by a GP.

> GP1 (FG2): *"O*ne of the reasons I would suggest is that the *advance care plan discussion hasn't happened."*

The above quote highlights how preference discussions and ACP (resources) are integral to avoiding emergency admissions and facilitating a home death. A Macmillan nurse described how the process of ACP can result in patients having a better understanding about their care and they therefore feel more empowered to direct it (reasoning). This prompts them to ask questions and review their decisions, engaging in effective shared decision making.

> MacMillan nurse (FG1): *"So if it's (advance statement) in the* house it gives them a chance to sit and read through it as well you *know? Often people don't like to look through things when* som*eone's, a professional's there, but if they've got it to look at you can encourage them, and if they've got more questions they can understand more about what's going on."*

Supporting the MacMillan nurse, GP1 described how communication about appropriate actions was essential, to enable planning.

> GP1 (FG2): *"I suppose it's really difficult to, to give one example, because all cases are so unique and so different and we're coming to the story at all different places, it's hard to really say isn't it?... Bu*t in essence you want discussions and action that's appropriate and timely, that's what we're trying to achieve isn't it? So* communication and appropriate action to ensure a good death is *what all of this is trying to achieve"*

Comprehensive communication strategies such as ACP were also seen as an anticipatory mechanism that reduces patient and family stress.

> GP1 (FG2): *"It's what we expect to happen, this is what we, this is what we can do, if it's like this, if it's like that, and it takes the* pressur*e off them, you've talked to the families, you've said* remember when we talked about the plan, and remember when we *said if, and they go, ah yeah, yeah."*

Therefore, patients' understanding of their illness, their preferences (reasoning) and their palliative care are enhanced through use of preference discussions and ACP (resources) which is likely to lead to less emergency admissions but clearly facilitates home deaths.

However, if an emergency admission occurs, this three way open, honest and comprehensive communication system between the GP, patient and carer breaks down. The primary care health staff are not significantly involved during the patient's hospital stay, patients are usually in a position where they are not able to comment on the care they receive as they are so unwell, and families become emotional, scared and disempowered. Supporting this, Ned and Caroline (bereaved

relatives) explained how their mother had gone into hospital after a brain haemorrhage and had remained there for some time having futile investigative tests, against their will.

> Caroline (bereaved relative): *"If you like that's a bit like what they were doing with (Ned's mother), to say well we know this lady's had a brain haemorrhage, we want to know what's happening,* well we know there is something going on in her head that involves blood pressure and, so probably this but we need to prove, we *need to prove what's happening so we can do nothing."*

Caroline and Ned were extremely upset by their mother's extended hospital stay and futile tests but felt that they did not have the experience, knowledge or empowerment (reasoning) to challenge the medical staff at the hospital and request their mother's discharge.

> Caroline (bereaved relative): *"(You have less experience) than the* medics do, and so inevitably you are going to be slightly shocked, and not certain whether there is going to be the possibility of, erm, some form of effective treatment, and, it was, it was clear when she came out four days later that no one had done anything, apart *from, apart from find out what was happening."*

> Caroline (bereaved relative): *"Perhaps we weren't strong enough* (to take her out of hospital). But realistically we have less *experience of how someone is in that situation…*
>
> Ned (bereaved relative): It*'s knowledge, it's coming back to knowledge."*

Hospitals are not a favourable context for challenging discussions to happen. They have a dominant curative culture (context). In such an emotionally charged situation and with inevitably less technical knowledge than the medical staff, families rarely feel confident enough to challenge a consultant's decisions about treatment and request their loved one's discharge or refuse curative intervention. Furthermore,

families may not be given the chance to engage in decision making (as above with Ned and Caroline). Hospitals can be disempowering places which have a curative focus and less long term contact with patients. The structure means that symptoms are not reported by the patient or family, a very different approach to care compared to that of palliative care provided in the community, where there is increasing demand to be patient centred, and acknowledgement of the family and the patient's expertise is paramount. Although patient centred care and shared decision making are aspired to in secondary care, they are more difficult to deliver. Supporting this, GP1 explained how she did not challenge the consultants when her own father was ill, thus questioning how families with no medical knowledge are supposed to be confident and empowered enough to challenge hospital procedures and the staff administering them.

> GP1 (FG2): *"Well once you're in a technical setting it's very* difficult to keep your brain straight. My dad was on ITU for 6 weeks with an open abdomen, *that's crackers isn't it? That's crackers. But I lost the plot as well because you're in such a* technical setting that you lose the plot. I mean, I look back and I think, he was a corpse, for goodness sake what was anybody *thinking, but you're in a high tech setting where everybody's doing* things constantly for 6 weeks. You lose the plot, you really lose the plot. So I wish somebody would have given me some, some sort of common sense, but you do lose the plot yeah. I think families do *that."*

This GP was not given the opportunity to think about the situation in a rational way and was not consulted on her opinion about her father's care, similar to Ned and Caroline. No options were presented for shared decision making to occur (resource) and therefore the open communication strategies mechanism did not 'fire'. Thus hospital is an inhospitable context for this mechanism. Furthermore, the open communication strategies such as ACP are not recognised or used in hospitals,

suggesting fragmentation between primary and secondary care which can cause issues.

Social care team lead (FG2): *"I can't help but think that there* could be loads and loads of great work done before that person ends up in emergency care and then admitted, and they could have all of that bumf with them but unless someone at the receiving end takes the time to look and read and find out, all of that could have just been a waste of time. So it feels as if, we need more than just a *document, there's got to be a buy in to be discussing between* profess*ionals and I suppose who's responsibility is that, is it the GP, is it the...?"*

Ward staff nurse (FG2): *"If we had this (information, ACP) as the* patients came through the door that would be really, really *useful."*

Additionally, if the patient does not die in hospital and is discharged, the ownership of the resources (ACP) can change. Patients and their family have been subjected to competing discourses about palliative care, and the predominant curative context has suggested that a high level of intervention is viable.

GP1 (FG2): *"The thing about the high interventions is that it makes it really difficult for the GPs because the, we, we don't want* them to be admitted but they get admitted, somehow, lots and lots and lots is done and they get sent home, so when they deteriorate again, it changes the, the families view of your ACP, because they suddenly want to like ditch it and say they want more of that, high input, intense, you know, it makes it very difficult to sell, sell your stall, because, (inaudible) in a whole host of people that admission *shouldn't have happened and yes we've prolonged life but so what, we're going for quality here ... it can skew the families ownership* of the ACP because now they think that admission is a good thing because they ca*n do things and they did live."*

The related outcomes of prolonging life may not be appreciated as much in secondary care due the short term basis of interactions, thus primary care may be

more focused on quality of life for patients. Secondary care has more of a curative focus than primary care. Thus primary care has an appreciation of a longer journey due to extended patient contact; they develop long term relationships with patients as they treat them over a longer period of time, in some cases a lifetime.

Thus, knowledge of a patient's preferences is an essential context in facilitating a home death. This allows preference discussions to open communication surrounding end-of-life care and ACP to occur (resources) which generates deeper understanding about palliative care and illness progression (reasoning) for all three parties involved: patient, carer and health care professional. However, if an emergency admission does happen, the hospital is not a favourable context for open communication strategies, as it is not equipped to take into account the resources (preference discussions and ACP) provided by primary care and changes the patient's and family's ownership (reasoning) of the ACP. Thus, preference discussions and ACP are integral in the community setting: they can prevent an emergency admission, and once an emergency admission has occurred they cannot be enacted due to the inhospitable context of hospital.

Context: Family and carers knowledge of the patient's preferences

The knowledge of patient preferences is an essential part of the ICP. Rachel and Linda (bereaved relatives) both explained how their husbands had expressed a strong preference to die at home and how these were stated very early in their palliative care journey.

> Linda (bereaved relative): *"No, he made it very clear from the first* visit of the, of the nurse, because she, the district nurse pointed out that there was erm, very nice 24 hour doctors beds in (local palliative care unit)? But he made it very clear from that moment

that was not for him, he wanted to die at home. If we could manage *that, then that's where he wanted to be."*

Rachel (bereaved relative): *"Ah when the, the night he was diagnosed he just turned to me and said I want to be at home."*

Both women refused to accept any form of help that would result in their husband changing location, despite the difficulties they faced. Rachel turned down the offer of the palliative care unit when she was exhausted from caring for her husband; Linda refused to consider planning her husband's death elsewhere despite the anticipation of difficult symptoms.

Rachel (bereaved relative): *"There was twice Dr. (name), she was* lovely, she said, erm, it was the Saturday night she said would you like us to get him into (palliative care unit) for a couple of nights *and I said no not now I've done the worst, you know."*

Linda (bereaved relative): *"But I don't feel any resentment about what I didn't do. Erm, I made it very clear, they were worried he* was going to have a bleed, I said whatever *he's going to have he can have here, I'll cope with it."*

Both Rachel and Linda (bereaved relatives) explained that their dedication to their husbands' home death was in part due to a pressure they felt to fulfil their dying husbands' wishes.

Rachel (bereaved relative): *"Aha, that was his wish. Yes because* it, you felt as if you were doing whatever you could for him, you *know? [...]* Ah yes that was what he wanted. You know, but. That *still isn't the national health's fault. That was what he wanted. But* then *I suppose it comes back to when somebody's terminally ill, their last wishes is what they want so you've got to work round, yes [...]* That was his choice, it was probably harder for me but it was his choice. But what do you do? Do you go against their wishes *when they're dying? You can't can you."*

> Linda (bereaved relative): *"That's… I feel, erm, that was what* (husband) wanted, and, I had to do everything I could to make that *alright for him […] But he made it very clear from that moment* that was not for him, he wanted to die at home. If we could manage *that, then that's where he wanted to be. And from that moment I* realised how much it meant to him, so there was no way anybody *was going to change that."*

The experience described by the bereaved spouses - pressure, personal responsibility, dedication and loyalty - may not be felt as much by care home staff; although it is possible that they may develop relationships and bond with long term residents. Regardless, the dedication family members feel to their loved one's dying wish to remain at home is a context that discourages emergency admissions and facilitates a home death.
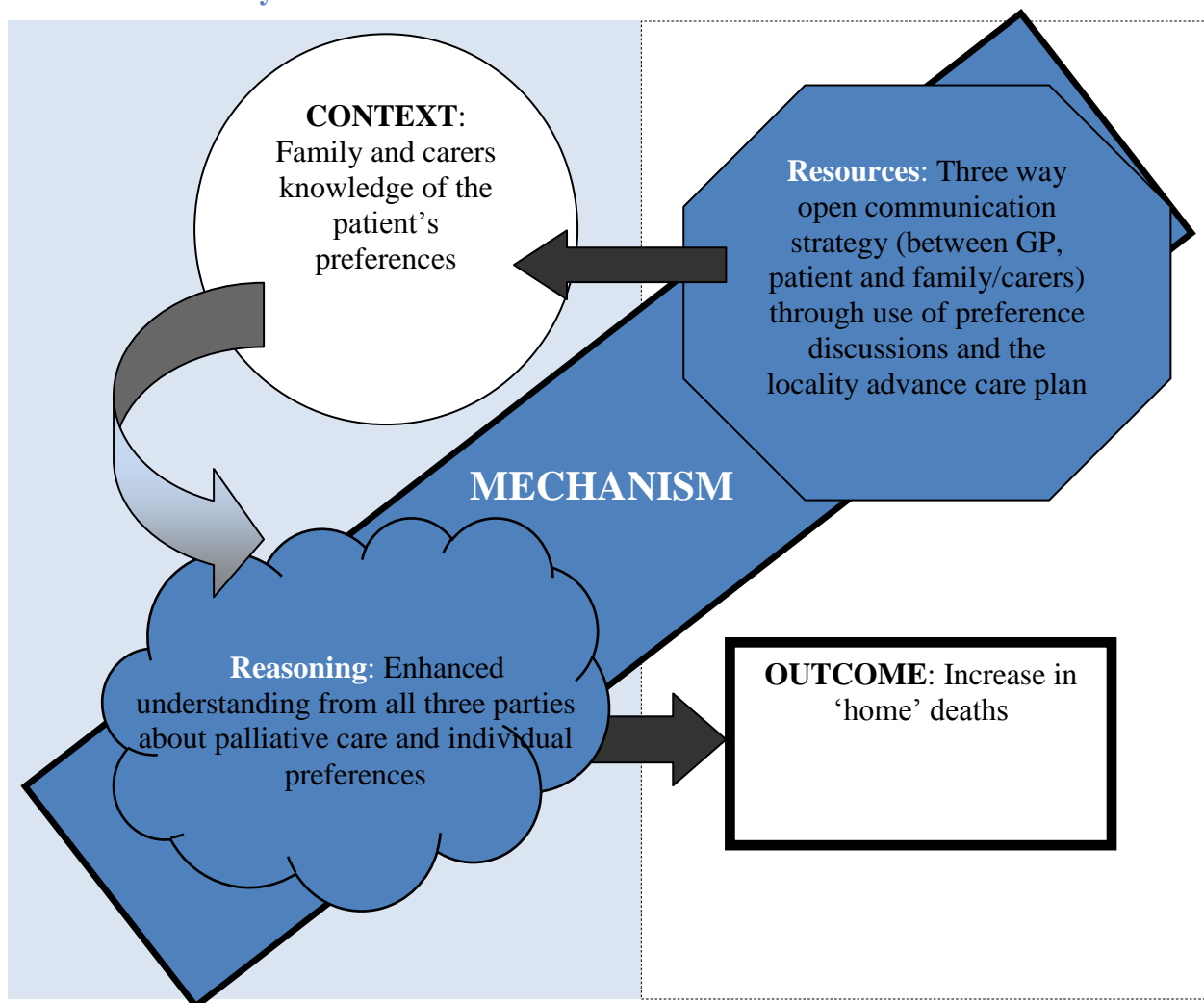
Figure 37: CMOC2, open communication strategies to increase 'home' deaths

Having preference discussions and ACP (resources) as part of the ICP encourages discussions about care, including place of care and what kind of care a person wishes to receive which empowers them to adhere to their palliative care plan (reasoning). These discussions can take place between a triad of people, health care professionals, the family and the patient. If a family member or carer knows the palliative care persons preferences (context) and the patient remains in their own or care home (context), open communication strategies can be used with the GP and more 'home' deaths occur, as shown in Figure 37.

CMOC3 – Care home deaths

Outcome: No significant increase in care home deaths

In order to find whether care home deaths were increasing, a one-way repeated measures ANOVA was conducted. This compared numbers of care home deaths from 2007 to 2012, using Death Audit data. Mauchly's Test of Sphericity was not significant (p > .05), meaning that sphericity was assumed and thus sphericity assumed values are reported. There was no significant effect of time on care home deaths (F(5, 45) = 1.78, p > .05, $\eta_{p}^{2} = 0.17$).

The means and standard deviations for home deaths from 2007 to 2012 are presented in Table 16; the means show an increase in care home deaths since pre-ICP implementation (2007) to most recent data (2012), but with variation between these two dates.

Table 16: Care home deaths in the participating GP practices using Death Audit data.

Time Period	N	Mean	Standard Deviation
2007	12	10.6	9.61
2008	12	11.8	9.66
2009	12	10.9	9.53
2010	12	13.2	12.88
2011	12	11.8	11.35
2012	12	15.7	14.42

The means show small variation between years, with a large increase in the most recent data, 2011 to 2012. The standard deviations are increasing steadily for care home deaths from 2007 to 2012 (excluding 2010 to 2011). This means that the spread of numbers is becoming wider; they are not all as closely clustered around

the mean as they were at the beginning of data collection (2007). Thus some practices have very few care home deaths, for example Practice M who had no care home deaths in 2012, and some practices have a lot more care home deaths in comparison, for example, Practice D who had 48 care home deaths in 2012. There is a wide range of values in the data, which increases with time. This could be attributed to some GP practices providing medical cover for more care homes than others. For example, Practice D provides the majority of care for residents in several care homes, whereas Practice M does not provide care for a specific care home in the locality. Thus as the negative contexts are replaced with more hospitable contexts (support from the family and deeper understanding about palliative care due to the ICPs efforts to discuss and plan death) and care home deaths increase, the mean increases (more patients die in their care home) and the scores vary more drastically, as practices who do not cover care homes cannot increase their score, whereas practices that do cover care homes increase their score substantially.

Despite care home deaths not showing a statistically significant increase from 2007 to 2012, they do show a large increase from 2011 to 2012, as shown in Figure 38. This may be due to the recently implemented end-of-life care plan in care homes.
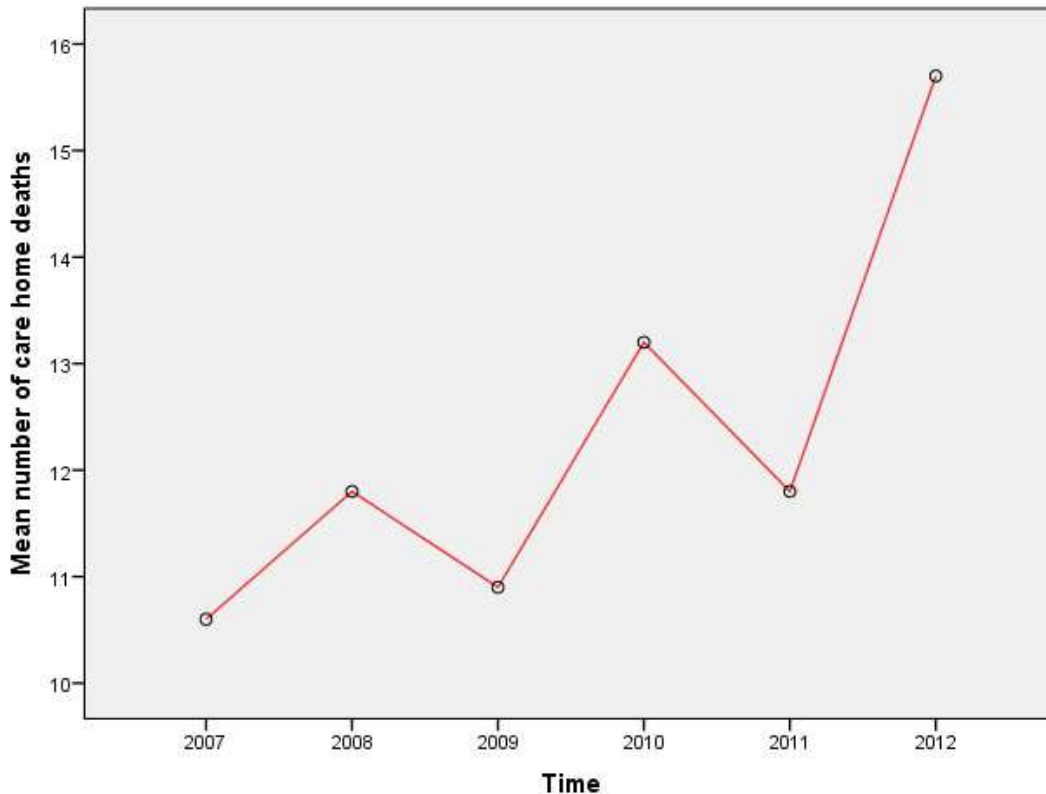
Figure 38: Mean number of care home deaths in the fourteen GP practices between 2007 and 2012, using Death Audit data.

Mechanism: Fear of reprimand and consequences of a 'wrong' decision

Care home staff in the locality have a fear of reprimand. This was exemplified when

a care home staff member explained how he and his colleagues feel that it is safer to

call an ambulance in case of future questioning about their decision.

> Care home staff member (FG3): *"Erm, but I guess it is a bit like litigation in that you've got to cover yourself and when somebody comes to you and says well why didn't you get emergency (services), I mean it's like erm, resuscitation. Years ago we wouldn't have even consi*dered resuscitating any residents but now *you resuscitate somebody unless you've been told otherwise no*t *to."*

A GP from the locality also commented upon care home staff members' fear of

reprimand and consequences, using recent examples.

GP1 (FG2): *"The a*mbulance control have very strict criteria, with you know, they start resuscitating and get them in an ambulance, *you can't say excuse me they're very old and palliative, I mean there was a case, there's been a case recently in (name of care* home) of a very old lady who dropped down, and the staff got in *trouble for not resuscitating her. It's difficult."*

GP1 (FG1): *"There was a case in a nursing home of, I'll just tell* you briefly so you understand my issue, a colleague who was working in a nursing home was looking after a lady who was clearly very elderly, clearly very ill and the family said they would *not want her to be resuscitated... but the lady did not have* capacity, and the GP quite rightly was worried about signing the *DNR, because she wasn't immin*ently about to die but he could hear the families views that they would not want her resuscitated. He chose not to sign the DNR. Erm, because if you look at all of our GMC guidelines we are supposed to, erm, talk to the family about it and talk to the patient about it, and he sort of dilly dallied *around, well lo and behold didn't she go and literally clutch her* chest and drop to the floor in the nursing home. The carer knew *that the family has said that they wouldn't want her resuscitated so* she hesitated, phoned the ambulance and said this lady has *arrested, but I know the family don't want her resuscitated. The* man, it was all recorded, and the operator said does this lady have *a signed DNR? Well no she doesn't but, well you will start CPR.* The poor lady, the poor lady survived the CPR, ended up in hospital and died. The nurse was arrested and disciplined for not starting CPR. Erm, and the family were up in arms that she had been resuscitated."

The GP also stated that patients' family support is extremely important when a crisis occurs and care home staff need to manage death in the care home as opposed to calling for an ambulance and having the patient admitted.

GP1 (FG2): *"I mean, it is part of the education we do with them* (care home staff), but you have to remember some of the staff that, *some of the staff are not, they're just not paid to take that level of responsibility, because you're actually deciding to, they can be, they can be just teenagers and it's a hell of a responsibility isn't it* to ring *up someone's family and say your patient, you know, your mums deteriorated but we're not doing anything, you know it's* very difficult for them, and I think, I think your back up then is the

> *family. It's the family that need to be saying to the staff, please do not, you know, we've already discussed this and this is what we want to happen. Your protection is the family."*

Fear of reprimand and responsibility for death were also commented upon by one of the bereaved relatives, Ned. He also felt that these two factors played crucial roles in the high number of emergency admissions for palliative care patients from care homes. He referred to reprimand being not only institutional but also public, through the media.

> Ned (bereaved relative): *"And, err, your mot*her*. Erm, but then, then you've got this terrible fear, you know of, of, I'm gunna get* sued or am I going to get in the Newspapers you know, somebody died at (residential home) that should have gone to hospital and *that, also the impulse of the carers to… to care! To worry… to care… Ring an ambulance! You know? Let's see if we can get her fixed."*

> Ned (bereaved relative): *"And nobody wants to be responsible (for death) either."*

Although it is not a formally recognised version of ACP as stated by Deciding Right (NHS North East 2012) (such as a locality advance care plan, advance statement or DNACPR), in 2011 care homes started to implement their own form of end-of-life care planning (resource) when people first become residents at the care home. This incentivised end-of-life care plan (Appendix 35) is completed with the resident and their family members whilst they complete their initial general care plan. This care plan asks residents to state their preferences surrounding location of end-of-life care, their preferences for medical intervention, if residents have a DNACPR form, a LPA-HW and also addresses spiritual requirements and funeral arrangements.

Care home staff member: *"There has been more emphasis on doing end-of-life care plans in the past few years (in care homes). And actually in (locality) we get assessed by a local authority and it's all linked to how much we get paid. And they've had a big emphasis on end-of-life care plans and basically you get marked down if you don't have one. So there has been an increase in end-of-life care planning"*

The care home end-of-life care planning may be a more effective way of achieving a statement of preferences that are active in the minds of carers. A GP in FG3 stated that they felt potentially care home staff were better equipped to discuss end-of-life care with residents due to their experience of witnessing previous patients' journeys through palliative and end-of-life care.

GP 6 (FG3): *"Are we any more expert in discussing that (preferences) than you (care home staff)?... I mean you've seen patients who've come and gone through the home, you've seen good deaths and you've seen the benefits of having a care plan, you've seen the benefits of, the disadvantage of not having a DNAR, because they end up in hospital and things happen to them. Maybe people like you are the best people (to implement advance care plans)."*

Another GP in FG3 felt that the use of end-of-life care planning by care home staff may provide them with more ownership of the plan (reasoning) and avoid crises of confidence in actions when medical emergencies occur, as they have a familiar, care home completed plan to refer to.

GP 4 (FG3): *"That's kind of giving the carers (care home staff) more ownership of this instead of being just medically driven."*

As stated previously, the patient's family is a strong source of support for care home workers when managing death. This end-of-life care plan is often carried out with

family members present and thus may provide care home workers with more reassurance of their support. Furthermore, care home staff reasoning is being changed to have more ownership of a resident's preferences for end-of-life care through use of the recently implemented end-of-life care plan (resource) in care homes. This makes the residents' preferences more active in the minds of those who care for them (care home staff) than if preferences are discussed with a health care professional, thus increasing their understanding and ownership of the plan for an end-of-life situation. This increased ownership from the care home end-of-life care plan may reduce care home staffs' fear of reprimand and would explain the substantial increase in care home deaths from 2011 to 2012 as it was implemented in 2011.

Context: Litigious society

Health care professional-patient relationships produce potential civil, criminal and administrative liability (Selkin 2011). This poses an issue for those caring for palliative care patients, especially when they are caring in a professional setting and not regarded as a family member/carer (such as a care home worker). Discussions by participants in FG2 indicated that often emergency admissions are not initiated by a GP but by a member of the patient's family or care home staff. This was highlighted as a concern, as when an emergency admission is initiated by anyone other than health care professionals that are significantly involved in the patient's care, often important palliative care information is not conveyed to secondary care and patients receive unwanted procedures. FG2 and FG3 highlighted that care homes may initiate emergency admissions, as a result of staff shortages and lack of confidence to deal with end-of-life.

GP1 (FG2): *"In* some of the patients in care homes the reason it (emergency admission) happens is because of, erm, staffing levels on the weekend, and it can simply come down to that confidence and grade of staff in a nursing home who are not prepared to take responsibility and not paid to, and it can simply be down to that, a certain member of staff, on a weekend, in a care home, who *doesn't have confidence, and they ring, well they ring (emergency services) and then they're triaged by the ambulance control…"*

GP 4 (FG3): *"I think it also comes down to staffing levels in care* homes because it does vary from home to home undoubtedly. I mean that would probably sway it one way or another whether *people go to hospital or stay in the facility".*

The care home is a location where an emergency admission is more likely to occur, with the participants of FG2 identifying that many emergency admissions come from care homes in the locality. Within the care home there are several contexts which make an emergency admission more probable: the reduced number of staff in care homes at weekends and the competence, confidence or responsibility of care home staff. Most care home staff do not have expertise in palliative care, leaving them with low confidence to take responsibility in an end-of-life emergency situation with a resident. A care home staff member's job is usually related to basic care needs as opposed to decision making surrounding whether to attempt CPR on site or call an ambulance. However these staff members are regularly confronted with the need to make such decisions due to the population that they care for, despite their lack of knowledge and expertise (context).

However, the introduction of the care home end-of-life care plan has lessened the effect of the litigious context; care home staff now have ownership of the end-of-life care plan and thus have a heightened awareness to patients preferences, as identified as crucial previously in CMOC2. They also have increased support from

the family which can help them to keep the patient at home when an end-of-life crises occurs.

Summary
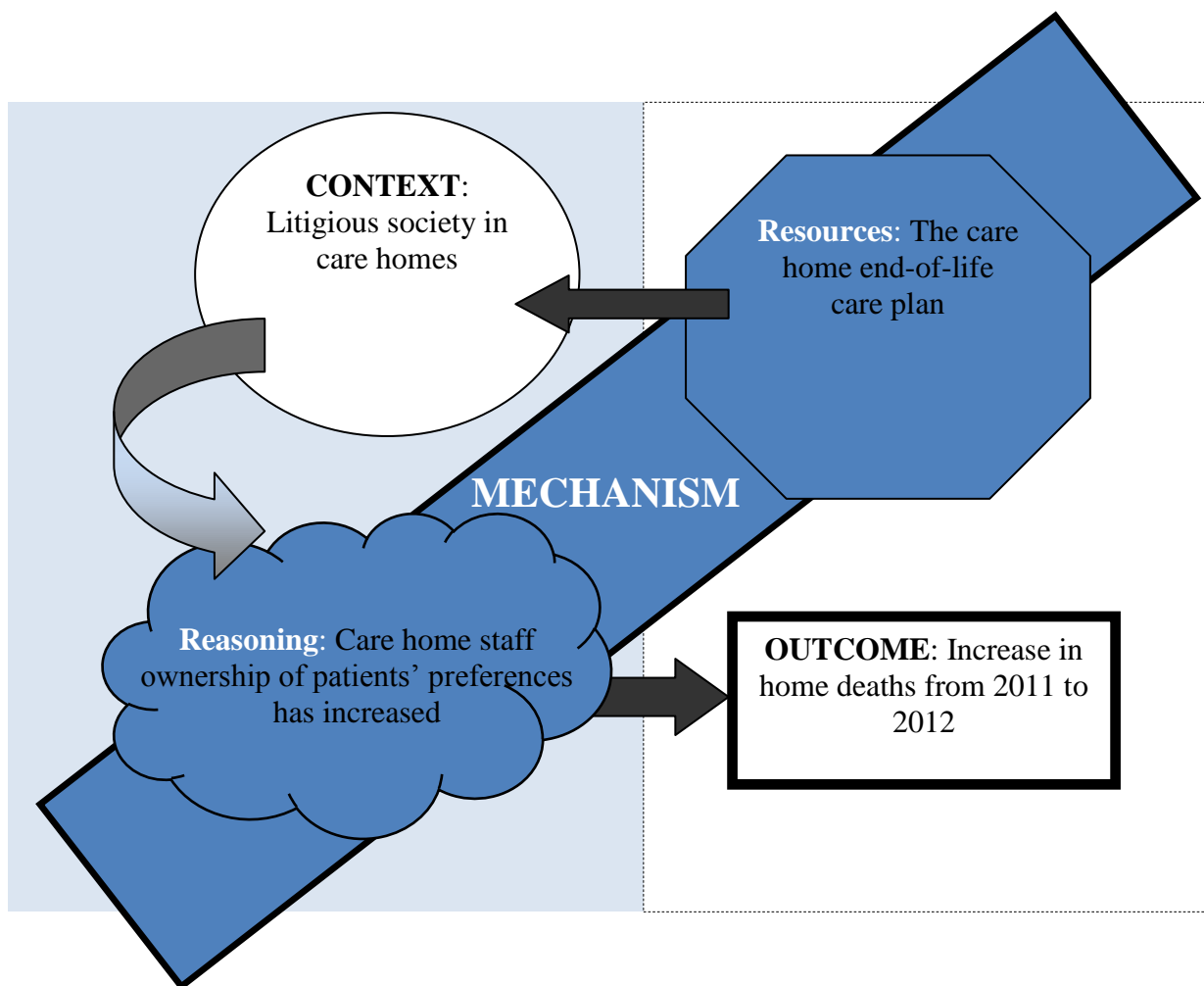
Figure 39: CMOC3, care home deaths

It is important to note here the difference between CMOC1 and CMOC3, specifically the differences between paid carers and family members who act as carers. A family member who acts as a carer for a dying relative has less fear of reprimand than a paid carer. A paid carer is acting within a job role rather than as a loved one who values the patient's interests above all else. Thus open

communication strategies between patients, family members (who act as carers) and health care professionals have the potential to be less formal (preference discussions as opposed to ACP) and the patient may still die in their preferred place, as their family member will ensure that this occurs. However, a paid carer, despite knowing the patient's wishes, may not have as strong a will or remit to provide the patient's preferred care. Thus inherent in the contexts in CMOC1 and CMOC3 are that the carers are family members or paid, respectively.

It is important that the people who care for palliative care patients have this person's preferences active in their mind and have some form of involvement and ownership of them. This means that if a crisis occurs, such as a sudden deterioration or collapse, the carer knows what to do. In care homes, staff need to have this heightened awareness. Care home staff have recently started to use end-of-life care plans (resource) which in a litigious society (context) gives them more ownership of the patient's care in a crisis (reasoning), as they have use of a familiar, care home completed document. This may have accounted for the increase in care home deaths from 2011 (outcome). This is depicted in Figure 39. Despite often being young and not having a lot of training in palliative care, care home staff or one of their colleagues will have completed this end-of-life care plan with the patient which provides them with the patient's family support and knowledge and ownership of patients' preferences. The end-of-life care plan has only been implemented recently and may be the reason why care home deaths have increased a lot more between 2011 and 2012, in comparison to earlier years, despite the ICP being implemented. Despite the care home end-of-life care plan not officially comprising part of the ICP its very existence contributes to care in this area. It is based on care planning principles and aims to identify patient preferences, thus it has the same ethos as the

ICP. It is also in line with national and local policy (Department of Health 2008, NHS North East 2012). However, the crucial difference is that it is created for use by and implemented by care home staff. The reality of practice is complex and this CMOC recognises this.

Chapter Summary

Three CMOCs have been established that result in varying outcomes. CMOC1 identified that home deaths are increasing in the locality (outcome), despite death being hidden from society in hospital in more recent history (context), due to the access carers had to immediate clinical advice (mechanism). CMOC2 identified that 'home' (own home and care home) deaths are increasing, with knowledge of patient preferences an essential context, which facilitates open communication strategies such as formal preference discussions and ACP (resources) that empower patients and their family members or carers (reasoning). However, if an emergency admission occurs, this CMOC is unable to 'fire' at all, as hospital is not a supportive context. CMOC1 and CMOC2 indicate that the ICP is achieving positive outcomes and keeping patients at home (care home and own home). However, CMOC3 indicates that care home deaths alone are not significantly increasing over time (outcome). This could be due to the litigious society context which results in care home staff having a fear of reprimand (reasoning) when confronted with end-of-life crises due to no ownership of patients' preferences for end-of-life care (reasoning). Yet, if the care home resident has a care home end-of-life care plan (resource) this can result in care home staff having a greater ownership of the residents preferences (reasoning) and less fear of reprimand. Thus the introduction of the care home end-of-life care plan has resulted in less negative implications of the litigious context, as

care home staff are now more likely to be aware of patients' preferences with support from their family. This has contributed to an increase in care home deaths from 2011 to 2012 (outcome). The care home end-of-life care plan is based on the same principles as the locality advance care plan and aims to identify preferences to ensure a good death.

In answer to the research question initially posed, the ICP does work for patients who wish to have a home death. However, until 2011 the ICP may have worked better for those in their own homes (as opposed to care homes) due to factors such as easy access to palliative expertise and multi component open communication strategies involving family members which are stronger than with care home staff due to personal allegiances. The ICP works to keep patients at home through open communication strategies; in each CMOC this is the common theme. Communication with expertise in OOH (CMOC1), use of preference discussions and the locality advance care plan as communication strategies (CMOC2), and care home staff's increased understanding (ownership) of residents' preferences due to use of the end-of-life care plan in care homes (CMOC3).

The programme theory initially stated was that the ICP can facilitate preferred place of death (outcome) and prevent emergency admissions (outcomes) by identifying patient preferences (context) and using ACP (mechanism). CMOCs identified that the ICP can facilitate home deaths, however, use of the ICP in care homes may have been laboured due to care home staff feeling disempowered to manage death and dying until implementation of the end-of-life care planning started in 2011. The programme theory should be modified to say that the ICP can facilitate 'home' death (outcomes) through use of open communication strategies (mechanism) in hospitable contexts (knowledge of patient preferences) that overcome societal issues

related to palliative care (death hidden from community, social taboo of death and dying and litigious society).

This chapter concludes the results section of the thesis. The findings will be summarised in the next section and discussed in relation to relevant literature in the Discussion. Implications for practice and research will also be outlined.

Chapter 9: Discussion

In this discussion the overall programme theory of the ICP will be explored, which identifies the ICP as a translational tool to implement shared decision making, patient centred care and proactivity in practice. Study findings will then be discussed in terms of the existing literature on ICPs. Implications for practice, challenges, limitations and future research will also be considered.

The overall programme theory; the ICP as a translational tool

The literature in the introduction highlighted translational problems between palliative care policies, the concepts they promote and practice (Chapter 1, p.6). This thesis highlighted various constraints to implementing proactive care, patient centred care and shared decision making, including the ageing population, time constraints in primary care and definitions of palliative and end-of-life care. Candidate theories that offer some explanation as to how translation might happen in practice despite these barriers were identified – CQI, diffusion of innovation and NPT. CQI was used to understand how the ICP worked in terms of PCQV; the visits provided motivation for health care professionals delivering the ICP and a non-judgemental atmosphere to discuss and solve problems. The Diffusion of Innovation Theory offered exploratory avenues for embeddedness including relative advantage, opinion leads and champions. However, the NPT was not relied upon as this model focuses on the routinisation of a social programme and since the ICP had only been in place for 2 years when data collection took place its explanatory potential was

limited. All of the refined programme theories were combined in order to create Figure 40; the overall programme theory of the ICP explaining its success. This programme theory highlights the ICP as a translational tool underpinned by three key mechanisms - proactivity, patient centred care and shared decision making.

CONTEXT: Comprehensive understanding of curative, palliative and end-of-life care which aids early identification of patients (palliative care registration).

Resources: Shared decision making – (1) Multi component shared decision making (involving family members and/or carers), (2) Shared decision making between health care professionals.

MECHANISM

Reasoning: Enhanced operationalisation of proactivity and patient centeredness

OUTCOME: Patient has a preference based death (which is often at home)

Figure 40: The overall programme theory of the ICP.

The ICP is a tool that helps the translation of the political mandate into practice.

> *"Staff on the ground… do not stand to gain from pronouncements* within policies and government reviews about the need for good communication. They also need to be provided with the resou*rces… to implement good communication"* (Parry 2013, p. 2).

The whole ICP can be construed as a CMOC encompassing the findings of all the programme theories refined throughout this thesis. A good, preference based death with the holistic needs of a palliative care patient addressed (outcome) is achieved when patients are identified early by a GP practice that collectively has a good comprehension of curative care, palliative care and end-of-life care (context). In Chapter 5 (p.162), CMOC 1 highlighted the importance of having consensual definitions within a GP practice in order to provide high quality palliative care and this was reflected in the refined programme theory for the chapter. This consensual definition is an essential context, as it allows palliative care patients to be identified early in their illness and have the input required for a good death. Furthermore, this context allows for the use of shared decision making in open communication strategies between health care professionals, patients and their family members, which results in planning for end-of-life and appropriate documentation (resources). This was exemplified in Chapters 7 and 8 (p.231 and p.262, respectively). Chapter 7 highlighted how health care professionals' attempts to engage patients in shared decision making can be blocked by the patient or their family members. In this circumstance no planning for a preference based death can occur. In Chapter 8 the refined programme theory highlighted the importance of shared decision making as an open communication strategy involving more than two experts - the patient's family or carers should also be included to make it multi-component shared decision making. Furthermore, Chapter 4 (p.117) highlighted that communication between health care professionals could also be considered as shared decision making. These

resources allow for enhanced operationalisation of proactivity and patient centeredness (reasoning). In the context described above with the overall mechanisms described, a preference based death is more likely to occur. Thus, the initial programme theories have been refined throughout the study and in combination have contributed to this final overall programme theory (figure 40).

Pragmatically, the overall programme theory was developed by undertaking a review of all the CMOC diagrams throughout the thesis and the final five refined programme theories from the end of each chapter. Commonalities and differences were searched for in order to find the overall ICP programme theory, which focusses on the implementation of national policy into the locality. The operationalisation of shared decision making, proactivity and patient centred care has been identified as difficult in the literature (see Chapter 1, pg.6). The overall programme theory for the ICP can be seen as a translational tool to convert national policy into local practice. The role of proactive care, patient centred care and shared decision making in the overall programme theory of the ICP are discussed further below.

Shared Decision Making

As with most practice development efforts, interpersonal relationships between health care professionals and patients embody the intervention and have the ability to bring about change (Entwistle and Cribb 2013). Accordingly, shared decision making has been referred to as the crux of patient centred care (Institute of Medicine 2001, Godolphin 2009, Ferrer and Gill 2013) and appears throughout the findings of this thesis. Policies to promote shared decision making are prominent in the United States, Canada and the UK (Elwyn, Laitner et al. 2010), thus the

characteristics of shared decision making have been well documented (Charles, Gafni et al. 1997, Godolphin 2009). It is known that most patients and their relatives prefer shared decision making over strict autonomy or health care professional directed decision making (Shields, Morrow et al. 2004, Murray, Pollack et al. 2007, Coulter 2010). Furthermore, the literature has indicated that involving patients in care decisions makes a potentially significant and lasting difference to health care outcomes (Stewart 1995, Elwyn, Edwards et al. 2000), as supported by this thesis (Chapter 8, p.262). However, the literature also highlights that quality shared decision making only occurs about 10% of the time (Braddock, Edwards et al. 1999, Godolphin 2009) and that it is often poorly implemented (Campion, Foulkes et al. 2002, Elwyn, Edwards et al. 2003, Towle, Godolphin et al. 2006, Young, Bell et al. 2008). This may be because shared decision making has been conceptualised and driven through a top down approach from national policy or (previously) a PCT. The shared decision making mechanism in the overall ICP programme theory is different; it is a local initiative implemented and driven by local health care professionals who appreciate the locality and its unique features, thus it is more likely to be used due to local ownership. Shared decision making can face difficulties in practice due to personal characteristics; Chapter 7 (p.231) highlighted that it is not only health care professionals who can form a barrier to shared decision making but patients also. Patients must be able to articulate their health problems and feelings and communicate with the health care professional in order to understand and share relevant information (Towle and Godolphin 1999). The consultation recordings evidenced that this is not always easy for patients, even when given the opportunity to engage in a preference or end-of-life conversation. Research has previously identified that successful communication is often frustrated by deficiencies in the patient's ability to comprehend information presented to them

due to anxiety (Ley, Bradshaw et al. 1973) or denial (Gattellari, Butow et al. 1999). These are two psychological dispositions that can feature heavily in palliative care and featured in the thesis findings. Engaging patients in shared decision making in this context is very difficult. It is important to understand and explore the underlying associates of denial and information avoidance in palliative care as a shared decision making model in which one party pre-dominates (in this case the health care professional as the patient does not wish to engage) may result in a suboptimal decision. This is because neither partner (the health care professional or the patient) has the essential and adequate expertise required for making a shared decision (Gattellari, Butowa et al. 2001).

However, it may be that the GP and the patient together still do not have adequate expertise for making a decision. A systematic review of the effects of shared decision making on patient satisfaction, treatment adherence and health status by Joosten, DeFuentes-Merillas et al. (2008) states that "the involvement of family members in shared decision-making may be important" (p.220). Godolphin (2009) suggest that shared decision making may also involve a team of health care professionals working collaboratively or significant others including family members and carers. Despite this, the literature still has a strong focus on shared decision making between only two experts – the patient and the health care professional (Charles, Gafni et al. 1997, Charles, Gafni et al. 1999, Murray, Charles et al. 2006). Evidence in the literature argues that health care professionals in primary care see an individual in the context of their family and wider social network and are thus aware of the impact of ill health on one individual on the rest of the patient's social network (Cartwright and Anderson 1979, Murray, Charles et al. 2006), yet there are still no strong claims for family members (or significant

others providing care) to be involved in shared decision making about treatment decisions. Arguably, this might have particular significance in palliative and end-of-life care. The findings from this study indicate that the involvement of the family and other significant individuals, such as care home staff, in shared decision making in palliative care can be crucial (Chapter 8, pg.262). A multi component communication strategy that involves not only the health care professional and patient but also those in close proximity is indeed essential in achieving patient focused palliative care aims, such as a home death. This shared decision making also needs to be placed in a context where the decisions reached are documented and communicated more broadly to those who are not so proximate but also require this valuable information - the OOH service, secondary and social care teams, for example. A partnership between the health care professional and patient only can result in family members or carers not being informed or consulted about plans or decisions. This can be detrimental as it is often family members or paid carers who provide the majority of care and thus may have a significant input into whether the plan is feasible. This study indicates that multidimensional shared decision making may be more effective as a mechanism in palliative and end-of-life care than the traditional model. Patients do not live in isolation and thus the family members and carers they live with are also experts who need to be involved in the shared decision making process. The need for paid carers' involvement in shared decision making was further exemplified in that care home deaths increased when paid carers implemented the end-of-life care plan (Chapter 8, pg. 262), which involves patients making decisions about preferences for end-of-life, similar to the locality advance care plan. Although a health care professional was not present when the end-of-life care plan was completed, it meant that an open communication strategy was created between the care home resident (patient), their family members (if present) and the

carer. Furthermore, the patient may have then had their preferences discussed with a health care professional, thus reinforcing the decisions that they have previously made using the end-of-life care plan. Therefore it can be taken that shared decision making may benefit from being as multipartite as possible in order to constitute a successful mechanism in palliative care that triggers enhanced patient centeredness and proactivity.

Policy makers perceive shared decision making as necessary due to its potential to sustain the health care system (Coulter 2006) and promote the right of patients to be involved in decisions concerning their health (Straub, Nebling et al. 2008, Légaré, Ratté et al. 2010). However, this thesis highlights that understanding the conversations that take place between health care professionals as shared decision making can play a crucial role in care planning. Chapter 4 (Embeddedness of the ICP as a new initiative, p.117) highlighted the importance of having the nursing team on site at the GP practice as it promotes informal contact, enhances professional relationships and facilitates MDT meetings. This communication between professionals is a crucial part of the shared decision making mechanism in the overall programme theory, as it allows for shared decision making to occur between health care professionals in relation to patients. Enhanced professional relationships mean that health care professionals work more comfortably with one another. This is enhanced by informal contact (short conversations in between surgeries) and more formal, frequent MDT meetings. Chapter 5 (p.163) highlighted that shared decision making between health care professionals is facilitated by use of the palliative care register as a framework, providing a structured way to discuss palliative care in MDT meetings, facilitating proactivity and patient centeredness (reasoning). This also contributed towards three of the practices being identified as

'high performers' in Chapter 4 (p117). Shared decision making between health care professionals has also been a facilitator in generating a shared understanding of the definition of 'palliative care', 'end-of-life care' and 'curative care', which forms the overall programme theory context. Once health care professionals in the locality were sensitised to the appropriate definitions through the creation of a consensus (context), they could then use their strengths in practice to improve palliative care registrations. This is extremely important as palliative care registrations can be the first step in using a palliative care framework with a patient. Thus, if a consensual definition is not present, palliative care registrations will not take place and the ICP is not implemented, hence making consensual definitions the essential overarching context for the overall programme theory of the ICP.

This thesis thus highlights a new understanding of shared decision making, that between health care professionals. A lot of the same principles apply - the meeting of experts; developing a partnership; determining and acting in response to the other person's ideas; identifying relevant choices and evaluating research evidence for the most appropriate course of action; making or negotiating a decision in partnership; and resolving conflict, agreeing an action plan and completing arrangements for follow up (Godolphin 2009).

Although the ICP had some implementation tools (CQI PCQV, Palliative Care Partnership) more could have been provided to ensure it was implemented fully into all GP practices. Practices in which the overall programme theory carried more explanatory potential were those that had strong leaders and peer support (champion or opinion leads) and were therefore influenced to see the relative advantage of the ICP. Thus it is reasonable to assert that shared decision making between health care professionals in these practices may have been more likely. Thus, the programme

theory mechanism was more likely to fire. Strong communication within practices was through a cascade of information, dissemination of this information and knowledge transfer. A diagram outlining the types of implementation possible is provided from Greenhalgh, Robert et al. (2004). Their 'Conceptual and Theoretical bases for the spread of innovation in service organisations' figure can be used to help understand the findings related to implementation in this thesis.
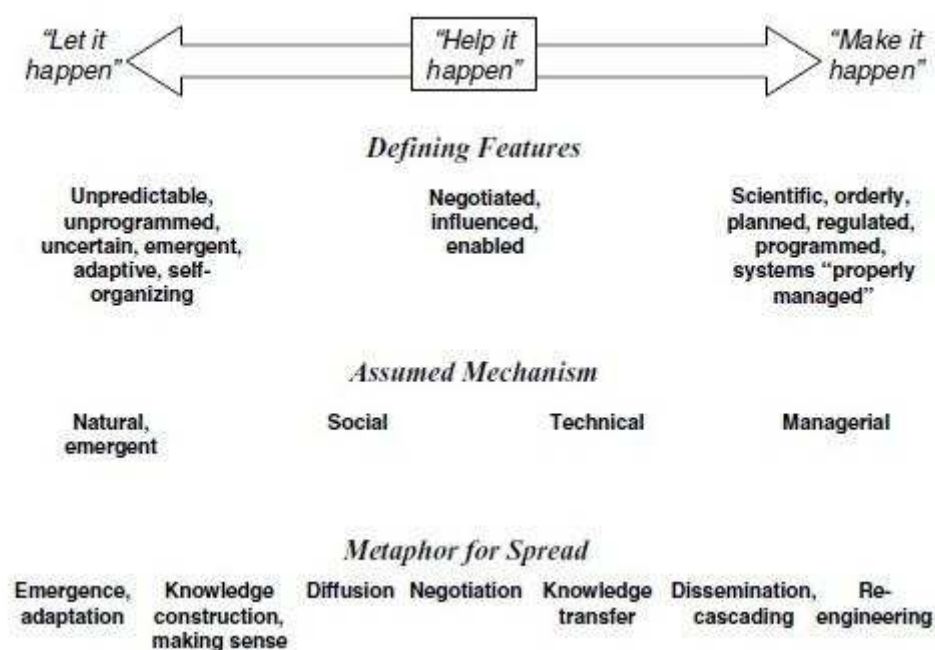
Figure 41: Greenhalgh, Robert et al., (2004) - Conceptual and Theoretical bases for the spread of innovation in service organisations, reproduced with permission from Wiley (Appendix 36).

The Greenhalgh, Robert et al. (2004) diagram (Figure 41) explains how innovations may be implemented more readily when a technical or managerial factor is present. Thus, it explains why in some practices the overall programme theory worked better (due to enhanced shared decision making facilitated by peer opinion leaders and a champion). The champion and opinion leaders can be considered as technical and managerial – they have an expert knowledge of palliative care and are respected within their organisations so could be considered within a managerial role which

pushes the palliative agenda at MDT meetings. The need for not only clinical expertise in palliative care but also administrative and policy leadership in the implementation of new initiatives has been identified in the literature (Weissman 2003, Murray, Barclay et al. 2008, Walshe, Caress et al. 2008). However, there is currently no literature on the effect that champions or peer opinion leads have on professional or clinical outcomes in palliative care provided by primary care, only the description of the need for them. The findings of this study contribute to the Greenhalgh model (Figure 41) in that they highlight the importance of champions and opinion leads in palliative and end-of-life care. The practices that had a champion or opinion lead had implemented the ICP in a more structured way; they can be considered to be closer to the 'Make it happen' end of the scale (Figure 41) and may have used shared decision making within the practice more frequently (in part also due to more frequent MDT meetings). Alternatively, the practices that did not have strong peer support can be considered to be in closer proximity to the 'Let it happen' end of the scale. Thus it is vital to understand as much as possible about opinion leaders and champions who have the potential to persuade other health care professionals to change their practice and how they work to aid implementation and embeddedness of new initiatives (Locock, Dopson et al. 2001). The presence of opinion leads or champions may mean that the overall programme theory can work better because shared decision making between health care professionals is improved and the agenda is directed to include discussions about the ICP. Shared decision making between health care professionals warrants further investigation and understanding in terms of the positive results it can have in practice.

Shared decision making was conceptualised and implemented around twenty years ago and constituted one of the biggest reforms of the 1990s (Balster Liontos 1994).

However, it has been developed and understood more in recent times, with previous forms of shared decision making being more health care professional focused as opposed to an equal input from two experts. However, this thesis highlights that shared decision making in palliative care could advance further (to acknowledge the role of significant others surrounding patients and to recognise shared decision making between health care professionals) and is an essential mechanism in the overall programme theory for the ICP.

Patient centred care

Research focusing on advance directives and living wills (that are no longer in use now but have the same principles as ACP) has shown that although patients have positive attitudes towards these tools, they seldom complete them (Joos, Reuler et al. 1993, Kelner and Bourgeault 1993, Singer, Choudhry et al. 1995). The findings from this thesis support this, in that preference discussions occur more than is formally documented (Chapter 6, p.199). Furthermore in the past, interventions to increase advance directives only had modest effects (Luptak and Boult 1994, Markson, Fanale et al. 1994, Hanson, Tulsky et al. 1997). Related to this, ACP interventions have been found to have no impact on the number of DNACPR forms completed; patient-health care professional agreement on treatment options; days in the intensive care unit; pain or use of hospital resources (The SUPPORT Principal Investigators 1995). Furthermore, a review of ACP and advance directives concluded that advance treatment preferences are difficult to form, communicate and implement (Miles, Koepp et al. 1996). ACP is underpinned by theoretical concepts from law (Justice 2007) and ethics (autonomy and beneficence) (Gillon 1994) and has a focus on stating preferences for those who may lose capacity

(Department of Health 2008, Robinson, Bamford et al. 2010). Thus the difference between ACP and care planning more generally is that ACP will usually take place when there is an anticipation of deterioration in the individual's condition in the future, with associated loss of capacity for decisions and/or ability to communicate choices to others (Department of Health 2008). However, this thesis highlights that ACP was carried out with people who were unlikely to lose capacity, including those with cancer diagnoses, despite its main aim to capitalise on autonomy whilst it is present. This study suggests that preference discussions and use of the locality advance care plans were resources of the mechanism, to implement patient centred care into practice, through a multi component communication strategy that should include the patient's family and/or carers. A model by Martin, Thiel et al. (1999) can be used to explain the mechanism of the programme theory. This model found that from the perspective of participants, the primary goal of ACP was preparation for death which consisted of three facets. Firstly, ACP was a way of facing death, it provides a tool to confront and accept death, plan goals and outline situations that the patient might wish to avoid. This provides the patient with a sense of fulfilment. Secondly, it allowed patients to express their treatment preferences, regardless of whether it was predicted that they would lose capacity, and provided patients with a sense of control. Finally, it allowed patients to communicate with loved ones about their death and relieved the burden of them potentially witnessing a prolonged death or having to make decisions for the patient (Martin, Thiel et al. 1999). The findings from this thesis suggest that a multi component communication strategy using ACP is the overall effective mechanism of the ICP which allows health care professionals, patients, family members and carers to plan for a good death. Although the findings suggested barriers to using the locality advance care plan (time constraints and fear of incorrect assessments of capacity), the model has

explanatory potential as to why preference discussions are sometimes perceived as sufficient for patients, as they allow for the three stages to occur without formal documentation. Additionally, the overall programme theory stated above (Figure 40), with open communication strategies using shared decision making as a crucial mechanism would also support this, suggesting that preference discussions may (in some cases) be sufficient to support open communication strategies without formal documentation. Whilst it is recognised that documenting preferences (using the locality advance care plan or advance statement) is important in order to inform other care providers of patients' preferences (for example, OOHs and ambulance services) and may strengthen the multicomponent shared decision making mechanism, it could be that the formal documentation of preferences may be more important for those at risk of losing capacity. Thus, the model by Martin, Thiel et al. (1999) switches the primary focus of the goals of ACP from ethical and lawful (where capitalising on capacity is the priority) to psychosocial. Using this model, and the overall programme theory stated at the beginning of this chapter, ACP is a translational tool/mechanism to encourage patient centred care through multipartite shared decision making. Furthermore, the Martin, Thiel et al. (1999) model is more in tune with the psychosocial ethos of palliative care. It has explanatory potential as to why GPs and patients often have positive attitudes towards advance care plans but do not complete one, as they can achieve their psychosocial goals without documenting them formally (just through preference discussions). Furthermore, Martin, Thiel et al. (1999) suggest that the goal of ACP should be to strengthen relationships with loved ones, not necessarily the health care professional – thus substantiating the claim earlier that shared decision making should be understood as a multi component communication strategy, which plays a key role as a mechanism in the overall programme theory. Thus the findings and overall programme theory

from this thesis build upon the Martin, Thiel et al. (1999) model, indicating that ACP is a tool to provide patient and family centred palliative care. As identified in this study, the reasoning behind initiating preference discussions was health care professionals' desire to enhance their patient centred practice rather than to prepare for loss of capacity (Chapter 6, p.199). It is reasonable to assert that now that the use of the advance statement is in place (overcoming some time constraints) and training on capacity assessment has been provided, the reasoning behind the use of the advance statement will also be to provide patient centred care. The overall programme theory highlights that having preference discussions and completing a locality advance care plan, advance statement or DNACPR (collectively known as using ACP) is not an end in itself. It can be considered as a mechanism that can facilitate palliative care discussions and meet the overall psychosocial goals that the patient may have (Martin, Thiel et al. 1999), which then facilitates proactive and patient centred care. This model supports the mechanism of the overall programme theory in this study suggesting that ACP is a translational shared decision making mechanism for patient centred and proactive care. The thesis contributes to this model suggesting that patients' family members and carers should always be involved in shared decision making and ACP.

Proactivity

The use of multicomponent shared decision making that includes ACP (mechanism) is also a way for health care professionals to work proactively as it allows for them to put in place the relevant requirements for the patient's preferences. There is an inherent need for palliative care to be proactive through early identification and impeccable assessment and treatment (Froggatt and Hoult 2002, Norton, Hogan et

al. 2007, Burns, Johnson et al. 2008). Proactivity was identified as a common theme throughout the findings (for example, Chapter 4, Embeddedness, CMOC3 context focused on the drive to provide patient centred and proactive care; Chapter 5, Identifying and registering palliative care patients, CMOC2, health care professionals found it difficult to work proactively with those who had non-cancer illnesses; Chapter 6, Preference discussions and the locality advance care plan, CMOC1, the reasoning behind initiating preference discussions was to provide proactive care) and can be considered as an integral part of the mechanism in the overall programme theory; thus it is essential in the provision of successful palliative and end-of-life care. The GSF is centred on proactive and patient centred care (Thomas 2003, The National Gold Standards Framework Centre 2009) and the ICP uses some of the same tools. However, the GSF relates the tools' beneficial effect to enhanced coordination and communication rather than proactivity (Hansford and Meehan 2007). However, the reasoning that these tools trigger in health care professionals has previously never been explored – the overall programme theory highlights that they provide enhanced confidence that a patient is appropriate for palliative care. Thus they are tools that can enhance proactive working in palliative care.

The findings also identified barriers to working proactively: complexity of non-cancer illnesses, time constraints, the avoidance of diminishing patients' hopes, and lack of confidence in assessing capacity. All of these barriers have an impact on whether the overall programme theory mechanism can fire and thus could be considered as inhibiting contexts.

The unpredictable trajectory of non-cancer illnesses was a barrier to working proactively and the risk of 'prognostic paralysis' (Stewart and McMurray 2002), as

described in the literature, was confirmed in this thesis. Prognostic paralysis is exhibited by health care professionals for patients with uncertain illness trajectories and involved prevarication when considering palliative care issues (Stewart and McMurray 2002). Although estimating prognosis is an inexact science, health care professionals must avoid not prognosticating at all (prognostic paralysis) (Murray 2005). The unpredictable trajectory of non-cancer patients is recognised in the literature and in practice; however this has not been related to the difficulties of placing palliative care patients on a register. Related to prognostics, health care professionals in this study identified a marker for change from curative care to palliative care; a change in patients' condition or needs. The context of the overall programme theory requires healthcare professionals to have consensual definitions of active care, palliative care and end-of-life care. This marker can only be used in this conducive context. A change in the patient's condition or needs is a non-time dependent marker that has not previously been explored in relation to how this affects the use of proactive palliative care tools (such as ACP). This marker allowed for national policy (palliative care for all regardless of diagnosis) (Department of Health 2008) to be translated into practice in a context conducive to the shared decision making mechanism. Thus, this informal marker, based on well-developed knowledge of a patient and their overall trajectory, is a valuable part of the context which allows palliative care conversations to be initiated and timely progression from curative care.

A further barrier to health care professionals working proactively and broaching ACP is the false hope some patients have about their prognosis. Health care professionals then do not want to diminish these patients' hopes. Thus, false hope can create an inhibitive context for the shared decision making mechanism to take

place. The literature suggests that information can be given to patients without negativity or instilling false hope using phrases such as "there is little chance of A or B but a real chance of C" (Penson 2000). It is thought that this approach puts emphasis on what the patient can hope for (Penson 2000). However, findings from this study (Chapter 6, pg. 199 and Chapter 7, pg. 231) highlight that it is not easy to engage patients who have false hope in ACP, thus suggesting that the technique suggested by Penson (2000) may not be effective. Thus although false hope has been explored in the literature, some of the techniques to overcome it may not be viable in practice. Furthermore, the root of false hope about prognosis, which these findings highlighted as secondary care, has not been previously investigated as a barrier to ACP in primary care. In order for health care professionals to be able to broach ACP and work proactively, secondary care must also acknowledge that the patient is appropriate for palliative as opposed to curative care. Thus consensual definitions between primary and secondary care may allow for less false hope to be instilled in patients and facilitate a conducive context which allows for the overall mechanism of shared decision making to fire. This is especially important due to ACP being previously identified in this discussion as a psychosocial mechanism that has value beyond capitalising on capacity.

Another barrier to ACP was highlighted in relation to non-cancer patients in these findings; health care professionals have a fear of repercussions from inaccurately assessing mental capacity which is required for ACP. The literature states that if a non-cancer illness such as dementia is empathetically discussed at an early stage it would allow the patient to express their wishes whilst they had capacity (Robinson, Hughes et al. 2005), which may increase the use of advance statements to deliver more proactive and patient centred care (Hughes and Robinson 2004). However,

although the premise of ACP is meant to be to document preferences before capacity is unstable, in practice this is not always viable. This thesis highlighted that often preference discussions occur in the amber phase, when patients are declining and thus can have capacity issues, especially in those with non-cancer diagnoses. Since the premise of ACP is that it happens prior to a time when an assessment for capacity is needed there has been little research into the assessment of capacity as a barrier. The findings from this study are grounded in practice - they suggest that ACP can occur late and that in this case capacity will need assessment, which health care professionals have low confidence in doing and a fear of repercussions from an inaccurate assessment. However, the overall programme theory mechanism can still fire in these circumstances, in the form of preference discussions. Yet, formal documentation of these preferences, which is a more robust method, may not be possible. In order for health care professionals to work proactively they must have an understanding that even when patients are identified in the amber phase, efforts to document preferences are still valuable.

Study findings in relation to the current literature on ICPs

The limited literature on palliative care ICPs suggests that they result in positive outcomes for patients (increased home deaths, improved quality of life and mood, optimal symptom control) (Bakitas, Lyons et al. 2009, Bower, Roderick et al. 2010, Temel, Greer et al. 2010) and health care professionals (increased job satisfaction, ability to provide palliative care, communication and coordination) (Hall, Goddard et al. 2011, Reymond, Israel et al. 2011). However, they give limited understanding of the underlying reasons behind the success, no explanation of mechanism or context. The findings from this study, although drawn from one practice example,

highlight underlying mechanisms with more translational potential (implementation, shared decision making, patient centred care, and proactivity). They show the importance of identifying and understanding underlying mechanisms (resources and reasoning), alongside conducive contexts. Inhibitive contexts and mechanisms are also important to identify, as they highlight what could be changed to achieve positive outcomes in a specific situation. Collectively, the CMOCs identified in this thesis uncover general themes and needs (described above) to provide high quality palliative and end-of-life care in primary care. This highlights the potential of realist evaluation to contribute to the knowledge translation agenda of research findings into practice.

Implications for practice

The study findings highlight that new social programmes require active implementation strategies that encourage the innovation to become embedded into practice. They also indicate the importance of context and how this can affect the implementation and effectiveness of a social programme.

The findings highlighted that shared decision making in palliative care should be a lot more inclusive in practice, involving more significant individuals than just the patient and the health care professional. This may allow for more realistic plans and less undesired outcomes (for example, emergency admissions). Building upon this, the role of ACP should be reconsidered as a psychosocial tool in practice to aid in shared decision making, rather than a tool with the main goal of capitalising on capacity in order to provide patient centred care to those who lose autonomy for health care decisions. This reconsideration of ACP may make it easier for health care professionals (and potentially care home staff) to engage with and aid

discussions surrounding death and dying which have previously been identified as difficult. Thus, as the End of Life Care Strategy (Department of Health 2008) states, palliative care is appropriate for all, as is ACP; it is not only for those who are likely to lose capacity. Furthermore there is scope for shared decision making to play a more explicit role between health care professionals forming the best care possible for a patient. It could be said that this already occurs in MDT meetings but conceptualising it as shared decision making in practice may facilitate communications and aid health care professionals in their interactions. Barriers to proactive care in palliative care still remain and these are areas that health care professionals need to focus on in order to provide higher quality palliative care for all. If these barriers are not addressed, issues related to ethical justice will continue to occur in terms of provision of palliative care to those with non-cancer diagnoses, especially those who lose capacity (Koffman 2012). Furthermore, in order to provide proactive care and avoid solely reactive care, health care professionals must be given time efficient tools. These implications are relevant to many individuals involved with the ICP - health care professionals, care home staff, care home managers, patients, family members, carers, OOH staff, and commissioners due to the broad scope of individuals involved with the ICP.

Challenges

Greenhalgh, Robert et al. (2004) highlight that drawing realist conclusions about the generative causality of particular programme theories can only be achieved though much negotiation and contestation. Developing and refining CMOCs in this study has been a time consuming and demanding process, and although it is presented in a logical and neat format in the thesis, the process was somewhat disordered. This

was due to the methodology (realist evaluation) and several forms of data collection and analysis that were used collectively and concurrently to form many CMOCs. However, the continuous refinement of CMOCs has resulted in findings that reflect the complexities of health care, primary care and palliative and end-of-life care. For example, the embeddedness CMOC4 (I) and CMOC4 (II) were developed over a long period of time throughout which they were constantly refined. Initially, I considered the MIQUEST and Death Audit data and what the numbers meant; use of more interventions and more 'home' deaths were undoubtedly positive outcomes. Following this my attendance at PCQV, the Palliative Care Partnership and integration into the field identified a difference between practices. There were those that were very involved, attended Palliative Care Partnership meetings, engaged in PCQV discussions enthusiastically, discussed issues as a team, and those that did not. This prompted me to wonder whether those GP practices that behaved in this positive way used more interventions and/or had more 'home' deaths. Looking at the MIQUEST and death audit data some practices did have higher numbers than others, but this was a very subjective observation. The cluster analysis transformed my observations from the field and of the data into a robust outcome – there were three high performing practices out of the fourteen under study. From here I needed to establish the common essential context and mechanism that led to increased embeddedness in these three practices. The shared nursing team on site was identified first. This was initially thought of as a mechanism. However, further consideration refined the shared nursing team on site into a context that facilitated MDT meetings. The mechanism was then identified using my own knowledge of the locality, conversations with the founder and confirmed in FG3. I knew of some key individuals who attended the Palliative Care Partnership regularly, took interest in the study and could be considered as a champion or an opinion lead.

Conversations with the founder and within FG3 confirmed (without prompt) that these people were key figures in pushing the palliative agenda in their practice. Hence the mechanism was formed, having a champion or opinion lead (resource) who pushes the palliative agenda within the team and highlights its relative advantage (reasoning). Although this seems fairly straightforward to explain it required a lot of thinking, sketching (using the CMOC diagrams) and collaborative working with the founder, the health care professionals in FG3 and my supervisors who offered methodological support. It also required adjudication between competing theories, i.e. was it the champions and opinion leads in the practices or was it that these teams generally had enhanced communication skills? This could have been the case but FG3 participants highlighted the champion and opinion leads in the three high performing practices as pivotal.

Facilitating the refinement of CMOC was the increased understanding of contexts, mechanisms and outcomes as the project progressed. At first I found it difficult to decipher between contexts and mechanisms especially, a difficulty reported by other realists (Jagosh, Pluye et al. 2013). Deciding what constitutes a context and a mechanism requires intense thought and debate - the ICP offers a great variety of resources, used in an array of contexts impacting at a range of levels. However, I found as my time working with realist evaluation progressed, so did my knowledge of the ICP and I feel this facilitated my ability to formulate CMOCs with increasing explanatory potential. I also found that drawing several versions of a CMOC (using the CMOC figure framework used throughout this thesis) often helped me to decipher between context and mechanism and the exact formulation of each. Finally, understanding mechanisms in terms of resource and reasoning was extremely helpful, a technique suggested by Dr. Gill Westhorp on the Realist And

Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) Discussion list (RAMESES 2014). Using resources and reasoning allowed me to understand fully what tool was being used (resource), and whose decision making process this was changing (reasoning). This method was also helpful when discussing mechanisms with health care professionals in FG3. Identifying these two factors often made the mechanism more obvious, which in turn highlighted the context. Furthermore, throughout my time using realist evaluation I developed an understanding that the concept of mechanisms 'firing' in context did not always apply. This is because, at the individual level especially, reasoning is often on a continuum. People have enhanced patient centred practice or increase their confidence due to a resource. The resource in itself sometimes does not produce the reasoning but can instead enhance it, thus mechanisms often have increasing degrees of activation. However, at the system or practice level, it is sometimes more definitive; for example if the ICP is not present, it is not embedded into practice – the mechanism cannot fire. I feel that use of resources and reasoning highlights and explains the complexity of CMOCs; human volition is not often comprised of complete oppositions, and often there are spectrums. For example, different GPs will be situated at different points on the continuum of patient centred practice. Mechanisms can have degrees of activation as opposed to being categorical ('firing' or not 'firing').

Not only was the understanding and refinement of CMOCs difficult but also the change from a positivist standpoint to realist logic of analysis. Sporadically I would feel a positivist mind frame creep back in and would have to pull myself back in to the realist evaluation world. Facilitating working within a realist logic and confirmation of its value was made apparent when I read non-realist literature. Time

and again, I was left wondering what made an intervention work, even when it was reported as successful.

Undoubtedly realist evaluation is time consuming and can be frustrating to use. Yet these negatives are overcome by the satisfaction derived from creating refined and robust programme theories that provide credible explanations for observed outcomes. Those outcomes can collectively then inform practice more generally, for example in terms of shared decision making. Now I have become experienced with realist evaluation I feel that it offers a wealth of knowledge to the research field alongside a refreshing change from successive causality. It moves on from using a pure science technique with complex humans. Rather than trying to fit square boxes in to round holes it embraces human volition and understands that it is an inherent feature in the process of complex social programmes.

Limitations

An issue that is beyond the control of the study is the variability in recording of GP practice data (MIQUEST and Death Audit). Health care professionals could be using ICP tools such as palliative care registrations, preference discussions and advance care planning and not recording this use. However, the qualitative results seem to reflect health care professional and patient experiences. For example, most palliative care patients and bereaved relatives recalled preference discussions but few had completed locality advance care plans. Also, health care professionals described their dislike of the locality advance care plan format and the time consuming paper work it generated. In relation to palliative care registrations, the quantitative data identified less non-cancer registrations than cancer registrations, despite increases in non-cancer death registrations from 2011 to 2012. Not only

does the literature describe the difficulties in the non-cancer trajectory (Murray, Boyd et al. 2005) but health care professionals in focus groups commented on the difficulty they have when registering non-cancer patients on the palliative care register. Finally, the embeddedness chapter identified that there is an underlying context and mechanism to explain why some practices have embedded the ICP better than others, explaining that outcomes could not just be linked to a recording artefact. These examples and supporting evidence indicate that the recordings that health care professionals do on the data templates are representative of what actually happens in practice, although potential variability needs to be acknowledged.

Another limitation is the self-selected or health care professional selected recruitment. Focus groups included motivated health care professionals prepared to give up their time to participate in the study. However, these individuals were very honest, for example, stating their dislike and neglect of the locality advance care plan. Patients and bereaved relatives participating in interviews, consultation recordings and the QDDM were selected by health care professionals. However, there was no other means of access to these potentially vulnerable people. All participants were very candid in their discussions and often would comment on negative issues that they had encountered, thus providing a balanced view of the service.

A potential criticism of the study could be that the focus of the research has been on health care professionals' decisions - decisions to use tools, register patients, and facilitate home deaths. However, focusing solely on patient experiences or outcomes would have happened if more traditional quantitative or qualitative research paradigms were used, assuming the causal relationship between

intervention and outcomes. The focus on health care professionals in this thesis is due to the use of realist logic; the search for underpinning mechanisms. Health care professionals embody these mechanisms and thus they were the primary focus of the study, as the aim was to discover if the ICP worked, how and in what circumstances. This is why some lines of enquiry were not pursed, such as bereaved relatives having feelings of allegiance to their loved ones wishes and not accepting end-of-life care in a hospice for example. The purpose of using interview data was to highlight their experience of the ICP and provide practical information to health care professionals concerning how it works and how it could potentially be used more efficiently. For example, quotes from bereaved relatives about guilt and allegiance to their loved ones highlighted that a bed in the palliative care unit had been offered when end-of-life was approaching. By this time, participants felt that they had lived through the worst of their loved one's worsening health and had refused to use the service. Interviews with palliative care patients and bereaved relatives thus helped to understand the implementation of the pathway (for example, if the palliative care unit is offered late in the patient's illness it is not accepted due to feelings of allegiance and guilt). It could be that people's relationships and closeness will always form a context for services implementation, and it could be that allegiance and guilt are particularly salient in palliative and end-of-life care. However, exploring further the explanatory potential of such feelings in interviews would have caused additional emotional strain and been unethical. The interview of people in highly emotionally charged situations, such as a bereavement, is an acknowledged challenge in qualitative research and can only be conducted under very strict ethical guidance. Thus, this study highlights that guilt and allegiances may be overarching inhibitive contexts that health care professionals need to operate within in order to trigger shared decision making, and that early

implementation may minimise the impact of these feelings on poor uptake, but this could not ethically be tested with greater certainty.

The ICP is adaptive, which is to its credit. The recognition of the locality advance care plan's flaws from various sources resulted in the change to the advance statement to facilitate the documentation of patient preferences. This makes this section of the ICP evaluation less relevant to the locality but still generates important findings in terms of underlying principles. The practicality of tool use in a time constrained primary health care environment needs consideration, as does the assessment of mental capacity in ACP.

The data set in this study was complex and management of it was difficult. There would have been benefits in collecting and analysing data iteratively (for example, complete interview 1 and follow interview 1 issues up in interview 2 to confirm or dispute interview 1 claims). However, NHS ethics procedures meant that a semi-structured interview schedule was required that could not be deviated from, apart from when this was initiated by participants. However, I always had previous interviews in mind throughout data collection and informal refinement occurred, so that for example, if a participant of their own accord discussed an issue that I had understood from a previous interview to have explanatory potential, I would follow that line of enquiry. The focus groups on the other hand were used explicitly to refine programme theories and all focus groups were used to make sense of data form different sources. For example, the focus groups provided explanation as to why some patients with a predictable illness trajectory may not have had ACP; false hope had prevented this. Additionally the breadth of data collection meant that all data triangulated to refine understanding. For example, early analysis of GP practice data highlighted that preference discussions were significantly increasing, but the

use of locality advance care plans was not. All patients and bereaved relatives interviewed reported not having locality advance care plans but all had engaged in preference discussions. In order to explain this, the focus groups highlighted that health care professionals did not like to use the locality advance care plan due to capacity assessment and time constraints. Consultation recordings also highlighted that sometimes professionals found it difficult to engage some patients in ACP altogether. The explanation (theory) that emerged from all these data strands was that often once a patient is ready to engage it is too late to use the locality advance care plan (due to time constraints and capacity issues) and this was further confirmed in the focus group. Thus programme theories were refined and tested through different data strands. There was also strength in exploring the explanatory potential of one idea (programme theory) in one data strand and then seeking explanation of this in other data strands, with the ICP founder or in PCQV. This process, at different stages of maturation, was then presented to health care professionals as collective sense makers during the focus groups to further refine theory development. This method of data collection and analysis did mean that at times decisions had to be made between different segments of evidence. Data was always chosen that had the strongest explanatory potential and was corroborated by alternative data sources, the ICPs founder, or the PCQVs.

Finally, the interviews and focus groups provided data on interesting aspects of care which have not been presented here. Although interesting, this data did not offer sufficient explanatory potential to be presented in this thesis. For example, one patient had concerns regarding social care and her dislike of the lack of continuity in the carers that came to her house every day. Another example was the fear of end-of-life paraphernalia including the syringe driver, which was referred to by a

bereaved relative and one of the nurses in a focus group. This data did not possess enough explanatory potential because it could not be related to a component part of the CMOC. For example, the fear of end-of-life paraphernalia was never linked to emergency admissions or increased likelihood to call an ambulance. Furthermore, the social taboo of death and dying is an important overarching context, which participants commented on. They felt that this taboo needed to be 'broken down' for progression in palliative care to occur. Although the social taboo of death and dying did not bear direct influence on the mechanisms detailed in this thesis, it is nevertheless an important context to all social programmes implemented in palliative care, including the ICP. Furthermore, some CMOC include contexts that are inherently underpinned by this taboo (for example, death being hidden in CMOC1, Chapter 8, p.263; litigious society in CMOC3, Chapter 8, p.285).

Future research

Future research should focus on the role of active implementation strategies for new initiatives. This thesis supports Greenhalgh, Robert et al. (2004) in that active implementation may impact on the success of an intervention. Related to this, understanding how to identify and use champions' energies in providing active implementation of interventions is pivotal, as the literature is currently sparse in this area (Greenhalgh, Robert et al. 2004). Further research about champions and peer opinions would generate a deeper understanding of how champions work and if they can be developed.

ACP could be reconceptualised and therefore require further research. The traditional focus of ACP on capacity has meant that other important aspects of it have been ignored. This thesis makes a case for ACP to be a tool to implement

shared decision making, allowing the patient to face death and strengthen the relationships with their family. Furthermore, shared decision making needs to be investigated as a multi component communication strategy, as opposed to just the meeting of two experts. The role of shared decision making between health care professionals should be explored as a facilitator to MDT working. Following from this, the role of ACP should be researched. It could have a much broader role for all patients regardless of whether their capacity is likely to diminish. It could help patients face death, plan for it, discuss it with their family and generally take control of their care. This therefore supports the need to investigate shared decision making as a multi component communication strategy that also includes the patient's family. Therefore the role of ACP in practice and its effect on patients requires further investigation.

Barriers to proactive care were identified throughout this thesis; all of which could impact on participation and shared decision making (Burt, Rick et al. 2013). This could have a negative effect on ACP. The barriers to proactive care (and thus the barriers to ACP) need to be explored and ways to overcome them need to be identified. The insights developed in this thesis could be used to develop more understanding of how, why and in what circumstances ACP and care planning in general lead to successful outcomes.

Conclusion

This thesis occupies a currently important political space. The LCP has been subject to great media attention and review (BBC News 2013, Neuberger, Aaronovitch et al. 2013) and recent news articles have suggested that palliative care registers and advance care planning may be subject to the same scrutiny (Daily Mail 2013). A

recent article in The Daily Mail (2013) suggests that palliative care registers and advance care planning are carried out to reduce health costs rather than plan for a good death. Unarguably, the NHS does need to save money, and deaths at home may be a piece in this economic jigsaw, especially as they are the preference of many patients. In the article, Dr. Anthony Cole, acting chairman of the Medical Ethics Alliance, acknowledged the need to save money, but also highlighted a danger of uninformed patient choice leading to lack of wanted medical support in their final days of life. Although uninformed patients can lead to uninformed decisions about end-of-life care, the patients interviewed in this study were very aware of their preferences and decisions. They appreciated the conversations they had had about end-of-life care with health care professionals and valued their clinical advice. Unfortunately, referring to palliative care registers as 'death lists' and advance care planning as 'end-of-life advanced care plans to reduce cost' will only result in a poor public understanding of these tools, when this research demonstrates that they are actually helping people to die in their preferred place. Furthermore, some participants were acutely aware of this wider political and media context and expressed the need to open up a societal dialogue about death and dying.

This research has highlighted important findings for the locality, some of which have already been fed back and acted upon, and for palliative care in primary care and the community in general. The findings surrounding implementation, shared decision making, patient centred care, and proactivity are informative, transferable and identify important issues that need to be addressed within practice and the academic literature.

The goal of palliative and end-of-life care should be to have good quality of life before a good death. When a person has a terminal disease and time to digest their prognosis, a good death should be planned, personalised, symptom controlled, peaceful and holistically assessed with needs met. This ICP attempts to do this in an organised process, with positive outcomes increasing since its implementation. It operationalises attempts to break down barriers to improve palliative and end-of-life care for care providers, patients, and their relatives.

"How people die remains in the memory of those who live on"

- Dame Cicely Saunders, Founder of the Modern Hospice Movement (1918-2005)

Appendices

Appendix 1 – Guidance on use of the Liverpool Care Pathway for the Dying Patient

Dear Colleague,

Northern Clinical Networks & Senate

Liverpool Care Pathway (LCP):

End of Life Network Regional Response

You will be aware that the Neuberger Review has recommended the 'phasing out' of the Liverpool Care Pathway (LCP) and its replacement by End of Life Care Plans that will be condition-specific. The Secretary of State has accepted this recommendation. This letter is intended to update practitioners on the current situation and offers guidance on the management of patients through this transition.

While accepting the need for change we must all be careful that patients continue to benefit from high standards of care at the end of their lives. The national and regional guidance is clear that the "proper" use of the Liverpool Care pathway (or its equivalent) should continue until new care planning tools are introduced. As an example, St Oswald's hospice is actively involved in the evaluation of one such care planning tool, though will continue to discharge patients on the LCP where this is appropriate.

The enclosed guidance is intended to provide practical support in the use of the LCP at the present time. It is understandable that patients and their relatives will have questions and concerns about the pathway and advice is offered in this regard.

From a clinical point of view, this does not represent any change from what has been seen as good practice for a number of years.

We are aware that use of the LCP - or its equivalent - now varies significantly across the region and so it is particularly important that good communication is part of any transfer or handover of care.

Thank you for all your continued hard work in this difficult area. Yours sincerely

Dr E Kendrick   Dr M Prentice   Dr Mike Guy
Chair End of Life Network   Medical Director   Medical Director
Northern Clinical Networks   CNTW Area Team   DDT Area Team

End of Life Group Guidance

The first priority is to maintain the excellent standards of care that tools such as the Liverpool Care Pathway, have enabled. **The correct use of the Liverpool Care Pathway - or its equivalent - continues to be endorsed both nationally and regionally** until such time as new care planning tolls are available.

1) One of the criticisms of care at the end of life included in the Neuberger Report is the failure of staff adequately to inform patients and families that the patient is believed to be dying; families in distress may not understand nuances so it is important to communicate the message that death is likely over the next few hours/days explicitly, and to record this conversation in the case notes. We see lots of examples of good practice in this regard during our audits of end of life care, so do keep up this difficult but good work

We suggest therefore that whether you are using the LCP or not:

When the realistic possibility of the patient's death within hours or days is realised by the caring team, a senior clinician should make this possibility known to the patient (if appropriate) and to the patient's family/carers (unless permission is explicitly declined by the patient). The conversation must be recorded in the patient's notes, and both the conversation and the record should include:

• Time, date and names of participants in discussion

• That the patient is sick enough to die/dying appears inevitable (as appropriate) and how death might be expected to occur

• That patient (if applicable) and family/carers had an opportunity to ask questions

• That care will be based on best comfort care as described by the LCP (possibly alongside resuscitative measures if there is a possibility of reversing the deterioration to

death)

• If family do not accept that the patient is dying, the clinician has explained the basis for that clinical judgement. This may include acknowledging that diagnosis of dying is an art rather than a science, thus sharing any uncertainty.

2) The symptom management guidelines contained in the LCP that include prescribing of safe starting doses and careful titration of drugs to achieve best possible symptom relief with least possible side effects, should be followed regardless of whether the paper LCP document is in use. Advice on the use of palliative care drugs can be found in the North of England Cancer Network Palliative and End of Life Care guidelines at http://www.gp-palliativecare.co.uk/files/north_england_cancer_network_palliative_care_guidelin es_feb_09. pdf

The effects of drugs being used to provide symptom relief, whether intermittently or by infusion, should be explained to patient (where appropriate) and family/carers. Families should be warned if sedation is a

possible consequence of comfort drugs used for eg breathlessness or anxiety.

When symptoms do not settle quickly, or a prescriber would like advice for any reason, the palliative care team should be consulted as usual.

3) Any decisions made in advance e.g. ADRT, (Advance Decision to Refuse Treatment), DNACPR (Do Not Attempt Cardio Pulmonary Resuscitation), LPA (Lasting Power of Attorney), EHCP (emergency health care plan) must be identified, actioned, documented and shared with all members of the patients team in line with local policy and the Mental Capacity Act 2005.

4) A decision regarding current and any future investigations, treatments and medications has been made in partnership with the patient. Where this is not possible the 'Best interests' process should be followed as set out in Deciding Right which can be found at: http://www.cnne.org.uk/end-of-life-care---the-clinical-network/Decidingright/plusresources

5) Any as required medication or equipment needed has been ordered and is in place.

6) For all dying patients there should be regular assessment and management of symptom control and comfort measures.

7) Patients and their families should be communicated with regularly to ensure their needs are being addressed and that they know what is happening.

8) All dying patients need a regular multidisciplinary review, including the senior clinician to re-assess the situation and make sure all their needs are being met. The decision to remain on the LCP or other documentation using the LCP principles must be reviewed and documented regularly.

9) Offering oral fluids where the patient can swallow and good mouth care is an important part of managing comfort.

10) All dying patients and their families must have the provision of psychological, social and spiritual support.

11) Following death the relative/carer must be supported in their understanding of what to do next and the patient's death should be communicated to all appropriate services.

12) **For those patients, families or organisations that choose not to use the LCP, medical and nursing care plans should be documented on the normal paper/ electronic systems.** Staff need to ensure that exactly the same assessments, communication and regular reviews take place that would have been done on the LCP, to make sure that dying patients receive optimal care.

Please note that NEAS will no longer accept someone being on the LCP as a surrogate DNACPR form and so all patients discharged on the LCP where resuscitation is not appropriate will need to have a regional DNACPR form completed.

Appendix 2 – Dalkin, Jones et al. (2012)

BMJ
open
accessible medical research

Understanding integrated care pathways in palliative care using realist evaluation: a mixed methods study protocol

Sonia Michelle Dalkin,[1] Diana Jones,[1] Monique Lhussier,[1] Bill Cunningham[2]

[1]School of Health, Community and Education Studies, Northumbria University, Newcastle upon Tyne, UK
[2]West Locality Northumberland Clinical Commissioning Group, Tanners Burn House, Hexham, Northumberland, UK

Correspondence to
Sonia Michelle Dalkin; sonia. dalkin@northumbria.ac.uk

ABSTRACT

Introduction: Policy- and evidence-based guidelines have highlighted the need for improved palliative and end-of-life care. However, there is still evidence of individuals dying undignified deaths with little pain control, therefore inflicting unnecessary suffering. New commissioning powers have enabled a 2-year pilot of an innovative integrated care pathway (ICP) designed to improve arrangements for individuals with life-limiting illnesses requiring palliative care. A novel feature of the ICP is its focus on palliative care over the last 6 months of life, aiming to intervene early to prepare for and ensure a good death. What is not known is if this pathway works, how it works and who it works for.

Methods and analysis: A realist evaluation and a complex analytical framework will investigate and discover context, mechanism and outcome conjectures and configurations of the ICP and thus facilitate exploration of how it works and who it works for. A mixed methods approach will be used with small sample sizes to capture the breadth of the ICP. Phase 1 will identify if the pathway works through analysis of NHS Morbidity Information Query and Export Syntax data, locality Death Audit data and the Quality of Dying and Death Questionnaire. Phase 2 employs soft systems methodology with data from focus groups with health professionals to identify how the pathway works. Phase 3 uses the Miller Behavioural Style Scale and interviews with palliative care patients and bereaved relatives to analyse communication in palliative care.

Ethics and dissemination: Ethical approval has been granted from the NHS local ethics committee (REC reference number: 11/NE/0318). Research & Development approval has been gained from four different trusts, and relevant voluntary organisations and the local council have been informed about the research. This protocol illustrates the complexity inherent in evaluating a palliative care ICP. Identification of whether the pathway works, how it works and who it works for will be beneficial to all practices and other care providers involved as it will give objective data on the impact of the ICP. Results will be disseminated throughout the study for continuous quality improvement of the ICP. Outcomes from each data collection phase will be disseminated separately if analysis warrants it; all data collection will be utilised in the realist evaluation. The research provides a potential for the dissemination of the

ARTICLE SUMMARY

Article focus
■ This article is a protocol of a realist evaluation of a palliative care ICP, which was developed in Primary Care by health practitioners. The ICP itself uses elements of long-term chronic illness care in order to provide holistic, supportive, high-quality palliative care. The focus of the article is to detail how the ICP will be evaluated, using a variety of data collection tools, which will identify contexts and mechanisms that lead to improved outcomes, thus taking the main focus away from just the outcomes alone. The identification of contexts and mechanisms for improved outcomes is known as realist evaluation and will provide a better knowledge of the essential conditions of effectiveness when the ICP is implemented in other localities.

Key messages
■ The key aim of this article is to detail the creation of a complex realist evaluation, which utilises a unique and varied methodological framework. It is hoped that through this article, others will understand the groundwork needed to set up and execute a realist evaluation.

Strengths and limitations of this study
■ The protocol details a complex evaluation of a unique palliative care ICP using a new and innovative methodology: realist evaluation.
■ Some may perceive the small sample sizes in the qualitative sections of the study as a weakness. However, the aim of the study is not to find a robust causal mechanism; this would be premature with an ICP in its infancy. The aim is to unpack the contexts and mechanisms that work in certain circumstances, from this conditions crucial for effectiveness can be highlighted, which are essential for implementation of the ICP in other localities.
■ The ICP involves 15 general practitioner practices, which collectively care for 80 300 patients. The study described will use Morbidity Information Query and Export Syntax and Death Audit data from all 15 practices and will conduct the other sections of research within selected practices, both rural and suburban.
■ Finally, palliative care is commonly misunderstood in the literature and in the field. This paper addresses this confusion and fills a gap in the literature.

pathway to other localities through the transferable knowledge it will generate, from its focus on the contexts that are crucial for successful implementation, the mechanisms that facilitate implementation and the outcomes achieved.

BACKGROUND

End-of-life and palliative care are local, regional and national priorities requiring continuous evaluation and improvement. Policy and evidence-based guidelines have identified a need for improved palliative and end-of-life care services.[1] [2] However, there is still evidence in the field, media and literature of individuals dying undignified deaths with little pain control, therefore inflicting unnecessary suffering on the patient and on their relatives.[3] [4]

In one semirural locality in the North East of England, an innovative integrated care pathway (ICP) has been created through use of new commissioning powers to implement and continually improve arrangements for individuals with life-limiting illnesses requiring palliative care. The ICP, which has been in use since January 2010, includes several interventions: palliative care registration, Advance Care planning, a traffic light system of illness progression, the ordering of just in case drugs and use of the voluntary sector to fill gaps in care. The ICP involves 15 general practitioner (GP) practices, which collectively care for 80 300 patients. The project reported here has been jointly funded by the NHS North of Tyne in collaboration with Northumbria University and will provide an opportunity to explore in detail the ways in which the pathway works.

In the research literature, improvements in end-of-life care through the use of ICPs have been noted.[5] [6] The most researched and reported ICP related to end-of-life care is the Liverpool Care Pathway (LCP)[7]; however, this ICP focuses solely on the last few days of life as opposed to palliative care for those with life-limiting illness. The terms 'palliative care' and 'end-of-life care' are often used interchangeably; this is confusing and makes the generation of evidence difficult. In this research, the term 'palliative care' is utilised in line with a palliative diagnosis, which is given when an individual is presented with a limited prognosis. Therefore, the disease can be terminal at diagnosis, for example, those with advanced prostate cancer, yet some individuals may be diagnosed but live with well-managed symptoms for many years, hence the intent is to treat as opposed to cure. The term 'end-of-life care' should be used in reference to the last days and hours of life.[8]

While the prominent success of ICPs at the end of life is clearly demonstrated in the literature,[9–11] evidence of the effectiveness of palliative care ICPs for those with life-limiting illness is lacking. The ICP draws on principles derived from many areas of healthcare including the LCP and chronic disease management. However, little is known about the transferability of evidence generated

in relation to the LCP and chronic disease management to a palliative care ICP; therefore, these factors are key parts of the study described here. There is also a lack of understanding about the detailed way in which the ICP may achieve success; information is needed on how positive outcomes are attained and for whom they are most beneficial. It would be premature to aim to establish linear cause and effect type relationships without first attaining a better understanding of the conditions for effectiveness. This ICP is complex, involving multiple organisations and a multidisciplinary style of work. It therefore requires a novel methodological approach to evaluation as described in this protocol.

Evaluation efforts for complex interventions are unlikely to establish firm linear causal relationships.[12] Taking a step away from seeking to find if a programme 'works' and moving towards highlighting the conditions necessary for success is crucial in complex intervention evaluation. The focus here is on the inner potential of a system: the interventions, the mechanisms, the changes in routine practice.[13] Pawson and Tilley,[14] the developers of realistic evaluation, present an explanatory formula which will be used throughout this study: outcome = mechanism + context. This formula purports that new initiatives' final results (outcomes) are dependent on the introduction of appropriate ideas and interventions (mechanisms) and the appropriate existing social and cultural condition (contexts). In metaphoric terms, causality is attributed to the right substance being activated in the right conditions. A simple time A versus time B comparison of data would not generate the understanding that is required. Therefore, this research aims to explore the inner potential of this palliative care ICP for individuals with life-limiting illness through context (C), mechanism (M) and outcome (O) conjectures and developing configurations. For example, in context A with mechanism B, outcome X is more probable. An example of this is provided in an attempt to modernise a health service[15]; in inner London (context), integrating services across providers (mechanisms) led to the patient having a seamless and consistent experience (outcome). The study described here is deemed complex according to the dimensions of complexity provided by the Medical Research Council,[12] which includes the number of groups or organisational levels targeted and number and variability of outcomes. In order to investigate the ICP, a three-phase protocol was formulated, which allows exploration of several realist evaluation conjectures. Each Context Mechanism Outcome (CMO) conjecture requires a different form of analysis thus requiring the development of a multifaceted analytical framework, as detailed in the remainder of the article.

AIMS, OBJECTIVES AND RESEARCH QUESTIONS
Study aim
The study will aim to systematically investigate key features of contexts (GP practices, norms about palliative care, relationships among organisations), mechanisms

(communication, staff training, IT systems) and outcomes (good death measure, reduced hospital admissions, practitioner, patient and family satisfaction) and their interactions in the ICP. It will identify and understand the features of a comprehensive palliative ICP for people with life-limiting illness.

Research question 1

Does the palliative care ICP work? Are the factors that drive the palliative care ICP (Advanced Care Planning, Palliative Care Register, Do Not Attempt Resuscitation forms) all being utilised as intended? Does the ICP lead to a good death in both the GPs' and bereaved families' experience?

Research question 2

What are the conditions of effectiveness of ICPs in palliative care, in terms of implementation context and intervention detail—for whom does the ICP work, how does it work and under what circumstances?

Research question 3

Who does the ICP work for? What are the patients', families' and bereaved families' experiences and opinions of the ICP?

Research question 4

Can patients' and health professionals' respective coping styles provide an explanatory framework for the research evidence indicating that conversations about palliative care are sometimes perceived as difficult?

Objectives

▶ To describe and develop an understanding of the *contexts* surrounding ICP implementation and discover how these contexts influence outcomes.
▶ To describe and develop an understanding of the structure, organisation, interventions and general implementation of the ICP (*the mechanisms*) and therefore understand how the ICP works.
▶ To explore the perceptions of the ICP from those involved including patients (palliative), staff (primary and secondary care), carers and family and friends of patients (*mechanisms and outcomes*).
▶ To investigate conversations about palliative care between health professionals and patients, and the effect of coping style (*mechanisms and outcomes*).
▶ To identify, describe and assess a range of *outcomes* of the ICP.

Design

Putting realistic evaluation into practice

There are three phases to the research, undertaken concurrently, within which the various CMO conjectures, generated as a starting point for exploration and understanding following immersion in the field and literature, are explored. It is believed that other CMO configurations are likely to emerge from the investigation, and this is embraced and accounted for by the research in terms

of its small participant numbers in all current sections of data collection. This allows the research to be flexible and responsive to emergent findings. This set up also inherently acknowledges the sensitive nature of the research and minimises research demands on participants. Within the three research phases, several analytical strategies will be utilised to make sense of the data (see section on Analytical framework). By highlighting the more beneficial contexts and mechanisms in different areas of the ICP, progress can be made in both refining and improving the ICP via feedback loops built into the design. Additionally, information about optimal conditions for implementation can be obtained, which will be useful for implementation of the palliative care ICP or any other similar health improvement initiatives, in other areas of the country.

Analytical framework

The CMO conjectures referred to above will be investigated using analytical frameworks, referred to as phase maps (table 1). It is envisaged that outcomes from phase maps 1 and 3 will feed into phase map 2. This is in order to facilitate the initial focus group and to ensure that a good breadth of data from several sources is continuously fed back into subsequent focus groups. Table 1 details the type of participants in each section of research and explicitly indicates which data collection tools will be utilised, how data will be analysed and which research question is being addressed.

Phase 1: does the palliative care ICP work?

MIQUEST and locality Death Audit data. Data collection: Phase map 1 details the use of quantitative data available from the 15 pilot sites in the form of the Death Audit and Morbidity Information Query and Export Syntax data. Both sets of data are routinely collected by practices: Death Audit data retrospectively since 2007 and MIQUEST searches run routinely since 2009. While some of the data overlaps, other data, such as that on Advance Care plans and sudden deaths, do not.

Data analysis: Descriptive statistics will be generated from the MIQUEST and Death Audit data.

The Quality of Dying and Death Questionnaire. Data collection: There are several 'good death' measures available in the literature; however, a recent systematic review found the Quality of Dying and Death Questionnaire[16] to be the most widely studied and best validated.[17] It will be used to determine how many individuals who experienced the ICP had a good death. This measure will be distributed to bereaved families and key healthcare workers involved in a patient's care.

Data analysis: Descriptive comparison of perceptions.

Phase 2: what are the conditions of effectiveness of ICPs in palliative care?

Data collection: Focus groups with health professionals from many different backgrounds and services will be carried out. This will include the ambulance service, a hospice, GPs, community matrons, district nurses and

Table 1 Phase maps—study participants, data collection and analyses for each research question

	Major research question answered	Specific research question answered	Participants providing data	Data source	Data analysis
Phase map 1	Does the palliative care ICP work?	Are the palliative care ICP factors all being conducted appropriately?	Palliative care patients from one of the practice sites	MIQUEST data base/locality Death Audit	Descriptive statistics
		Does the ICP lead to a good death in both the GPs and bereaved families experience?	Relatives of deceased palliative care patients and the health professionals previously involved in the patients palliative care	Quality of Dying and Death Questionnaire	Descriptive comparisons
Phase map 2	What are the conditions of effectiveness of ICPs in palliative care?	In terms of implementation context and intervention detail—for whom does the ICP work, how does it work and under what circumstances?	Health professionals involved with the ICP	Focus groups	Soft systems methodology
Phase map 3	Who does the ICP work for?	What are the patients, families and bereaved families opinions and experiences of the ICP?	Palliative care patients and their families and bereaved families of palliative care patients	Interviews	Interpretive phenomenological analysis
			Palliative care patients and their GPs	Coping Style Questionnaire	Classified as monitor or blunter
				Voice recording of consultations	Interpretive phenomenological analysis

GPs, general practitioners; ICP, integrated care pathway.

social services. Three focus groups will be conducted to allow an understanding of how the ICP works and therefore lead to a model that will represent the real-world ICP from practitioners' viewpoints. Furthermore, this model will help to highlight the contexts and mechanisms that are key to producing effective outcomes. It is envisaged that these focus groups may also enhance the ICP itself as they will provide practitioners with opportunities to reflect on the ICP and summarised discussions will be fed back. This will allow the research project to build on practitioners' combined organisational memory, experience and wisdom.

Data analysis: Soft systems methodology (SSM) will be the analytical framework for this section of research. It is an epistemology that formulates carefully built models of systems, which will be used to represent and analyse the real-world situation. They will then be set against perceptions of the real world by a process of comparison, which will initiate debate leading to solutions of how to improve the real-world situation through purposeful action.[18] SSM aims to provide assistance in coherently expressing and operating the learning cycle from meanings to intentions to relevant action without the rigidity of a technique.[18 19] SSM has been used to aid understanding in public health, outpatient services and chronic

disease management[20–22]; however, it has not yet been used in the investigation of a palliative care ICP. The use of focus groups will aid in the validation and development of the SSM map and also help the ICP grow and mature into a more efficient and effective initiative, as in Tolson et al.[23]

Phase 3: who does the ICP work for?
Coping style. Data collection: A palliative diagnosis or information about palliative care can both be classed as distressing health-threatening information, which is difficult for the doctor to deliver and for the patient to receive.[24–26] The literature suggests conversations about death occur infrequently and that this may be due to professionals not feeling at ease with broaching the subject.[27–29] It is proposed that in such health-related risk situations, individuals utilise distinctive attentional processing styles, which allow them to be classified as a high or low monitor.[30] When faced with a health-related risk, high monitors generally seek information, magnify disease-related cues and display greater dissatisfaction about the amount of information provided. Alternatively, blunters psychologically distract themselves from health-related risk information and desire less knowledge.

4

335

The proposed use of coping style classification in this project will be to investigate whether matched coping styles between patients and health professionals offer any explanatory potential for outcomes achieved. For example, if a monitor health professional and a monitor patient (classified through use of the Miller Behavioural Style Scale)[30] have a consultation, it is hypothesised that their conversation about death will have a more positive outcome than a conversation between a monitor health professional and blunter patient. Individuals will be classified as monitors or blunters, and following from this, recordings of conversations/consultations about palliative care will be made.

Data analysis: The questionnaire data will be analysed by classifying individuals as monitors or blunters. The audio recording of the consultation will be analysed using thematic analysis. It is acknowledged that palliative care conversations take place over time. Therefore, GPs will have the opportunity to record up to three consultations with one patient, if they believe that this is necessary.

Interviews with palliative patients and bereaved family members.
Data collection: Semi-structured interviews will be conducted with palliative care patients, their families and friends, and bereaved families and friends of palliative care patients. This provides rich in-depth qualitative data about the ICP, whether it is working for patients and family of patients and if it contributes to a good death. It is also envisaged that information from these interviews will feed back (anonymously) into the focus groups with the healthcare professionals in order to facilitate SSM modelling.

Data analysis: The transcripts of the interviews will be analysed using IPA.[31]

Participants

In order to fulfil the research aims, the study will recruit GPs, nurses, charity staff from local organisations, the ambulance service, community matrons, social service staff, palliative care patients, bereaved family members, and friends and carers of palliative care patients.

In each different CMO conjecture, a different practice will be selected for data collection, from the 15 practice sites. This will avoid over burdening health professionals, palliative care participants and bereaved family, friends and carers of palliative care patients. The three practices selected are rural, semirural and urban. Palliative care participants will be selected via a GP screening method to ensure no one is contacted who is suffering from cognitive deficits or severe psychological distress. Palliative care patients and bereaved family members, friends and carers will be invited to participate in the study via letter. Health professionals will be invited via email or letter.

ETHICS AND DISSEMINATION

Research suggests that ICPs in end-of-life care are successful,[5–7] and therefore, a similar approach to the palliative care of those with life-limiting illness may be beneficial to staff, patients and families. However, examination of syntheses of this research indicates that currently the literature in this area is sparse. This study is part of a PhD thesis that aims to elucidate if the new ICP works and, if so, how it works and who it works for. Several outcomes are anticipated from the study, including: trends in quantitative measures from MIQUEST data and locality Death Audit data, qualitative information from the interviews, focus groups and Quality of Dying and Death Questionnaire, SSM models of the ICP and innovative information on coping style and communication in palliative care. These outcomes will allow the generation of knowledge about the key operational factors that make the ICP a success and how these are influenced by delivery context. Additionally, this study will generate knowledge about the ICP that will improve it via feedback while the research takes place and will provide information to aid implementation of the ICP in other geographical areas.

The study will also highlight gaps in knowledge about palliative care and therefore the development of novel forms of care may be created and implemented as a result. This new knowledge could be utilised by a wide spectrum of organisations and individuals working in this area including new clinical commissioning consortia, GP practices, acute hospital trusts, specialist palliative care services, social care, community services, registered charities, educationalists, patient advocates, and policy makers to guide ICP implementation, service delivery and service improvement. Currently, there is a vast amount of policy and little practical implementation[12]; this study may aid in implementing a long-term change in the GP practice sites.

The ICP has been implemented since January 2010 in one locality of Northumberland involving 15 GP practices serving 80 300 patients. A 1-year data collection phase commenced in March 2012. The use of qualitative and quantitative data means that there will be a considerable amount of data generated with a wide range of outcomes. The quantitative MIQUEST and Death Audit data from the 15 GP practices involved with the ICP, and study dates back from 2009 to 2007, respectively, and includes many outcomes; therefore, it yields a considerable amount of information about various outcomes over a substantial period of time.

Ethics

The conduct of the study will conform to relevant ethical and legal guidelines covering informed consent, confidentiality and data storage. Ethical approval was obtained from the LREC through use of the Integrated Research Application System on 12 January 2012. Research and Development approval was gained from four different NHS trusts due to the various participant groups in this study. The voluntary sector and the council were also informed of the study, and permission has been gained to invite their staff to participate in the study where appropriate.

Dissemination

This study is large scale and will form a PhD thesis and will be available in hard copy in Northumbria University library and via the university's online repository once completed. As data collection occurs, platform presentations will be given and academic posters will be displayed at relevant conferences. Additionally, publications will be drafted; therefore, each section of data collection has a potential for publication. Potential publications include mapping of focus group's discussions surrounding the palliative care ICP; analysis of bereaved family members' experience of terminal care and caring for a loved one; an IPA of patient's experience of palliative care; a statistical review of MIQUEST and Death Audit data; results from a matched health professional and bereaved relative Quality of Death and Dying Questionnaire; coping style and palliative care relationships and their effect on consultations. All data that are collected will be utilised in the realist evaluation, and publications are also expected from this analysis. The results from the study will also be fed back to the locality as they are analysed in order to aid continuous quality improvement.

Steering group

This research has a dedicated steering group, which aims to monitor progress of the study, address governance and ethical issues and overcome barriers in access and resources. The steering group includes experienced researchers from Northumbria University, a GP with expertise in palliative care, a service user, a palliative care Masters programme leader from Northumbria University and a Research & Development lead representing the NHS study sponsor. This steering group has been important in both setting up the project and achieving milestones such as LREC and Research & Development approval.

Conclusions

A novel and complex approach to practice has been matched with a novel and complex evaluation methodology. While much of the learning generated by this research will be on palliative care processes, there will also be key methodological messages about developing CMO conjectures early in a project and populating them with evidence.

REFERENCES

1. Department of Health. *Building on the Best: Choice, Responsiveness and Equity in the NHS.* London: Department of Health, 2003.
2. Department of Health. *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life (Executive Summary).* London: Department of Health, 2008.
3. *BBC News Health.* http://news.bbc.co.uk/1/hi/health/4896948.stm
4. Birmingham K. Elderly denied a 'good death'. *Nurs Older People* 2006;18:5—6.
5. Rotter T, Kinsman L, James EL, *et al.* Clinical pathways: effects on professional practice, patient outcomes, length of stay and hospital costs. *Cochrane Database Syst Rev* 2010;(3): CD006632.
6. Di Leo S, Beccaro M, Finelli S, *et al.* Expectations about and impact of the Liverpool care pathway for the dying patient in an Italian hospital. *Palliat Med* 2011;4:293—303.
7. Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. *BMJ* 2003;326:30—4.
8. Lunney JR, Lynn J, Foley DJ, *et al.* Patterns of functional decline at the end of life. *JAMA* 2003;289:2387—92.
9. Mirando S, Davies PD, Lipp A. Introducing an integrated care pathway for the last days of life. *Palliat Med* 2005;19:33—9.
10. Hockley J, Dewar B, Watson J. Promoting end-of-life care in nursing homes using an integrated care pathway for the last days of life. *J Res Nurs* 2005;10:135—52.
11. Ellershaw J, Gambles M, McGlinchey T. Benchmarking: a useful tool for informing and improving care of the dying? *Support Care Cancer* 2007;16:813—19.
12. Medical Research Council. *Developing and Evaluating Complex Interventions: New Guidance.* http://www.mrc.ac.uk/complexinterventionsguidance
13. Pawson R. Evidence-based policy: the promise of realist synthesis. *Evaluation* 2002;8:340—58.
14. Pawson R, Tilley N. *Realistic Evaluation.* London: Sage, 2005.
15. Greenhalgh T, Humphrey C, Hughes J, *et al.* How do you modernize a health service? A realist evaluation of whole scale transformation in London. *Milbank Q* 2009;87:391—416.
16. Curtis JR, Patrick DL, Engelberg RA, *et al.* A measure of the quality of dying and death: initial validation using after-death interviews with family members. *J Pain Symptom Manage* 2002;24:17—30.
17. Hales S, Zimmerman C, Rodin G. The quality of dying and death: a systematic review of measures. *Palliat Med* 2010;24:127—44.
18. Checkland P, Scholes J. *Soft Systems Methodology in Action.* Chichester: Wiley, 1992.
19. Checkland P. Soft systems methodology: a 30 year retrospective. *Syst Res* 2000;17:S11—58.
20. Fahey DK, Carson ER, Cramp DG, *et al.* Information communication technology in public health: the role of systems modelling. *HIJ* 2003;9:163—81.
21. Lehaney B, Paul RJ. The use of soft systems methodology in the development of a simulation of out-patient services at Watford general hospital. *J Oper Res Soc* 1996;47:864—70.
22. Unertl KM, Weigner MB, Johnson KB, *et al.* Describing and modelling workflow an information flow in chronic disease care. *Am Med Inform Assoc* 2009;16:826—36.
23. Tolson D, McIntosh J, Loftus L, *et al.* Developing a managed clinical network in palliative care: a realistic evaluation. *Int J Nurs Stud* 2005;44:183—95.
24. Buckman R. Breaking bad news: why is it still so difficult? *Br Med J (Clin Res Ed)* 1984;288:1597—9.
25. Ptacek JT, Eberhardt TL. Breaking bad news: a review of the literature. *JAMA* 1996;276:496—502.
26. Ptacek JT, Ptacek JJ. Patients perceptions of receiving bad news about cancer. *J Clin Oncol* 2001;19:4160—4.
27. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA* 1995;274:1591—8.
28. Hofmann JC, Wenger NS, Davis RB, *et al.* Patient Preferences for communication with physicians about end-of-life decisions. *Ann Intern Med* 1997;127:1—12.
29. National End of Life Care Programme. *Talking About End of Life Care: Right Conversations, Right People, Right Time.* http://www.endoflifecareforadults.nhs.uk/publications/talking-about-eolc
30. Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease: implications for cancer screening and management. *Cancer* 1995;76:167—77.
31. Brockia JM, Weardena AJ. A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychol Health* 2006;21:87—108.

Invitation letter 9 for practices to provide their MIQUEST and death audit data

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Dear Practice Manager,

Your practice is invited to take part in this research study.

We would like you to provide your GP practice's MIQUEST and death audit data. We are undertaking research into the new Palliative Care Integrated Care Pathway in [the locality]. It is a study funded by NHS North of Tyne Primary Care Trust and Northumbria University.

This study is part of Sonia Dalkin's PhD at Northumbria University which investigates the new palliative care system in [the locality]. It hopes to find out new and interesting things about the system, including how it works, and who it works for (for example, patients, family, carers, GPs, nurses). It will also help the system improve itself, therefore improving palliative care as the study is taking place. This research is important as its overall aim is to inform and improve palliative care practice on both a local and national level so that individuals have open and easy access to the supportive care they need, which will ultimately lead to a peaceful death.

I would like to invite you to take the time to read the **Information Sheet** included with this letter. This will give you more information about the study and what you would do if you participated. If you would like to participate once reading the information sheet, please complete the consent form and email it back to sonia.dalkin@northumbria.ac.uk. As one of the researchers in this study I can be contacted if you would like to find out more information or ask questions. My contact details are at the end of this letter and in the information sheet.

If you have decided you do not want to take part in the study, you do not need to do anything.

Thank you for taking the time to read this letter.

Dr. Bill Cunningham, GP and Chair of the Palliative Care Partnership

Contact Details [Address, home and mobile phone number, email address]

Information Sheet 9 - Information sheet for practices to request MIQUEST and death audit data

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Information Sheet

Dear Practice Manager,

We would like to invite you to take part in this research project. Before you make a decision about taking part, please take the time to read the following information carefully and carefully and discuss this request and the study with GP colleagues in your practice.

By taking part, you will be contributing to a local study that aims to make a real difference to life limiting illness and palliative care. This will be done through identification of pathway mechanisms that contribute to a successful outcome in an Integrated Care Pathway (ICP). This could then improve the quality of palliative care delivered in [the locality], and the rest of the county.

What is the purpose of the study?

[The locality] has created a new ICP which provides individuals who have life limiting illness with access to supportive palliative care including the best symptom control, shared decision making about treatment and generally increased choice about care, leading to a peaceful death with an individual's needs fully met. This research aims to find out how the ICP works. For example, does it encourage better communication between patients and GPs, or better planning and co-ordination? We would also like to hear from patients, family members, carers and health professionals, in a variety of ways, about their experience of the ICP.

Why has the practice been invited to take part in the study?

You have been invited to take part as you have been identified as a GP practice in [the locality] using the life limiting illness and palliative care ICP, and providing MIQUEST and death audit data.

Does the practice have to take part?

No, taking part in this study is voluntary and you do not have to take part. We would like the practice manager to give consent on behalf of the practice. If you decide you would like to take part, we will ask you to reply to this email in order to confirm your consent to us utilising the MIQUEST and death audit data from your practice.

If you take part and decide that you have changed your mind and no longer wish to be involved you can stop taking part and withdraw at any time. You do not need to provide a reason. There will be no detrimental effects on the practice and your patients will still have access to services on the palliative are pathway.

What will happen to the data if I consent to the study using it?

If the practice consents to the use of its MIQUEST and death audit data, simple statistics will be performed on the data sets. This will allow the generation of knowledge such as the amount of individuals dying in their preferred place, and whether there is a significant difference between the amount of individuals on the palliative care register, in comparison to last year. If you consent to the practice MIQUEST and death audit data being used we would like the practice manager to reply to this email (email address: sonia.dalkin@northumbia.ac.uk) to confirm this and attach the completed consent form (attached to this email).

Dr. Bill Cunningham is a member of the research steering group and will therefore ensure that all data is used appropriately and the individuals performing analysis on the data will have the ability to use it effectively.

What will be the cost of taking part?

There will be no financial cost to taking part. Additionally, this will not take any of your time; you will just provide the data.

How might taking part affect the practice?

The practice will not be required to spend any time with the researchers. They will simply be asked to give consent for their data to be used, similar to its current use by NHS North of Tyne PCT.

Will taking part in the project be private and confidential?

Yes. We will follow ethical and legal practice and all information the practice provides will be handled in confidence. This research is also for an educational project, as the chief investigator (Sonia Dalkin) is doing a PhD. All information the practice provides will be completely confidential in regards to this educational project and any future publications. Anything that you provide will not be able to be traced back to the practice in published reports. The researchers will not be able to access any information about the patients as the data will be anonymised before the researchers are given access. All information will be stored on a secure, password protected computer within Northumbria University. It will only be able to be accessed by Sonia Dalkin, (the chief investigator), Dr. Anna Jones (academic supervisor), Dr. Monique Lhussier (academic supervisor) and Dr. Bill Cunningham (academic supervisor and

GP). Any written and recorded information will be destroyed six years after the study ends. Practices will be provided with feedback from the analysis that is completed in order to help them improve their current performance.

What will happen if the practice does not want to carry on with the research?

The practice can withdraw from the research at any time they can and they do not need to provide a reason. There will be no detrimental effects on the practice and your patients will still have access to services on the palliative are pathway.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Newcastle and North Tyneside 1 Research Ethics Committee.

What if there is a problem?

If you have any query, please feel free to contact the researcher (contact details provided below). We hope this is not the case, but would you wish to complain formally about the study, you can do this through the NHS complaints procedure or by contacting the Principal Supervisor, Dr. Anna Jones at Northumbria University. Both of their contact details are below:

Dr. Anna Jones [contact information]

NHS North of Tyne PCT complaints [contact information]

Contact details

Please feel free to contact the chief investigator if you have any further questions.

Sonia Dalkin (Chief Investigator) [contact details]

What happens now?

Many thanks for taking time to read about this study. If you would like to take part please reply to this email within 2 weeks of receiving it. Consent should be given by the practice manager on behalf of the practice. You will then receive a confirmation email.

Many Thanks,

Dr. Bill Cunningham [contact details]

Consent form for Practices to agree to the use of MIQUEST and death audit data

Version 1 – 7.10.11

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

Yes No

1. I confirm that I have read and understand the information sheet dated 24/11/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

☐ ☐

Yes No

2. I understand that the participation is voluntary and that the practice is free to withdraw at any time without giving any reason, without legal rights being affected.

☐ ☐

Yes No

3. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for these individuals to have access to the data I provide.

☐ ☐

Yes   No

4. I agree to take part in the above study.

☐ ☐

Name of Participant _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone: ██████████.

Invitation letter for bereaved relatives for Quality of Death and Dying Measure

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Dear Sir/Madam,

Firstly may we say that we are extremely sorry for the recent loss of your loved one. We are contacting you as we are doing research into the new Palliative Care Integrated Care Pathway in [the locality] that your loved one had experience of. It is a study funded by NHS North of Tyne Primary Care Trust and Northumbria University and we think you could help contribute to the research.

What will this study do?

This study is part of Sonia Dalkin's PhD at Northumbria University which investigates the new palliative care system in [the locality]. It hopes to find out new and interesting things about the system, including how it works, and who it works for (for example, patients, family, carers, GPs, nurses). It will also help the system improve itself, therefore improving palliative care as the study is taking place. This research is important as its overall aim is to inform and improve palliative care practice on both a local and national level so that individuals have open and easy access to the supportive care they need, which will ultimately lead to a peaceful death.

How could you take part?

If you are interested in taking part, we will ask you to fill in a short questionnaire which will ask questions about your relative's death. This is so that we can find out how well the system is working and if it is helping individuals die peacefully.

What to do if you are interested in taking part and want more information?

If you would like to find out more information about the study, please take the time to read the **Information Sheet** included with this letter. This will give you more information about the study and what you would do if you participated. We would like

you to share the information sheet with your friends and family if you wish to, as they could possibly be involved also. You may also contact the researcher if you would like to find out more information or ask questions. The contact details of Sonia Dalkin are at the end of this letter and in the information sheet.

If you have decided you do not want to take part in the study, you do not need to do anything.

Thank you for taking the time to read this letter.

Contact Details

Sonia Dalkin, Principal Researcher.

Room H007

Coach Lane Campus East

Northumbria University

Newcastle upon Tyne

NE7 7XA

sonia.dalkin@northumbria.ac.uk

███████████

Information Sheet for bereaved relatives approached to complete the Quality of Death and Dying Measure

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Information Sheet

Part 1

We would like to invite you to take part in this research project. Before you make a decision about taking part we want to make sure you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and talk to others about the study if you wish. Part 1 will provide a brief summary of the research and part 2 will give more detailed information about the study.

Below is a list of terms used in this document that you may not be familiar with:

- Service user: This is any person who comes into contact with the National Health Service (NHS). This includes patients, carers, family members and advocates.

- Integrated Care Pathway (ICP): An integrated care pathway involves many teams working together, for example the GP surgery, the community nurses, the North east ambulance service and Tynedale hospice at home all working together to provide the best possible care for patients.

If you have any difficulties, or need help to understand the information please contact us and we will be happy to help. By taking part, you will be contributing to a local study that aims to make a real difference to life limiting illness and palliative care. This will be done through identification of pathway mechanisms that contribute to a successful outcome in an ICP. This could then improve the quality of palliative care delivered in [the locality], and the rest of the county. Please take time to decide whether you would like to take part.

What is the purpose of the study?

[The locality] has created a new ICP which provides individuals who have life limiting illness with access to supportive palliative care including the best symptom control, shared decision making about treatment and generally increased choice about care, leading to a peaceful death with an individual's needs fully met. The ICP is now in place and you will have experienced it in some way or form in your late loved ones care. This research wants to find out how the ICP works, for example, does it enable better communication between patients and GPs, or better planning and co-ordination? We also want to look at who the ICP is benefitting, does it benefit palliative care patients? Are families happy with it? Are health professionals happy with it? So, we would like to hear from patients, family members, carers and health professionals, in a variety of ways, about their experience of the ICP.

Why have I been invited to take part in the study?

You have been invited to take part as you have recently been bereaved and it is our understanding your loved one was a palliative care patient. We are very interested in hearing about your experience and how you found the ICP. We may also ask how you think your loved one felt about the care they received. Your loved one's GP will fill in the same questionnaire as you so we can get an idea of how everybody felt the experience was. The GP will not see your answers to the questionnaire and you will not see their answers. Your loved one's GP practice will have no access to the data you provide in this study.

Do I have to take part?

No, taking part in this study is voluntary and you do not have to take part. We will explain the study to you in this Information Sheet and if you have any questions or you are unsure whether you understand everything please feel free to contact us (our contact details are on the bottom of this information sheet). If you decide you would like to take part, we will ask you to sign the reply slip at the end of this Information Sheet to show you have agreed for a member of the research team to contact you to arrange the questionnaire to be posted to you.

If you take part and decide that you have changed your mind and no longer wish to be involved you can stop taking part and withdraw at any time. You do not need to provide a reason. There will be no detrimental effects on you or your care form the NHS. You and your family will still have access to services on the palliative care pathway.

What will happen to me if I take part?

If you decide you would like to take part in this research, we would like you to fill in the reply slip at the end of this Information Sheet. The researcher (Sonia Dalkin) will then send you a questionnaire that you will fill in and send back. We will provide you with a stamped and addressed envelope. You will also receive a consent form which

will just make sure that you understand what we are doing with the information you give us.

You will not be contacted again once you have returned the questionnaire and consent form in the stamped and addressed envelope provided.

What will be the cost of taking part?

There will be no financial cost to taking part. We will however ask for 30 minutes (maximum) of your time.

How might taking part affect me?

This study will not involve any physical risks, but answering questions about your experiences might be emotional or tiring. We cannot promise the study will help you but the information we get from this study will help improve the treatment of palliative care patients. If you do feel distressed or upset by the questionnaire you can contact Dr. Bill Cunningham who will be happy to talk to you about the study and provide support.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

Will taking part in the project be private and confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. This research is also for an educational project, as the chief investigator (Sonia Dalkin) is doing a PhD. All information you provide will be completely confidential. Anything that you provide will not be able to be traced back to you as you will be given a number instead of using your name. Additionally, your loved one's GP practice will not have access to any of the recorded data from this study.

All information will be stored on a secure, password protected computer within Northumbria University. It will only be able to be accessed by Sonia Dalkin, (the chief investigator), Dr. Anna Jones (academic supervisor), Dr. Monique Lhussier (academic supervisor) and Dr. Bill Cunningham (academic supervisor and GP). All personal information will be destroyed when the study ends (names will already have been replaced with a number and addresses will be destroyed) and any written and recorded information will be destroyed six years after the study ends.

Breaking confidentiality

If you tell us something during the study that suggests you or someone else is at serious risk of harm we would then have to breach confidentiality. This means that we

would report the issue to someone who could help. We will however inform you that we are going to do this, and it will not affect the standard of care that you receive.

What will happen if I don't want to carry on with the research?

If you wish to withdraw from the research at any time you can and you do not need to provide a reason. Please remember there will be no detrimental effects on you or your care from the NHS. You and your family will still have access to services on the palliative care pathway.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Newcastle and North Tyneside 1 Research Ethics Committee.

What if there is a problem?

If there is a problem or you are not happy with the study please contact one of the researchers (contact details provided below) and we will do our best to answer any questions or queries you may have. We hope this is not the case, but if you are still unhappy and wish to complain formally, you can do this through the NHS complaints procedure or by contacting the Principal Supervisor, Dr. Anna Jones at Northumbria University. Both of their contact details are below:

Dr. Anna Jones [contact details]

NHS North of Tyne PCT complaints procedure [contact details]

Additional Information

This study aims to identify how palliative care can be improved and provide best support to people with life limiting illnesses. If, for any reason, you are no longer able to provide us with any feedback once your interview is completed, we would still really value being able to use the questionnaire data. This is so that your experiences may help improve palliative care for other people. By agreeing to take part in the study, you are also giving consent for us to use your interview data at any point in the future, in relation to studying palliative care.

Contact details

If you have any concerns or would like further information about the study, please feel free to contact us.

Sonia Dalkin (Chief Investigator) [contact details]

Dr. Bill Cunningham

GP and Chair of the Palliative Care Partnership [contact details]

What happens now?

Many thanks for taking time to read about this study. If you would like to take part please fill in the reply slip below within two weeks of receiving it and send it via the stamped and addressed envelope provided. The reply slip will then be securely passed on to Sonia Dalkin. If you need help to fill in the reply slip please contact us. When we receive the reply slip we will then post you a copy of the questionnaire.

✂ _____

I would be interested in taking part in the study, and hereby give permission to be sent a questionnaire by the research team. I understand that before taking part, I will need to fill in a consent form and that if I want to I can withdraw from the study at any time, and that this will not affect my standard of care from the NHS.

Name   _____

Signature   _____

Date   _____

Home   address   for   questionnaire   to   be   sent   to:
_____
_____
_____

Appendix 8

Quality of Dying and Death Measure consent form for bereaved relatives

Version 1

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

Yes No

1. I confirm that I have read and understand the information sheet dated 24/11/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

☐ ☐

Yes No

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐ ☐

Yes No

3. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for these individuals to have access to the data I provide.

☐ ☐

Yes No

4. I agree to take part in the above study.

☐ ☐

Name of Participant _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone: ███████████.

Invitation letter for Quality of Death and Dying Measure for Health Professionals

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Dear Health Professional,

You are invited to take part in this research study.

We are doing important research into the new Palliative Care Integrated Care Pathway in [the locality]. It is a study funded by NHS North of Tyne Primary Care Trust and Northumbria University.

What will this study do?

This study is part of Sonia Dalkin's PhD at Northumbria University which investigates the new palliative care system in [the locality]. It hopes to find out new and interesting things about the system, including how it works, and who it works for (for example, patients, family, carers, GPs, nurses). It will also help the system improve itself, therefore improving palliative care as the study is taking place. This research is important as its overall aim is to inform and improve palliative care practice on both a local and national level so that individuals have open and easy access to the supportive care they need, which will ultimately lead to a peaceful death.

How could you take part?

If you are interested in taking part, we will ask you to fill in a short questionnaire which will ask questions about a palliative care patient's death.

What to do if you are interested in taking part and want more information?

If you would like to find out more information about the study, please take the time to read the **Information Sheet** included with this letter. This will give you more information about the study and what you would do if you participated. You may also contact the researcher if you would like to find out more information or ask questions. The contact details of Sonia Dalkin are at the end of this letter and in the information sheet.

If you have decided you do not want to take part in the study, you do not need to do anything.

Thank you for taking the time to read this letter.

Contact Details

Sonia Dalkin, [contact details]

Appendix 10

Information sheet for health professionals approached to complete the Quality of Death and Dying Measure

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Information Sheet

Part 1

We would like to invite you to take part in this research project. Before you make a decision about taking part we want to make sure you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and talk to others about the study if you wish. Part 1 will provide a brief summary of the research and part 2 will give more detailed information about the study.

If you have any difficulties, or need other help to understand the information please contact us and we will be happy to help. By taking part, you will be contributing to a local study that aims to make a real difference to life limiting illness and palliative care. This will be done through identification of pathway mechanisms that contribute to a successful outcome in an Integrated Care Pathway (ICP). This could then improve the quality of palliative care delivered in [the locality], and the rest of the county. Please take time to decide whether you would like to take part.

What is the purpose of the study?

[The locality] has created a new ICP which provides individuals who have life limiting illness with access to supportive palliative care including the best symptom control, shared decision making about treatment and generally increased choice about care, leading to a peaceful death with an individual's needs fully met. The ICP is now in place and as a health professional in [the locality] you have been selected as a potential participant due to your involvement with the ICP. This research wants to find out how the ICP works, for example, is it better communication between patients and GPs, or is it better planning and co-ordination? We also want to look at who the ICP is benefitting; does it benefit palliative care patients? Are their families happy with it? Are health professionals happy with it? So, we would like to hear from patients, family members, carers and health professionals, in a variety of ways, about their experience of the ICP.

Why have I been invited to take part in the study?

You have been invited to complete this questionnaire as the family of a previous palliative care patient you worked closely with have agreed to answer questions on the death of their loved one. It is hoped this will help us decipher whether the ICP is working to its full potential and identify areas where it could potentially be improved. The deceased palliative care patient's family will not see your answers to the questionnaire, and you will not see their answers.

Do I have to take part?

No, taking part in this study is voluntary and you do not have to take part. We will explain the study to you in this Information Sheet and if you have any questions or you are unsure whether you understand everything please feel free to contact us (our contact details are on the bottom of this information sheet). If you decide you would like to take part, we will ask you to sign the reply slip at the end of this Information Sheet to show you have agreed for a member of the research team to contact you to arrange the questionnaire to be posted to you.

If you take part and decide that you have changed your mind and no longer wish to be involved you can stop taking part and withdraw at any time. There will be no detrimental effects on you, your patients or your employment. Your patients will still have access to services on the palliative care pathway.

What will happen to me if I take part?

If you decide you would like to take part in this research, we would like you to fill in the reply slip at the end of this Information Sheet. The researcher (Sonia Dalkin) will then send you a questionnaire that you will fill in and send back. We will provide you with a stamped and addressed envelope. You will also receive a consent form which will just make sure that you understand what we are doing with the information you provide us with.

You will not be contacted again in relation to this section of the research once you have returned the questionnaire and consent form in the stamped and addressed envelope provided. However, it is likely that you might be contacted and asked if you wish to take part in other parts of the research, such as focus groups. You do no have to participate in all or any of the research you are invited to take part in. You can take part in some sections and not others and you can withdraw from any section of research at any time. Please remember that there will be no detrimental effects on you, your patients or your employment if you choose to withdraw. Your patients will still have access to service on the palliative care pathway.

What will be the cost of taking part?

There will be no financial cost to taking part. We will however ask for 30 minutes (maximum) of your time.

How might taking part affect me?

This study will not involve any physical risks, but answering questions about your experiences might be emotional or tiring. We cannot promise the study will help you but the information we get from this study will help improve the treatment of palliative care patients. If you do feel distressed or upset by the questionnaire you can contact Dr. Bill Cunningham who will be happy to talk to you about the study and provide support.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

Will taking part in the project be private and confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. This research is also for an educational project, as the chief investigator (Sonia Dalkin) is doing a PhD. All information you provide will be completely confidential. Anything that you provide will not be able to be traced back to you as you will be given a number instead of using your name.

All information will be stored on a secure, password protected computer within Northumbria University. It will only be able to be accessed by Sonia Dalkin, (the chief investigator), Dr. Anna Jones (academic supervisor), Dr. Monique Lhussier (academic supervisor) and Dr. Bill Cunningham (academic supervisor and GP). All personal information will be destroyed when the study ends (names will already have been replaced with a number and addresses will be destroyed) and any written and recorded information will be destroyed six years after the study ends.

Breaking confidentiality

If you tell us something during the study that suggests you or someone else is at serious risk of harm we would then have to breach confidentiality. This means that we would report the issue to someone who could help. We will however inform you that we are going to do this.

What will happen if I don't want to carry on with the research?

If you wish to withdraw from the research at any time you can and you do not need to provide a reason. This will not affect your employment or your patient's access to the palliative care pathway services.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed

and given favourable opinion by Newcastle and North Tyneside 1 Research Ethics Committee.

What if there is a problem?

If there is a problem or you are not happy with the study please contact one of the researchers (contact details provided below) and we will do our best to answer any questions or queries you may have. We hope this is not the case, but if you are still unhappy and wish to complain formally, you can do this through the NHS complaints procedure or by contacting the Principal Supervisor, Dr. Anna Jones at Northumbria University. Both of their contact details are below:

Dr. Anna Jones [contact details]

NHS North of Tyne Complaints [contact details]

Additional Information

This study aims to identify how palliative care can be improved and provide best support to people with life limiting illnesses. If, for any reason, you are no longer able to provide us with any feedback once your interview is completed, we would still really value being able to use the questionnaire data. This is so that your experiences may help improve palliative care for other people. By agreeing to take part in the study, you are also giving consent for us to use your interview data at any point in the future, in relation to studying palliative care.

Contact details

If you have any concerns or would like further information about the study, please feel free to contact us.

Sonia Dalkin (Chief Investigator) [contact details]

Dr. Bill Cunningham, GP and Chair of the Palliative Care Partnership [contact details]

What happens now?

Many thanks for taking time to read about this study. If you would like to take part please fill in the reply slip below within two weeks of receiving it and post it to the address provided above for Sonia Dalkin. You will then be posted a copy of the questionnaire. Please return the questionnaire and the consent form that you have received to Sonia Dalkin as soon as possible.

✂---

I would be interested in taking part in the study, and hereby give permission to be contacted by a member of the research team. I understand that before taking part, I will need to fill in a consent form and that if I want I can withdraw from the study at any time. I understand that this will not affect my employment or my patient's access to services.

Name _____

Signature _____

Date _____

Address   (for   questionnaire   to   be   sent   to):

_____

_____

_____

Appendix 11

Quality of Death and Dying Consent form for health professionals

Version 1

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

Yes No

1. I confirm that I have read and understand the information sheet dated 24/11/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

☐ ☐

Yes No

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐ ☐

Yes No

3. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for these individuals to have access to the data I provide.

☐ ☐

Yes No

4. I agree to take part in the above study.

☐ ☐

Name of Participant _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone ███████.

Appendix 12 - The Quality of Dying and Death Measure

In the box provided next to each statement please rate it from 0 to 10, where **0 was a "terrible experience" and 10 was an "almost perfect experience".** How would you rate the following aspect of your loved ones dying experience…

1. Having pain under control.

2. Having control of event.

3. Being able to feed oneself.

4. Having control of bladder, bowels.

5. Being able to breathe comfortably.

6. Having energy to do things one wants to do.

7. Spend time with your children as much as you want. (or I have no children)

8. Spend time with your friends and other family as much as you want.

9. Spend time alone.

10. Be touched and hugged by loved ones.

Reminder: 0 = Terrible Experience, 10 = Almost perfect experience

11. Say goodbye to your loved ones. □

12. Have the means to end your life if you need to. □

13. Discuss your wishes for end-of-life care with your doctor and others. □

14. Feel at peace with dying. □

15. Avoid worry about strain on your loved ones. □

16. Be unafraid of dying. □

17. Find meaning and purpose in your life. □

18. Die with dignity and respect. □

19. Laugh and smile. □

20. Avoid being on dialysis or mechanical ventilation. □

21. Location of death (home, hospice, hospital). □

Reminder: 0 = Terrible Experience, 10 = Almost perfect experience

22. Die with/without loved ones present. □

23. State at moment of death (awake, asleep). □

24. Have a visit from a religious or spiritual advisor. ☐

25. Have a spiritual service or ceremony. ☐

26. Have health care costs provided. ☐

27. Have funeral arrangements in order. ☐

28. Spend time with spouse, partner. (or I have no spouse, partner) ☐

29. Spend time with pets. (or I have no pets) ☐

30. Clear up bad feelings. (or there were no bad feelings to clear up) ☐

31. Attend important events. (or there were no important events to attend) ☐

This is the end of the questionnaire. Thank you very much for filling it in. Please now return it using the stamped and addressed envelope provided.

Statistics about the psychometric properties of the measure

The Cronbach's alpha is commonly used as an estimate of the reliability of a psychometric test (Pallant 2010). The Cronbach's alpha for the QODD total score was 0.89 (Curtis, Patrick et al. 2002). A Cronbach's alpha of 0.7 – 0.9 is good. A Cronbach's alpha of >0.9 is excellent (Curtis, Patrick et al. 2002). A systematic review identified 6 published measure of the quality of death and dying (Hales, Zimmerman et al. 2010). Of the six published measures reviewed, the Quality of Dying and Death questionnaire (QODD) is the most widely studied and best validated (Hales, Zimmerman et al. 2010).

Appendix 13 - Research and Development approval

R&D Ref: 11DIAB003

22 December 2011

Miss Sonia Dalkin
17 The Orchard
Hepscott
Morpeth
Northumberland
NE61 6HT

NHS North of Tyne

Research & Development
NHS North of Tyne
Bevan House
1 Esh Plaza
Sir Bobby Robson Way
Great Park
Newcastle upon Tyne
NE13 9BA

Tel: (0191) 217 2783
Fax: (0191) 217 2510

Dear Miss Dalkin

Re: NHS Permission for Research

Re: Understanding an integrated care pathway in palliative care – context, approaches, outcomes
REC No: 11/NE/0318

Following submission of the above project to NHS North of Tyne, the project has been duly reviewed and research governance checks completed and satisfied.

I am pleased to advise you that NHS Permission for research has been granted for this study to take place in primary care for **GP locations at Corbridge Medical Group, Burn Brae Medical Group and Humshaugh and Wark Medical Group**. NHS permission has been granted on the basis of information described in the application form, protocol and supporting documents. The documents received and reviewed were those submitted and approved by the Research Ethics Committee on 28 August 2009.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework and NHS North of Tyne policies.

Approval is conditional upon you notifying the Trust of practices taking part in the study in our region.

This project has been registered on the PCT's research database and you should keep the R&D Team informed of your progress on an annual basis. This will allow the database to be kept up to date. In addition, we also have an obligation to monitor all projects and audit at least 10% of all research studies undertaken in our area and the database is used to identify such projects. If your project is selected, the R&D team will contact you.

In particular, it is a condition of our support that the R&D department *must* be notified of:

- commencement and completion of the study;
- any significant changes to the study design;
- any changes to research teams and any changes in the circumstances of researchers that may have an impact on their suitability to conduct research (eg. employment status, registration status, criminal record etc.)
- any decision made by a Research Ethics Committee regarding this study, including a copy of your ethics approval letter;

Passionate about health

Working on behalf of Newcastle and North Tyneside
Primary Care Trusts and Northumberland Care Trust

- any serious adverse effects on participants or staff. Please note that guidance of what constitutes an adverse event is available on the R&D website. (*www.northoftyne.nhs.uk/publications/research/*)
- any suspension or abandonment of the study;
- all funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- all publications and/or conference presentations of the findings of the study.
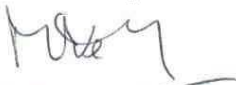
Where Honorary Research Contracts or Letters of Access are required, these will be issued separately. You should note that your research is unable to commence until you are in receipt of the Honorary Research Contract or Letter of Access.

The principal investigator is required to send an electronic copy of the final report and a lay summary to the PCT within twelve months of the completion date of the research project.

Commencement of any work related to this study, using resources or premises of primary care organisations in Northumberland, North Tyneside and Newcastle implies agreement with the above conditions.
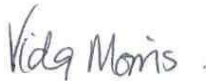
On behalf of the Trust, may I take this opportunity to wish you success in your study.

Yours sincerely

Dr Mike Guy
Medical Director, NHS North of Tyne, Bevan
House, 1 Esh Plaza, Sir Bobby Robson Way,
Great Park, Newcastle upon Tyne NE13 9BA

Vida Morris
Lead Nurse / Associate Director Patient Safety
NHS North of Tyne

Copies:
- Dr Bill Cunningham - w.cunningham@brinternet.com
- Dr Anna Jones - anna.jones@northumbria.ac.uk
- Shona Haining - shona.haining@northoftyne.nhs.uk
- Add to ReDA

Appendix 14 - letter to charitable organisations

Sonia Dalkin [contact details]

27/02/12

Dear Sir/Madam,

I am a PhD student at Northumbria University working in collaboration with NHS North of Tyne PCT. I am currently developing a study to investigate and evaluate the new life limiting illness and palliative care integrated care pathway in [the locality]. In order to get a full understanding of how the Integrated Care Pathway (ICP) works we would like to host 3 focus groups in 2012 at ███████████████████ in ████████, [the locality]. Since your organisation has been involved with the new ICP we would like to request approval for your staff to be approached to take part in the aforementioned focus groups.

These focus groups will involve 8-12 people each time. Your staff can attend one, two or all of the focus groups, it is completely up to them. They will be contacted via email with an invitation and information sheet and then provided with a consent form. The focus groups will include a variety of health professionals involved with the ICP, including GPs, community matrons, Macmillan nurses district nurses, hospice staff, ████████ Ambulance Service staff, ███████ Doctors Urgent care staff, charitable organisation staff and social workers.

The focus groups will discuss the ICP and prompt collaborative discussion about how the ICP works, what is beneficial about it and what is not beneficial. It is hoped that not only will this focus group generate data for the evaluation of the ICP, but it will also help the ICP improve as information generated from the focus groups will be anonymously fed back in order to have continuous quality improvement.

You and your staff would receive a short report at the end of the study detailing the information generated from the focus groups. The study has full ethical approval from the Newcastle North Tyneside 1 Committee. This approval was gained on 12.01.12

If you would like more information please don't hesitate to contact me via phone ███████████) or email (sonia.dalkin@northumbria.ac.uk). If you feel you have sufficient information to make an informed decision could you please contact me via email giving permission for me to approach your staff to ask them if they would like to take part in the focus groups. Alternatively, you can just fill in the slip below and return it to the address below.

Sonia Dalkin

Room H007, School of Health, Education and Community Studies

Coach Lane Campus, Northumbria University

Coach Lane

Newcastle Upon Tyne

NE7 7XA

I look forward to hearing from you.

Yours Sincerely

Sonia Dalkin

Post Graduate Research Student

I hereby give my approval for staff at ███████████████ to be approached to *take part in the focus groups for the study "Understanding Palliative Care Integrated* Care Pathways – Context, Approaches, Outcome*s".*

Name:
_____
_____

Signature:
_____
_____

Date: _____

Invitation letter for focus groups to health care professionals

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Dear Health Professional,

You are invited to take part in this research study.

We are doing research into the new Palliative Care Integrated Care Pathway in [the locality]. It is a study funded by NHS North of Tyne Primary Care Trust and Northumbria University.

What will this study do?

This study is part of Sonia Dalkin's PhD at Northumbria University which investigates the new palliative care system in [the locality]. It hopes to find out new and interesting things about the system, including how it works, and who it works for (for example, patients, family, carers, GPs, nurses). It will also help the system improve itself, therefore improving palliative care as the study is taking place. This research is important as its overall aim is to inform and improve palliative care practice on both a local and national level so that individuals have open and easy access to the supportive care they need, which will ultimately lead to a peaceful death.

How could you take part?

If you are interested in taking part, we will ask you to attend a focus group with a variety of health professionals to discuss the benefits and challenges of the new ICP.

What to do if you are interested in taking part and want more information?

If you would like to find out more information about the study, please take the time to read the **Information Sheet** included with this letter. This will give you more information about the study and what you would do if you participated. You may also contact the researcher if you would like to find out more information or ask questions. The contact details of Sonia Dalkin are at the end of this letter and in the information sheet.

If you have decided you do not want to take part in the study, you do not need to do anything.

Thank you for taking the time to read this letter. **Contact Details [Sonia Dalkin]**

Information sheet email to be sent to health professionals for focus groups

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Information Sheet

Part 1

We would like to invite you to take part in this research project. Before you make a decision about taking part we want to make sure you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and talk to others about the study if you wish. Part 1 will provide a brief summary of the research and part 2 will give more detailed information about the study.

If you have any difficulties, or need other help to understand the information please contact us and we will be happy to help.

By taking part, you will be contributing to a local study that aims to make a real difference to palliative care. This will be done through identification of pathway mechanisms that contribute to a successful outcome in an Integrated Care Pathway (ICP). This could then improve the quality of palliative care delivered in [the locality], and the rest of the county. Please take time to decide whether or not you would like to participate.

What is the purpose of the study?

[The locality] has created a new Integrated Care Pathway which provides individuals who have life limiting illness with access to supportive palliative care including the best symptom control, shared decision making about treatment and generally increased choice about care, leading to a peaceful death with an individual's needs fully met. The ICP is now in place and as a health professional in [the locality] you have been selected as a potential participant due to your involvement with the ICP. This research wants to find out how the ICP works, for example, is it better communication between patients and GPs, or is it better planning and co-ordination? We also want to look at who the ICP is benefitting; does it benefit palliative care patients? Are their families happy with it? Are health professionals happy with it? So, we would like to hear from

patients, family members, carers and health professionals, in a variety of ways, about their experience of the ICP.

Why have I been invited to take part in the study?

You have been invited to take part as you have been identified as a health professional working within [the locality] who has experience of the palliative care ICP.

Do I have to take part?

No, taking part in this study is voluntary and you do not have to take part. We will explain the study to you in this Information Sheet and if you have any questions or you are unsure whether you understand everything please feel free to contact us (our contact details are on the bottom of this information sheet). If you decide you would like to take part, we will ask you to reply to this email in order to confirm your attendance at the focus group.

If you take part and decide that you have changed your mind and no longer wish to be involved you can stop taking part and withdraw at any time. You do not need to provide a reason. There will be no detrimental effects on you, your patients or your employment. Your patients will still have access to services on the palliative care pathway.

What will happen to me if I take part?

If you decide you would like to take part in this research and the date, time and place of the focus group (stated in the email accompanying this letter) is convenient for you, we would like you to reply to this email (email address: sonia.dalkin@northumbia.ac.uk). The researcher, Sonia Dalkin, will then send you an email confirming she has received your reply and provide you with a consent form. This will ensure sure that you understand what we are doing with the information you provide us with in the focus groups. We ask that you fill in this consent form and bring it with you to the focus groups.

The focus group will last approximately 1 hour. It will take place with around 8 – 12 other health professionals form a variety of backgrounds. You do not have to contribute to any of the discussions if you do not wish to. Before the focus group, Sonia Dalkin will explain the study in person to all participants and answer any questions you may have. Your signed consent form will then be collected. Spare consent forms will also be available though we would prefer if you had ample time to read them before agreeing to participate. The interview will be recorded using a digital voice recorder and the chief investigator will also take notes.

The focus group discussions will cover topics such as:

- The ICP entails multidisciplinary work – how is this operationalised?

- What do you think the benefits of the ICP are?

- Are there any ways in which you think the ICP can be improved?

You may be contacted again about further focus groups, however attending one focus group does not mean you are have to attend the following future focus groups. It is also possible that you might be contacted and asked if you wish to take part in other parts of the research. You do not have to participate in all or any of the research you are invited to take part in. You can take part in some sections and not others.

What will be the cost of taking part?

There will be no financial cost to taking part in this study. We will however ask for 1 hour (maximum) of your time.

How might taking part affect me?

This study will not involve any physical risks, but answering questions about your experiences might be emotional or tiring. We cannot promise the study will help you personally but the information we get from this study will help improve the treatment of palliative care patients and aid the health professionals who work in the field. If you do feel distressed or upset by the focus groups you can contact Dr. Bill Cunningham who will be happy to talk to you about the study and provide support.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

Will taking part in the project be private and confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. This research is also for an educational project, as the chief investigator (Sonia Dalkin) is doing a PhD. All information you provide will be completely confidential in regards to this educational project. Anything that you provide will not be able to be traced back to you as you will be given a number instead of using your name. However, the researcher cannot guarantee confidentiality from others in the focus group.

All information will be stored on a secure, password protected computer within Northumbria University. It will only be able to be accessed by Sonia Dalkin, (the chief investigator), Dr. Anna Jones (academic supervisor), Dr. Monique Lhussier (academic supervisor) and Dr. Bill Cunningham (academic supervisor and GP). All personal information will be destroyed when the study ends (names will already have been replaced with a number and addresses will be destroyed) and any written and recorded information will be destroyed six years after the study ends.

Breaking confidentiality

If you tell us something during the study that suggests you or someone else is at serious risk of harm we would then have to breach confidentiality. This means that we would report the issue to someone who could help. We will however inform you that we are going to do this.

What will happen if I don't want to carry on with the research?

If you wish to withdraw from the research at any time you can and you do not need to provide a reason.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Newcastle and North Tyneside 1 Research Ethics Committee.

What if there is a problem?

If there is a problem or you are not happy with the study please contact one of the researchers (contact details provided below) and we will do our best to answer any questions or queries you may have. We hope this is not the case, but if you are still unhappy and wish to complain formally, you can do this through the NHS complaints procedure on the internet, or you can contact your local Primary Care Trust (PCT), NHS North of Tyne, or you can contact the Principal Supervisor, Dr. Anna Jones at Northumbria University. Dr. Anna Jones's details and North of Tyne PCT details are below:

Dr. Anna Jones [contact details]

NHS North of Tyne PCT complaints procedure [contact details]

Additional Information

This study aims to identify how palliative care can be improved and provide the best support to people with life limiting illnesses. If, for any reason, you are no longer able to provide us with any feedback once your interview is completed, we would still really value being able to use the focus group data. This is so that your experiences may help improve palliative care for other people. By agreeing to take part in the study, you are also giving consent for us to use your interview data at any point in the future, in relation to studying palliative care.

Contact details

If you have any concerns or would like further information about the study, please feel free to contact us.

Sonia Dalkin (Chief Investigator), [contact details]

Dr. Bill Cunningham, GP and Chair of the Palliative Care Partnership [contact details]

What happens now?

Many thanks for taking time to read about this study. If you would like to take part please reply to this email within 2 weeks of receiving it. You will then receive a confirmation email with the location of the focus group. A light lunch will be provided before the focus group commences.

Many Thanks,

Sonia Dalkin

Chief Investigator

Appendix 17

Consent form for focus groups with health professionals

Version 1

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

Yes No

1. I confirm that I have read and understand the information sheet dated 24/11/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

☐ ☐

Yes No

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐ ☐

3. I agree to being recorded by a digital voice recorder.

Yes No

☐ ☐

4. I agree for the researcher to take notes.

☐ ☐

Yes No

5. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for these individuals to have access to the data I provide.

☐ ☐

Yes No

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

Name of Participant _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone: ██████████.

Invitation letter for interviews with palliative care patients

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Dear Service User,

You are invited to take part in this research study.

We are doing important research into the new Palliative Care Integrated Care Pathway in [the locality]. It is a study funded by NHS North of Tyne Primary Care Trust and Northumbria University.

What will this study do?

This study is part of Sonia Dalkin's PhD at Northumbria University which investigates the new palliative care system in [the locality]. It hopes to find out new and interesting things about the system, including how it works, and who it works for (for example, patients, family, carers, GPs, nurses). It will also help the system improve itself, therefore improving palliative care as the study is taking place. This research is important as its overall aim is to inform and improve palliative care practice on both a local and national level so that individuals have open and easy access to the supportive care they need, which will ultimately lead to a peaceful death.

How could you take part?

If you are interested in taking part, we will ask you to attend an interview to discuss your experience of Palliative care.

What to do if you are interested in taking part and want more information?

If you would like to find out more information about the study, please take the time to read the **Information Sheet** included with this letter. This will give you more information about the study and what you would do if you participated. We would like you to share the information sheet with your friends, family are carers if you wish to, as they could possibly be involved also. You may also contact the researcher if you would like to find out more information or ask questions. The contact details of Sonia Dalkin are at the end of this letter and in the information sheet.

If you have decided you do not want to take part in the study, you do not need to do anything.

Thank you for taking the time to read this letter.

Contact Details

Sonia Dalkin, Principal Researcher [contact details]

Invitation letter for interviews with bereaved relatives and carers

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Dear Sir/Madam,

Firstly may we say that we are extremely sorry for the recent loss of your loved one. We are contacting you as we are doing research into the new Palliative Care Integrated Care Pathway in [the locality] that your loved one had experience of. It is a study funded by NHS North of Tyne Primary Care Trust and Northumbria University and we think you could help contribute to the research.

What will this study do?

This study is part of Sonia Dalkin's PhD at Northumbria University which investigates the new palliative care system in [the locality]. It hopes to find out new and interesting things about the system, including how it works, and who it works for (for example, patients, family, carers, GPs, nurses). It will also help the system improve itself, therefore improving palliative care as the study is taking place. This research is important as its overall aim is to inform and improve palliative care practice on both a local and national level so that individuals have open and easy access to the supportive care they need, which will ultimately lead to a peaceful death.

How could you take part?

You are invited to take part as you have recently lost a loved one who was a palliative care patient. If you are interested in taking part, we will ask you to attend an interview to discuss your experience of palliative care in [the locality].

What to do if you are interested in taking part and want more information?

If you would like to find out more information about the study, please take the time to read the **Information Sheet** included with this letter. This will give you more information about the study and what you would do if you participated. We would like you to share the information sheet with your friends and family if you wish to, as they could possibly be involved also. You may also contact the researcher if you would like to find out more information or ask questions. The contact details of Sonia Dalkin are at the end of this letter and in the information sheet.

If you have decided you do not want to take part in the study, you do not need to do anything. Thank you for taking the time to read this letter.

Contact Details

Sonia Dalkin, Principal Researcher [contact details]

Information sheet for interviews with palliative care patients' relatives

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Information Sheet

Part 1

We would like to invite you to take part in this research project. Before you make a decision about taking part we want to make sure you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and talk to others about the study if you wish. Part 1 will provide a brief summary of the research and Part 2 will give more detailed information about the study.

If you have any difficulties, or need other help to understand the information please contact us and we will be happy to help.

Below is a list of terms used in this document that you may not be familiar with:

- Service user: This is any person who comes into contact with the National Health Service (NHS). This includes patients, carers, family members and advocates.

- Integrated Care Pathway (ICP): An integrated care pathway involves many teams working together, for example the GP surgery, the community nurses, the North east ambulance service and Tynedale hospice at home all working together to provide the best possible care for patients.

By taking part, you will be contributing to a local study that aims to make a real difference to life limiting illness and palliative care. This will be done through identification of pathway mechanisms that contribute to a successful outcome in an ICP. This could then improve the quality of palliative care delivered in [the locality], and the rest of the county.

What is the purpose of the study?

[The locality] has created a new ICP which provides individuals who have life limiting illness with access to supportive palliative care including the best symptom control, shared decision making about treatment and generally increased choice about care, leading to a peaceful death with an individual's needs fully met. The ICP is now in

place and as a palliative care patient's relative in [the locality] you have been selected as a potential participant. This research wants to find out how the ICP works, for example, does it enable better communication between patients and GPs, or better planning and co-ordination? We also want to look at who the ICP is benefitting; does it benefit palliative care patients? Are families happy with it? Are health professionals happy with it? So, we would like to hear from patients, family members, carers and health professionals, in a variety of ways, about their experience of the ICP.

Why have I been invited to take part in the study?

You have been invited to take part as you are identified as a palliative care patient's friend, relative or carer and they would like you to take part in the study with them.

Do I have to take part?

No, taking part in this study is voluntary and you do not have to take part. We will explain the study to you in this Information Sheet and if you have any questions or you are unsure whether you understand everything please feel free to contact us (our contact details are on the bottom of this information sheet). If you decide you would like to take part, we will ask you to fill in the reply slip at the bottom of this information sheet and return it to the chief investigator (Sonia Dalkin) with the stamped and addressed envelope provided.

If you take part and decide that you have changed your mind and no longer wish to be involved you can stop taking part and withdraw at any time. You do not need to provide a reason. There will be no detrimental effects on you or your care from the NHS. You and your family will still have access to services on the palliative care pathway.

What will happen to me if I take part?

If you decide you would like to take part in this research we would like you to complete and return the reply slip at the bottom of this information sheet. The chief investigator (Sonia Dalkin) will then call your loved one to arrange a convenient time for an interview with you both. We will ask that you bring the consent form provided in this pack with you to the interview. This consent form will ensure sure that you understand what we are doing with the information you provide us with in the interview.

Before the interview, Sonia Dalkin will explain the study in person and answer any questions you may have. Your signed consent form will then be collected. Spare consent forms will also be available though we would prefer if you had ample time to read them before agreeing to participate. The interview will be recorded using a digital voice recorder and the chief investigator will also take notes.

The interview will last approximately 1 hour. You do not have to answer any question you do not wish to answer. The interview will cover topics such as:

- What experience of palliative care have you had?

- Have there been any instances where you think your care could have been handled better?

- Do you think the communication between all the different services is good? For example between the hospital and your GP?

Throughout the interview, the researcher (Sonia Dalkin) will check that she understands your point of view and has recorded it correctly, and that you are happy with it. You will not be contacted again once the interview has taken place. However, you can contact the researcher and request a summary of what the research finds or a copy of the full report if you wish. If you forget to tell the researcher something, you can contact her after the interview (her contact details are below, but will also be provided after the interview for you to take home) and she will add it to your record.

What will be the cost of taking part?

There will be no financial cost to taking part. We will however ask for 1 hour (maximum) of your time. Any money you spend on travel will be reimbursed.

How might taking part affect me?

Answering questions about your experiences of your loved one's care or your experience of the service might be emotional or tiring. You can stop for a break during the interview at any time, or stop the interview completely. You will not be at any physical risk in this study. We cannot promise the study will help you but the information we get from this study will help improve the treatment of palliative care patients. If you do feel distressed or upset by the questionnaire you can contact Dr. Bill Cunningham who will be happy to talk to you about the study and provide support.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

Will taking part in the project be private and confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. This research is also for an educational project, as the chief investigator (Sonia Dalkin) is doing a PhD. All information you provide will be completely confidential in regards to this educational project. Anything that you provide will not be able to be traced back to you as you will be given a number instead of using your name. Your GP practice will not have access to any of the recorded data from this study.

All information will be stored on a secure, password protected computer within Northumbria University in Newcastle. It will only be able to be accessed by Sonia Dalkin (the chief investigator), Dr. Anna Jones (academic supervisor), Dr. Monique Lhussier (academic supervisor) and Dr. Bill Cunningham (academic supervisor and GP).All personal information will be destroyed when the study ends (names will have already been replaced with a number and addresses will be destroyed) and any written and recorded information will be destroyed six years after the study ends.

Breaking confidentiality

If you tell us something during the study that suggests you or someone else is at serious risk of harm we would then have to breach confidentiality. This means that we would report the issue to someone who could help. We will however inform you that we are going to do this.

What will happen if I don't want to carry on with the research?

If you wish to withdraw from the research at any time you can and you do not need to provide a reason. Please remember that whether you decide to take part, not take part or take part then withdraw, the standard of care you receive from the NHS will no be affected.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Newcastle and North Tyneside 1 Research Ethics Committee.

What if there is a problem?

If there is a problem or you are not happy with the study please contact one of the researchers (contact details provided below) and we will do our best to answer any questions or queries you may have. We hope this is not the case, but if you are still unhappy and wish to complain formally, you can do this through contacting the NHS North of Tyne PCT or by contacting the Principal Supervisor, Dr. Anna Jones at Northumbria University. Both of their contact details are below:

Dr. Anna Jones [contact details]

NHS North of Tyne complaints procedure [contact details]

Additional Information

This study aims to identify how palliative care can be improved and provide best support to people with life limiting illnesses. If, for any reason, you are no longer able to provide us with any feedback once your interview is completed, we would still really value being able to use the interview data. This is so that your experiences may help improve palliative care for other people. By agreeing to take part in the study,

you are also giving consent for us to use your interview data at any point in the future, in relation to studying palliative care.

Contact details

If you have any concerns or would like further information about the study, please feel free to contact us.

Sonia Dalkin (Chief Investigator), [contact details]

Dr. Bill Cunningham,GP and Chair of the Palliative Care Partnership, [contact details].

What happens now?

Many thanks for taking time to read about this study. If you would like to take part please fill in the reply slip below and return it using the stamped and addressed envelope enclosed within 2 weeks. Sonia Dalkin (chief investigator) will then contact your relative, carer or friend to arrange a convenient time and place for the interview with both you and them.

✂ _____

I would be interested in taking part in the study, and hereby give permission to be contacted by a member of the research team. I understand that before taking part, I will need to fill in a consent form and that if I want I can withdraw from the study at any time and this will not affect the care my family or I receive.

Your Name   _____

Loves one's name _____

Signature   _____

Date   _____

Telephone number _____

Information Sheet for interviews with bereaved relatives, friends and carers

Version: 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Information Sheet

Part 1

We would like to invite you to take part in this research project. Before you make a decision about taking part we need you to make sure you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and talk to others about the study if you wish. Part 1 will provide a brief summary of the research and Part 2 will give more detailed information about the study.

Below is a list of terms used in this document that you may not be familiar with:

- Service user: This is any person who comes into contact with the National Health Service (NHS). This includes patients, carers, family members and advocates.

- Integrated Care Pathway (ICP): An integrated care pathway involves many teams working together, for example the GP surgery, the community nurses, the North east ambulance service and Tynedale hospice at home all working together to provide the best possible care for patients.

If you have any difficulties, or need other help to understand the information please contact us and we will be happy to help. By taking part, you will be contributing to a local study that aims to make a real difference to life limiting illness and palliative care. This will be done through identification of pathway mechanisms that contribute to a successful outcome in an ICP. This could then improve the quality of palliative care delivered in [the locality], and the rest of the county.

What is the purpose of the study?

[The locality] has created a new ICP which provides individuals who have life limiting illness with access to supportive palliative care including the best symptom control, shared decision making about treatment and generally increased choice about care, leading to a peaceful death with an individual's needs fully met. The ICP is now in

place and as a bereaved relative or carer in [the locality] you have been selected as a potential participant. This research wants to find out how the ICP works, for example, does it enable better communication between patients and GPs, or better planning and co-ordination? We also want to look at who the ICP is benefitting; does it benefit palliative care patients? Are families happy with it? Are health professionals happy with it? So, we would like to hear from patients, family members, carers and health professionals, in a variety of ways, about their experience of the ICP.

Why have I been invited to take part in the study?

You have been invited to take part as you are identified as a relative, friend or carer of someone who was a palliative care patient.

Do I have to take part?

No, taking part in this study is voluntary and you do not have to take part. We will explain the study to you in this Information Sheet and if you have any questions or you are unsure whether you understand everything please feel free to contact us (our contact details are on the bottom of this information sheet). If you decide you would like to take part, we will ask you to fill in the reply slip at the bottom of this information sheet and return it to the chief investigator (Sonia Dalkin) with the stamped and addressed envelope provided.

If you take part and decide that you have changed your mind and no longer wish to be involved you can stop taking part and withdraw at any time. You do not need to provide a reason. There will be no detrimental effects on you or your care from the NHS. You and your family will still have access to the services on the palliative care pathway.

What will happen to me if I take part?

If you decide you would like to take part in this research we would like you to complete and return the reply slip at the bottom of this information sheet. The chief investigator (Sonia Dalkin) will then telephone call you to arrange a convenient time for an interview. We will ask that you bring the consent form provided in this pack with you to the interview. This consent form will ensure sure that you understand what we are doing with the information you provide us with in the interview.

Before the interview, Sonia Dalkin will explain the study in person and answer any questions you may have. Spare consent forms will also be available though we would prefer if you had ample time to read them before agreeing to participate. The interview will be recorded using a digital voice recorder and the chief investigator will also take notes.

The interview will last approximately 1 hour. You do not have to answer any question you do not wish to answer. The interview will cover topics such as:

- What were yours and your loved one's experience of life limiting illness and palliative care in [the locality]?

- Have there been any instances where you think their care could have been handled better?

- Do you think the communication between all the different services is good? For example between the hospital and your GP?

Throughout the interview, the researcher (Sonia Dalkin) will check that she understands your point of view and has recorded it correctly, and that you are happy with it. You will not be contacted again one the interview has taken place. However, you can contact the researcher and request a summary of what the research finds or a copy of the full report if you wish. If you forget to tell the researcher something, you can contact her after the interview (her contact details are below, but will also be provided after the interview for you to take home) and she will add this to your record.

We would like to encourage you to bring along family, friends or carers to the interview if you wish to do so. Please let the researcher know if this is the case so she can provide an information pack for them also.

What will be the cost of taking part?

There will be no financial cost to taking part. We will however ask for 1 hour (maximum) of your time. Any money you spend on travel will be reimbursed.

How might taking part affect me?

Answering questions about your experiences might be emotional or tiring. You can stop for a break during the interview at any time, or stop the interview completely. You will not be at any physical risk in this study. We cannot promise the study will help you personally but the information we get from this study will help improve the treatment of life limiting illness and palliative care patients. If you do feel distressed or upset by the interview you can contact Dr. Bill Cunningham who will be happy to talk to you about the study and provide support.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

Will taking part in the project be private and confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. This research is also for an educational project, as the chief investigator (Sonia Dalkin) is doing a PhD. All information you provide will be completely confidential in regards to this educational project. Anything that you provide will not be able to be traced back to you as you will be given a number instead

of using your name. Additionally, your loved one's GP practice will not have access to any of the recorded data.

All information will be stored on a secure, password protected computer within Northumbria University. It will only be able to be accessed by Sonia Dalkin, (the chief investigator), Dr. Anna Jones (academic supervisor), Dr. Monique Lhussier (academic supervisor) and Dr. Bill Cunningham (academic supervisor and GP). All personal information will be destroyed when the study ends (names will already have been replaced with a number and addresses will be destroyed) and any written and recorded information will be destroyed six years after the study ends.

Breaking confidentiality

If you tell us something during the study that suggests you or someone else is at serious risk of harm we would then have to breach confidentiality. This means that we would report the issue to someone who could help. We will however inform you that we are going to do this.

What will happen if I don't want to carry on with the research?

If you wish to withdraw from the research at any time you can and you do not need to provide a reason. Please remember that whether you decide to take part, not take part or take part then withdraw, the standard of care you and our family receive from the NHS will not be affected.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Newcastle and North Tyneside 1 Research Ethics Committee.

What if there is a problem?

If there is a problem or you are not happy with the study please contact one of the researchers (contact details provided below) and we will do our best to answer any questions or queries you may have. We hope this is not the case, but if you are still unhappy and wish to complain formally, you can do this by contacting NHS North of Tyne Primary Care Trust or by contacting the Principal Supervisor, Dr. Anna Jones at Northumbria University. Both of their details are below:

Dr. Anna Jones [contact details]

NHS North of Tyne complaints procedure [contact details]

Additional Information

This study aims to identify how palliative care can be improved and provide best support to people with life limiting illnesses. If, for any reason, you are no longer able to provide us with any feedback once your interview is completed, we would still really value being able to use the interview data. This is so that your experiences may help improve palliative care for other people. By agreeing to take part in the study, you are also giving consent for us to use your interview data at any point in the future, in relation to studying palliative care.

Contact details

If you have any concerns or would like further information about the study, please feel free to contact us.

Sonia Dalkin (Chief Investigator), [contact details]

Dr. Bill Cunningham, GP and Chair of the Palliative Care Partnership [contact details]

What happens now?

Many thanks for taking time to read about this study. If you would like to take part please fill in the reply slip below and return it using the stamped and addressed envelope enclosed within 2 weeks. Sonia Dalkin (chief investigator) will then contact you to arrange a convenient time and place for the interview.

✂ _____

I would be interested in taking part in the study, and hereby give permission to be contacted by a member of the research team. I understand that before taking part, I will need to fill in a consent form and that if I want I can withdraw from the study at any time and this will not affect the care my family or I receive.

Name   _____

Signature   _____

Date   _____

Telephone number for researcher to contact you on (to arrange an interview): _____

Consent form for interviews with Palliative care patients

Version 1

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

Yes No

1. I confirm that I have read and understand the information sheet dated 24/11/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

Yes No

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I agree to being recorded by a digital voice recorder   YesNo

4. I agree to the researcher taking notes

Yes   No

5. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for

these individuals to have access to the data I provide.

6. I agree to take part in the above study.

Yes No

[ ] [ ]

Name of Participant _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone: ███████.

Appendix 23

Consent forms for interviews with bereaved relatives and carers of palliative patients.

Version 1

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

	Yes	No
1. I confirm that I have read and understand the information sheet dated 24/11/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.	☐	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐	☐
3. I agree to being recorded by a digital voice recorder	☐	☐
4. I agree to the researcher taking notes.	☐	☐
5. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for these individuals to have access to the data I provide.	☐	☐

6. I agree to take part in the above study.

Yes No

☐ ☐

Name of Participant _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone: ███████████.

Appendix 24

Consent form for interviews with palliative care patients' relatives

Version 1

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

1. I confirm that I have read and understand the information sheet dated 24/11/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

Yes No
☐ ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

Yes   No
☐ ☐

3. I agree to being recorded by a digital voice recorder.

Yes No
☐ ☐

4. I agree to the researcher taking notes

☐ ☐

5. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for

Yes No
☐ ☐

these individuals to have access to the data I provide.

                                                                          Yes No

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

Name of Participant _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone: ████████.

Appendix 25

Invitation letter for coping style questionnaire and consultation recording for palliative care patients

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Dear Service User,

You are invited to take part in this research study.

We are doing research into the new Palliative Care Integrated Care Pathway in [the locality]. It is a study funded by NHS North of Tyne Primary Care Trust and Northumbria University.

What will this study do?

This study is part of Sonia Dalkin's PhD at Northumbria University which investigates the new palliative care system in [the locality]. It hopes to find out new and interesting things about the system, including how it works, and who it works for (for example, patients, family, carers, GPs, nurses). It will also help the system improve itself, therefore improving palliative care as the study is taking place. This research is important as its overall aim is to inform and improve palliative care practice on both a local and national level so that individuals have open and easy access to the supportive care they need, which will ultimately lead to a peaceful death.

How could you take part?

If you are interested in taking part, we will ask you to fill in a questionnaire about how you cope with stressful health information. Your consultation with your GP will then be recorded.

What to do if you are interested in taking part and want more information?

If you would like to find out more information about the study, please take the time to read the **Information Sheet** included with this letter. This will give you more information about the study and what you would do if you participated. We would like you to share the information sheet with your friends, family are carers if you wish to, as they could possibly be involved also. You may also contact the researcher if you would like to find out more information or ask questions. The contact details of Sonia Dalkin are at the end of this letter and in the information sheet.

If you have decided you do not want to take part in the study, you do not need to do anything.

Thank you for taking the time to read this letter.

Contact Details

Sonia Dalkin, Principal Researcher [contact details]

Information sheet for MBSS questionnaire and consultation recording for palliative care patients

Version 3

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Information Sheet

Part 1

We would like to invite you to take part in this research project. Before you make a decision about taking part we want to make sure you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and talk to others about the study if you wish. Part 1 will provide a brief summary of the research and part 2 will give more detailed information about the study.

Below is a list of terms used in this document that you may not be familiar with:

- Service user: This is any person who comes into contact with the National Health Service (NHS). This includes patients, carers, family members and advocates.

- Integrated Care Pathway (ICP): An integrated care pathway involves many teams working together, for example the GP surgery, the community nurses, the North East ambulance service and Tynedale hospice at home all working together to provide the best possible care for patients.

If you have any difficulties, or need other help to understand the information please contact us and we will be happy to help. By taking part, you will be contributing to a local study that aims to make a real difference to life limiting illness and palliative care. This will be done through identification of pathway mechanisms that contribute to a successful outcome in an ICP. This could then improve the quality of palliative care delivered in [the locality], and the rest of the county. Please take time to decide whether you would like to take part.

What is the purpose of the study?

[the locality] has created a new ICP which provides individuals who have life limiting illness with access to supportive palliative care including the best symptom control,

shared decision making about treatment and generally increased choice about care, leading to a peaceful death with an individual's needs fully met. The ICP is now in place and as a palliative care patient in [the locality] you have been selected as a potential participant. This research wants to find out how the ICP works, for example, does it allow for better communication between patients and GPs, or better planning and co-ordination? We also want to look at who the ICP is benefitting; does it benefit palliative care patients? Are families happy with it? Are health professionals happy with it? So, we would like to hear from patients, family members, carers and health professionals, in a variety of ways, about their experience of the ICP.

Why have I been invited to take part in the study?

You have been invited to take part as you are on the palliative care register at your GP surgery.

Do I have to take part?

No, taking part in this study is voluntary and you do not have to take part. We will explain the study to you in this Information Sheet and if you have any questions or you are unsure whether you understand everything please feel free to contact us (our contact details are on the bottom of this information sheet). If you decide you would like to take part, we will ask you to fill in the reply slip at the bottom of this information sheet and return it to the chief investigator (Sonia Dalkin) with the stamped and addressed envelope provided.

If you take part and decide that you have changed your mind and no longer wish to be involved you can stop taking part and withdraw at any time. You do not need to provide a reason. There will be no detrimental effects on you or your care from the NHS. You and your family will still have access to services on the palliative care pathway.

What will happen to me if I take part?

If you decide you would like to take part in this research we would like you to complete and return the reply slip at the bottom of this information sheet, using the stamped and addressed envelope provided. The chief investigator (Sonia Dalkin) will then send you a questionnaire that asks questions about how you cope in various situations. It is well known that we are all different, and that different people cope in different ways. We are trying to find out if the way that people cope (for example, wanting to ask lots of questions or not wanting to know everything at once) affects how well a consultation goes between a GP and a patient.

We will also ask you to tell us when our next consultation with your GP is as we will wish to audio record it. We would ask that you bring the consent form provided in this pack with you to the consultation. This consent form will ensure sure that you understand what we are doing with the information you provide us with in the study.

Before the consultation, Sonia Dalkin will explain the study in person and answer any questions you may have. Your signed consent form will then be collected. Spare consent forms will also be available though we would prefer if you had ample time to read them before agreeing to participate. The consultation between you and your GP will be recorded using a digital voice recorder. The researcher (Sonia Dalkin) will not be sitting in on the consultation but will listen to the recording afterwards. Your GP may ask you to take part in more than one consultation recording. This consultation will be one of your regular consultations that you would normally have with your GP. Your GP will ask for your consent to record the consultation a maximum of three times, and each time, they will check if you are still happy with that (meaning that a conversation will never be recorded without your prior agreement). Even if you agreed for one recording, just say if you would rather not have subsequent ones recorded. At the end of the study the GP will check that you are still happy with the recording being given to the researcher (Sonia Dalkin). Communication about palliative care has been reported as difficult by patients and GPs. So, we would like to see if this might be because professionals and patients might have a different approach to stressful situations. This questionnaire and audio recording of your consultation will help us discover this.

You will not be contacted again by the researcher once the consultation has taken place. However, you can contact the researcher to ask any question, add any comment to what you have already told them, and/or request a summary of what the research finds or a copy of the full report if you wish.

We would like to encourage you to bring along family, friends or carers to the consultation if you wish to do so. Please let the researcher know if this is the case so she can provide an information pack for them also.

What will be the cost of taking part?

There will be no financial cost to taking part. We will however ask for 1 hour (maximum) of your time.

How might taking part affect me?

You will not be at any physical risk in this study. The consultation between you and your GP will be a consultation that you would normally have any way so there should not be any questions that you will feel uncomfortable with. However, please remember you do not have to answer any questions you feel uncomfortable with. Also, please feel free to ask your GP questions, and use this consultation like any normal appointment you would usually have with your GP. We cannot promise the study will help you but the information we get from this study will help improve the treatment of palliative care patients. If you do feel distressed or upset by the questionnaire you can contact Dr. Bill Cunningham who will be happy to talk to you about the study and provide support.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

Will taking part in the project be private and confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. This research is also for an educational project, as the chief investigator (Sonia Dalkin) is doing a PhD. All information you provide will be completely confidential in regards to this educational project. Anything that you provide will not be able to be traced back to you as you will be given a number instead of using your name. Additionally, your GP practice will not have access to any of the recorded data.

All information will be stored on a secure, password protected computer within Northumbria University. It will only be able to be accessed by Sonia Dalkin, (the chief investigator), Dr. Anna Jones (academic supervisor), Dr. Monique Lhussier (academic supervisor) and Dr. Bill Cunningham (academic supervisor and GP). All personal information will be destroyed when the study ends (names will already have been replaced with a number and addresses will be destroyed) and any written and recorded information will be destroyed six years after the study ends.

Your GP will be told that you are taking part in the study, as they too will be invited to take part, as they will be recorded during your consultation also. They will not have access to your questionnaire answers though.

Breaking confidentiality

If you tell us something during the study that suggests you or someone else is at serious risk of harm we would then have to breach confidentiality. This means that we would report the issue to someone who could help. We will however inform you that we are going to do this.

What will happen if I don't want to carry on with the research?

If you wish to withdraw from the research at any time you can and you do not need to provide a reason. Please remember that there will be no detrimental effects on you or your care from the NHS. You and your family will still have access to services on the palliative care pathway.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Newcastle and North Tyneside 1 Research Ethics Committee.

What if there is a problem?

If there is a problem or you are not happy with the study please contact one of the researchers (contact details provided below) and we will do our best to answer any questions or queries you may have. We hope this is not the case, but if you are still unhappy and wish to complain formally, you can do this through the NHS complaints procedure or by contacting the Principal Supervisor, Dr. Anna Jones at Northumbria University.

Dr. Anna Jones [contact details]

NHS North of Tyne Complaints Procedure [contact details]

Additional Information

This study aims to identify how palliative care can be improved and provide best support to people with life limiting illnesses. If, for any reason, you are no longer able to provide us with any feedback once your interview is completed, we would still really value being able to use the questionnaire and consultation recording data. This is so that your experiences may help improve palliative care for other people. By agreeing to take part in the study, you are also giving consent for us to use your interview data at any point in the future, in relation to studying palliative care.

Contact details

If you have any concerns or would like further information about the study, please feel free to contact us.

Sonia Dalkin (Chief Investigator), [contact details]

Dr. Bill Cunningham, GP and Chair of the Palliative Care Partnership [contact details]

What happens now?

Many thanks for taking time to read about this study. If you would like to take part please fill in the reply slip below and return it using the stamped and addressed envelope enclosed within 2 weeks. Sonia Dalkin (chief investigator) will then send you the questionnaire and ask you to return it using the stamped and addressed envelope that we will provide. You will then meet with the researcher (Sonia Dalkin) before your consultation for her to explain the study in person, answer any questions you may have and collect your consent form.

✂ _____

I would be interested in taking part in the study, and hereby give permission to be contacted by a member of the research team. I understand that before taking part, I will need to fill in a consent form and that if I want I can withdraw from the study at any time. This will not affect my care from the NHS.

Name _____

Signature   _____

Date   _____

Home   address   to   send   questionnaire   to:

_____

_____

_____

_____

Name of GP _____

Appendix 27

Consent forms for MBSS and consultation recording for palliative care patients

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

Yes No

1. I confirm that I have read and understand the information sheet dated 16/12/11 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

☐ ☐

Yes No

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐ ☐

3. I agree to having my next consultation recorded by a digital voice recorder.

☐ ☐

Yes No

4. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for these individuals to have access to the data I provide.

☐ ☐

	Yes	No
5. I agree to my GP being informed of my participation in the study.	☐	☐

	Yes	No
6. I understand that my GP may ask me to take part in a further 2 consultation recordings but I do not have to take part if I do not want to.	☐	☐

	Yes	No
7. I agree to take part in the above study.	☐	☐

Name of Participant _____
Date _____
Signature _____

Name of Researcher _____
Date _____
Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone: ███████.

Invitation letter for MBSS and consultation recording for health care professional

Version 2

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Dear Health Professional,

You are invited to take part in this research study.

We are doing research into the new Palliative Care Integrated Care Pathway in [the locality]. It is a study funded by NHS North of Tyne Primary Care Trust and Northumbria University.

What will this study do?

This study is part of Sonia Dalkin's PhD at Northumbria University which investigates the new palliative care system in [the locality]. It hopes to find out new and interesting things about the system, including how it works, and who it works for (for example, patients, family, carers, GPs, nurses). It will also help the system improve itself, therefore improving palliative care as the study is taking place. This research is important as its overall aim is to inform and improve palliative care practice on both a local and national level so that individuals have open and easy access to the supportive care they need, which will ultimately lead to a peaceful death.

How could you take part?

If you are interested in taking part, we will ask you to fill in a questionnaire about how you cope with stressful health information. A recording of a consultation with a palliative care patient (who has also filled in the questionnaire and given their consent to be recorded) will then be taken.

What to do if you are interested in taking part and want more information?

If you would like to find out more information about the study, please take the time to read the **Information Sheet** included with this letter. This will give you more information about the study and what you would do if you participated. You may also contact the researcher if you would like to find out more information or ask questions. The contact details of Sonia Dalkin are at the end of this letter and in the information sheet.

If you have decided you do not want to take part in the study, you do not need to do anything.

Thank you for taking the time to read this letter.

Sonia Dalkin, Principal Researcher [contact details]

Information sheet for MBSS and consultation recording for health professionals

Version 3

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

Information Sheet

Part 1

We would like to invite you to take part in this research project. Before you make a decision about taking part we want to make sure you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and talk to others about the study if you wish. Part 1 will provide a brief summary of the research and part 2 will give more detailed information about the study.

If you have any difficulties, or need other help to understand the information please contact us and we will be happy to help. By taking part, you will be contributing to a local study that aims to make a real difference to life limiting illness and palliative care. This will be done through identification of pathway mechanisms that contribute to a successful outcome in an Integrated Care Pathway (ICP). This could then improve the quality of palliative care delivered in [the locality], and the rest of the county. Please take time to decide whether you would like to take part.

What is the purpose of the study?

[The locality] has created a new ICP which provides individuals who have life limiting illness with access to supportive palliative care including the best symptom control, shared decision making about treatment and generally increased choice about care, leading to a peaceful death with an individual's needs fully met. The ICP is now in place and as a health professional in [the locality] you have been selected as a potential participant due to your involvement with the ICP. This research wants to find out how the ICP works, for example, does it enable better communication between patients and GPs, or better planning and co-ordination? We also want to look at who the ICP is benefitting; does it benefit palliative care patients? Are families happy with it? Are health professionals happy with it? So, we would like to hear from patients, family members, carers and health professionals, in a variety of ways, about their experience of the ICP.

Why have I been invited to take part in the study?

You have been invited to take part as you are identified as a health professional in [the locality] who has worked closely with a palliative care patient who has agreed to take part in this study also.

Do I have to take part?

No, taking part in this study is voluntary and you do not have to take part. We will explain the study to you in this Information Sheet and if you have any questions or you are unsure whether you understand everything please feel free to contact us (our contact details are on the bottom of this information sheet). If you decide you would like to take part, we will ask you to fill in the reply slip at the bottom of this information sheet and return it to the chief investigator (Sonia Dalkin) with the stamped and addressed envelope provided.

If you take part and decide that you have changed your mind and no longer wish to be involved you can stop taking part and withdraw at any time. You do not need to provide a reason. There will be no detrimental effects on you, your patients, or your employment. Your pati9ents will still have access to the services on the palliative care pathway.

What will happen to me if I take part?

If you decide that you would like to take part in this research we would like you to complete and return the reply slip at the bottom of this information sheet. The chief investigator (Sonia Dalkin) will then send you a questionnaire that asks questions about how you cope in various situations. It is well known that we are all different, and that different people cope in different ways. We are trying to find out if the way that people cope (for example, wanting to ask lots of questions or not wanting to know everything at once) affects how successful a consultation is between a GP and a patient.

We will also ask you to confirm with us when your next consultation with your palliative care patient is (we will inform you which patient has agreed to take part in this study, and they will have already told us when their appointment with you is). We wish to know when this appointment is as we would like to digitally voice record it. We would ask that you bring the consent form provided in this pack with you to the consultation. This consent form will ensure sure that you understand what we are doing with the information you provide us with in the study.

Before the consultation, Sonia Dalkin will explain the study in person and answer any questions you or the patient may have. Your signed consent form will then be collected. Spare consent forms will also be available though we would prefer if you had ample time to read them before agreeing to participate. The interview will be recorded using a digital voice recorder. The consultation between you and your palliative care patient will be recorded using a digital voice recorder. The researcher (Sonia Dalkin) will not be sitting in on the consultation but will listen to the recording

afterwards. We understand that conversations about palliative care and death do not occur in one consultation, therefore you may ask to record up to 3 consultations (maximum) with one patient. The patient will give written consent at the beginning to the chief investigator (Sonia Dalkin) and there after you will confirm with the patient, whilst the audio recorder is taping, that they are still happy to be recorded and participate in the research. Additionally, at the end of the last recording you will have to confirm that they are still happy to participate and that it is ok to pass on the recording to the research team. Communication about palliative care has been reported as difficult by patients and GPs. So, we would like to see if this might be because professionals and patients might have a different approach to stressful situations. This questionnaire and audio recording of your consultation will help us discover this.

What will be the cost of taking part?

There will be no financial cost to taking part in this study. We will however ask for 1 hour (maximum) of your time.

How might taking part affect me?

You will not be at any physical risk in this study. The consultation between you and your palliative care patient will be a consultation that you would normally have any way. We would like you to please use this consultation like any normal appointment you would usually have with your palliative care patient. We cannot promise the study will help you personally but the information we get from this study will help improve the treatment of palliative care patients. If you do feel distressed or upset by the questionnaire you can contact Dr. Bill Cunningham who will be happy to talk to you about the study and provide support.

This completes Part 1 of the information sheet. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

Will taking part in the project be private and confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. This research is also for an educational project, as the chief investigator (Sonia Dalkin) is doing a PhD. All information you provide will be completely confidential in regards to this educational project. Anything that you provide will not be able to be traced back to you as you will be allocated a number instead of using your name in the study write up.

All information will be stored on a secure, password protected computer within Northumbria University. It will only be able to be accessed by Sonia Dalkin, (the chief investigator), Dr. Anna Jones (academic supervisor), Dr. Monique Lhussier (academic supervisor) and Dr. Bill Cunningham (academic supervisor and GP). All personal

information will be destroyed when the study ends (names will already have been replaced with a number and addresses will be destroyed) and any written and recorded information will be destroyed six years after the study ends.

Your palliative care patient will be told that you are taking part in the study, as they will be recorded during your consultation also.

Breaking confidentiality

If you tell us something during the study that suggests you or someone else is at serious risk of harm we would then have to breach confidentiality. This means that we would report the issue to someone who could help. We will however inform you that we are going to do this.

What will happen if I don't want to carry on with the research?

If you wish to withdraw from the research at any time you can and you do not need to provide a reason. There will be no detrimental effects on you, your patients or your employment. Your patients will still have access to services on the palliative care pathway.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Newcastle and North Tyneside 1 Research Ethics Committee.

What if there is a problem?

If there is a problem or you are not happy with the study please contact one of the researchers (contact details provided below) and we will do our best to answer any questions or queries you may have. We hope this is not the case, but if you are still unhappy and wish to complain formally, you can do this through the NHS complaints procedure or by contacting the Principal Supervisor, Dr. Anna Jones at Northumbria University. Both of their contact details are below:

Dr. Anna Jones [contact details]

NHS North of Tyne PCT compaints procedure [contact details]

Additional Information

This study aims to identify how palliative care can be improved and provide best support to people with life limiting illnesses. If, for any reason, you are no longer able to provide us with any feedback once your interview is completed, we would still really value being able to use the questionnaire and consultation recording data. This is so that your experiences may help improve palliative care for other people. By agreeing to take part in the study, you are also giving consent for us to use your interview data at any point in the future, in relation to studying palliative care.

Contact details

If you have any concerns or would like further information about the study, please feel free to contact us.

Sonia Dalkin (Chief Investigator), [contact details]

Dr. Bill Cunningham, GP and Chair of the Palliative Care Partnership [contact details]

What happens now?

Many thanks for taking time to read about this study. If you would like to take part please fill in the reply slip below and return it using the stamped and addressed envelope enclosed within 2 weeks. Sonia Dalkin (chief investigator) will then send you the questionnaire and you will return it using the stamped and addressed envelope we will provide. You will then meet with the researcher before your consultation for her to explain the study in person, answer any questions you may have and collect your consent form.

✂ _____

I would be interested in taking part in the study, and hereby give permission to be contacted by a member of the research team. I understand that before taking part, I will need to fill in a consent form and that if I want I can withdraw from the study at any time. If I withdraw this will have no effect on my employment or my patient's access to palliative care pathway services.

Name _____

Signature _____

Date _____

Address to send questionnaire to:
_____
_____
_____

Date of next consultation with GP _____

Appendix 30

Consent form for MBSS and consultation recording for health professional.

Version 1

Understanding integrated care pathways in palliative care – context, approaches, outcomes.

[A Research Study]

CONSENT FORM

Title of Project: Understanding integrated care pathways in palliative care – context, approaches, outcomes.

Name of Researcher: Sonia Dalkin

Please tick the appropriate box

Yes No

1. I confirm that I have read and understand the information sheet dated 16/12/11 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

Yes No

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I agree to having my next palliative care consultation being recorded by a digital voice recorder.

Yes No

Yes No

4. I agree for the researcher to take notes

	Yes	No
5. I understand that relevant sections of the data collected during the study may be looked at by the chief investigator (Sonia Dalkin) and her supervisory team (Dr. Anna Jones, Dr. Monique Lhussier, Dr. Bill Cunningham). I give permission for these individuals to have access to the data I provide.	☐	☐
6. I agree to _____ (palliative care patient) being informed of my participation in the study.	☐	☐
7. I agree to take part in the above study.	☐	☐

Name of Participant _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

If you would like more details about the project, please do not hesitate to contact the researcher, Sonia Dalkin, by email: sonia.dalkin@northumbria.ac.uk or by telephone: ▮▮▮▮▮▮▮▮.

Appendix 31- Miller Behavioural Style Scale

Miller Behavioural Style Scale (MBSS)

Version 1

Monitor/Blunter Style Scale

1.   Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check all of the statements that might apply to you.

I would ask the dentist exactly what work was going to be done.

I would take a tranquilizer or have a drink before going.

I would try to think about pleasant memories.

I would want the dentist to tell me when I would feel pain.

I would try to sleep.

I would watch all the dentist's movements and listen for the sound of the drill.

I would watch the flow of water from my mouth to see if it contained blood.

I would do mental puzzles in my mind.

2.   Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.

I would sit by myself and have as many daydreams and fantasies as I could.

I would stay alert and try to keep myself from falling asleep.

I would exchange life stories with the other hostages.

If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.

I would watch every movement of my captors and keep an eye on their weapons.

I would try to sleep as much as possible.

I would think about how nice it's going to be when I get home.

I would make sure I knew where every possible exit was.

3.   Vividly imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days. Check all of the statements that might apply to you.

I would talk to my fellow workers to see if they knew anything about what the supervisor evaluation of me said.

I would review the list of duties for my present job and try to figure out if I had fulfilled them all.

I would go to the movies to take my mind off things.

I would try to remember any arguments or disagreements I might have had that would have resulted in the supervisor having a lower opinion of me.

I would push all thoughts of being laid off out of my mind.

I would tell my spouse that I'd rather not discuss my chances of being laid off.

I would try to think which employees in my department the supervisor might have thought had done the worst job.

I would continue doing my work as if nothing special was happening.

4.   Vividly imagine that you are on an airplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check all of the statements that might apply to you.

I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.

I would make small talk with the passenger beside me.

I would watch the end of the movie, even if I had seen it before.

I would call for the flight attendant and ask what exactly the problem was.

I would order a drink from the flight attendant or take a tranquilizer.

I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary.

I would talk to the passenger beside me about what might be wrong.

I would settle down and read a book or magazine or write a letter.

This is the end of the questionnaire. Thank you very much for taking the time to fill it in. Could you now please give the questionnaire back to the researcher via email or post. Again, thank you for your time.

Sonia Dalkin [contact details]

Questionnaire validation

Results from an MBSS validation study showed that coping-style scores accurately predicted informational strategy, particularly with the monitoring dimension (Miller, 1987).

Appendix 32 - Correspondence with Dr. Miller

Hi:

I have been on travel and facing deadlines.

I am most interested in your study and would love to hear more.

I am ccing my assistant who will answer your questions.

Generally it is stable over time, if the situation remains consistent. So, yes it is a trait.

If there are changes in the situation, then monitors especially may react with more anxiety and less adaptive responding.

They don't change how they respond to the items on the questionnaire, but their strategies may change over time as the situation changes.

Also some people are in the middle (a subset, perhaps a quarter) so that they are more influenced by changes in the situation.

Hope this helps for now.

Please give us any further details. That would be helpful.

Dr. Suzanne Miller
Professor, Senior Member
Director, Psychosocial and BioBehavioral Medicine Department
Fox Chase Cancer Center
Robert C. Young Pavilion - Room 4149
333 Cottman Avenue
Philadelphia, Pennsylvania 19111
Tel: (215) 728-4069
Fax: (215) 214-1651
Email: suzanne.miller@fccc.edu

Administrative Assistant: Mary Anne Ryan

email: (maryanne.ryan@fccc.edu) Tel: (215)728-5296

FCCC webpage: http://www.fccc.edu/research/pid/miller/

Adjunct Professor, Department of Psychiatry, University of Pennsylvania
Adjunct Professor, Department of Medicine, Obstetrics and Gynecology, and Public Health, Temple University
Adjunct Professor, Institute for Health, Health Care Policy, and Aging Research, Rutgers University

Appendix 33 - University ethical approval

northumbria UNIVERSITY

Professor Kathleen McCourt FRCN Dean

This matter is being dealt with by:

Research and Enterprise Office

School of Health, Community & Education Studies

Sonia Dalkin

17 The Orchard
Hepscott
Morpeth
Northumberland

NE61 6HT

Room H007

Coach Lane Campus East

Newcastle upon Tyne

NE7 7XA

Tel: 0191 215 6701

Fax: 0191 215 6083

E-mail: julie.blackwell@northumbria.ac.uk

28th September 2011

Dear Sonia

School of HCES Research Ethics Sub Committee

Title: Understanding integrated care pathways in palliative care - context, approaches, outcomes

Following independent peer review of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent CRB and occupational health clearance if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available from the following web link:
http://www.northumbria.ac.uk/researchandconsultancy/sa/ethgov/policies/?view=Standard

It is recommended that you submit the additional information regarding the clinical database to the NHS REC committee. Both the University and NRES strongly advise that the supervisor accompany the student when attending an external REC.

You may now also proceed with your application (if applicable) to:

- NHS R&D organisations for approval. Please check with the NHS Trust whether you require a Research Passport, Letter(s) of Access or Honorary contract(s).
- NHS Research Ethics Committee (REC). [They will require a copy of this letter plus the ethics panel comments and your response to those comments]. If your research is subject to external REC approval, a 'favourable opinion' must be obtained prior to commencing your research. You must notify the University of the date of that favourable opinion.

All researchers must also notify this office of the following:

- Commencement of the study;
- Actual completion date of the study;
- Any significant changes to the study design;
- Any incidents which have an adverse effect on participants, researchers or study outcomes;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely

Professor David Stanley

Chair, School Research Ethics Review Panel

421

Appendix 34 - NHS ethical approval

NHS
Health Research Authority

NRES Committee North East - Newcastle & North Tyneside 1

TEDCO Business Centre
Room 002
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 428 3564
Facsimile: 0191 428 3432

13 December 2011

Miss Sonia Dalkin
17 The Orchard
Hepscott
Morpeth
NE61 6HT

Dear Miss Dalkin

Study title: Understanding an integrated care pathway in palliative care – context, approaches, outcomes.
REC reference: 11/NE/0318
Protocol number: N/A

Thank you for your letter of 29 November 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternate Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

A Research Ethics Committee established by the Health Research Authority

Appendix 35 - Care home end-of-life care plan

`

RESIDENT'S FULL NAME:

We aim to care for people for the remainder of their lives. We are keen that we *respect Resident's and Relatives wishes with all aspects of their care and life* during their time at here. It is particularly important that we have plans in place to ensure that we respect and meet the wishes of the Resident and Relatives during the final stages of their life. Because we cannot predict when this will be it is important that we consider this in advance in order that we have plans in place.

RESUSCITATION:

Is there a 'Do Not Attempt Resuscitation' (DNAR) Form in Place?   Yes / No

If no is it you decision that you wish us to attempt Resuscitation?   Yes / No

---

If it is the wish of the Resident and their Relative every effort will be made by staff to care for the Resident at Burn Brae Lodge in the final stages of their life. This will include obtaining the support from community services such as the GP, District Nurses and MacMillan Nurses.

 Where would you like to be cared for at this time?   Burn Brae Lodge / Hospital / Hospice

Do you have a living will / advance directive?   Yes / No

If yes please give details and where this is held

If the medical opinion is that treatment is unlikely to be effective would you wish that:

(a) Every effort is made to treat the condition
Or

(b) Medical intervention is limited to relieving pain and keeping me / the resident comfortable

---

(Delete which **does not** apply)

Do you have any other wishes about medical intervention (for example no blood products etc.)?

Yes / No

If yes please give details

We hope that relatives and family feel able to be involved at this time if this is the residents and relatives wish.

Please detail below any particular wishes for family involvement and who you wish to be contacted:

Are there any religious issues that you would like to be observed during and / or after your life has ended? If so give details:

What are your final wishes? Burial / Cremation / Medical Science

Does anyone have Enduring Power of Attorney for you? If yes please give details:

Who will make the final arrangements for you?

Are there any other wishes or comments you would like to make for your care at this time?

SIGNED:	**DATE**
NAME:	
STATUS:	
IF RELATIVE DO YOU HAVE POWER OF ATTORNEY FOR CARE? YES / NO	
STAFF SIGNATURE:	
NAME:	
POSITION:	
	DATE

Appendix 36 – permission to use Greenghalgh, Robert et al., (2004) figure

Dear Sonia,

Thank you for your request.

Permission is granted for you to use the material requested for your thesis/dissertation subject to the usual acknowledgements and on the understanding that you will reapply for permission if you wish to distribute or publish your thesis/dissertation commercially.

Permission is granted solely for use in conjunction with the thesis, and the material may not be posted online separately.

Any third party material is expressly excluded from this permission. If any material appears within the article with credit to another source, authorisation from that source must be obtained.

Kind Regards

Emma Willcox

Permissions Assistant

Description: Description: cid:image003.jpg@01CD4E24.F19D75F0

Appendix 37 – Soft System Methodology Map

Worldwide view
- National EOL care strategy
- Mental capacity act
- Gold Standards Framework
- Society's view of death and dying
- Patient Centred Care – Shared Decision Making?
- GMC guidance, Deciding right documentation, Royal College of Physicians guidance

Owners (who could stop the Transformation?)
- Commissioners
- Unengaged/uninformed organisations (social care, GP practices, NDUC?)
- Patients and family – denial
- Oncologists/Radiotherapists
- Dementia patients

Environmental Constraints
- Time to complete a Care Plan (lengthy document)
- Uncertainty of documentation (focus group 1 – unsure where to record, desire for a simpler document)
- Cquin Targets for nurses (now include Advance Care Planning)
- Options available (removal of CS, TDHH reduced funding).

Input
- Engaged HP (believes in value of Care Planning, recognises a patient with the need for CP and is willing to give time to CP) motivation?
- A developed practitioner-patient relationship (Key worker GP/nurse)
- Timely discussions
- Receptive patient
- Skilled communication with patient

Transformation
Care Planning

Includes:
Preference Discussion
ACP
Advance Statements,
DNAR

Output
- Less inappropriate hospital admissions
- Shared Knowledge (patients, families, HPs - including social care, OOH notification)
- Clarity (for patient, family and system)
- Increased patient choice (depending on options available)
- Increase in coordinated care
- Patient empowerment (patient held document)
- Increased job satisfaction for HPs

Actors
- GPs (commissioned to under take Care Planning)
- Community Matrons (more often informal – preference discussion but introduction of Cquin target may change this?).

Customers
Direct: Patient and families
Indirect: HCP, Secondary care activity (less admissions and earlier discharges) & commissioners (achieving strategic objectives/financial balance)

426

References

Abarshi, E., et al. (2009). "General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands." Journal of Pain and Symptom Management **38**: 568-577.

Addicott, R. and S. Ross (2010). Implementing the end of life care strategy: lessons for good practice.

Addington-Hall, J. (1998). Reaching Out: Specialist Palliative Care for Adults with Non-malignant Diseases. London, NSHSPCS and Scottish Partnership

Agency for Palliative and Cancer Care.

Addington-Hall, J. and K. Hunt (2012). Non-cancer patients as an underserved group. A Public Health Perspective on End of Life Care. J. Cohen and L. Deliens. Oxford UK, Oxford University Press**:** 151 - 159.

Agar, M., et al. (2008). "Preference for place of care and place of death in palliative care: are these different questions?" Palliative Medicine **22**(7): 787-795.

Alexander, D. and E. Ritchie (1990). "''Stressors'' and difficulties in dealing with the terminal patient." Journal of Palliative Care **6**: 28-33.

Altheide, D. and J. Johnson (2011). Reflections on interpretive adequacy in qualitative research. The SAGE handbook of qualitative research**:** 581-594.

Alzheimer's Society (2013). "Demography." Retrieved 16.07.2013, from http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=412.

Anderson, R. (1995). "Patient empowerment and the traditional medical model. A case of irreconcilable differences? ." Diabetes Care **18**: 412-415.

Archer, M. (1995). Realist Social Theory: the Morphogenic Approach. Cambridge Cambridge University Press.

Archer, M., et al., Eds. (1998). Critical Realism: Essential Readings. London, Routledge.

Arnold, L., et al. (2012). "Patients who do not nominate a preferred place of death are more likely to die in hospital." BMJ Support Palliative Care **2**(9).

Atwal, A. and K. Caldwell (2002). "Do multidisciplinary integrated care pathways improve interprofessional collaboration?" Scandinavian Journal of Caring Sciences **16**(4): 360-367.

Austin, E. (1981). Guidelines for the Developing of Continuing Education Offerings for Nurses. New York, Appleton-Century-Crofts

Australian Council for Safety and Quality in Health Care (2005). National Patient Safety Education Framework Canberra, Australia.

Ayer, A. (1959). Logical positivism. New York, The Free Press.

Bailey, A., et al. (2005). "Improving Processes of Hospital Care During the Last Hours of Life." Archives of Internal Medicine **165**(15): 1722-1727.

Bakitas, M., et al. (2009). "Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer: The Project ENABLE II Randomized Controlled Trial." Americal Medical Association **302**(7): 741-749.

Balster Liontos, L. (1994). "Shared Decision-Making." ERIC Digest **87**.

Bandura, A. (1977). "Self-efficacy. Towards a unifying theory of behaviour change." Psychological Review **84**: 191-215.

Bandura, A. (1991). Self-efficacy mechanism in physiological activation and health-promoting behavior. Neurobiology of Learning, Emotion and Affect. . J. Madden. New York, Raven Press,**:** 229-269.

Barclay, S. (2010). "Having the difficult conversations about the end of life." British Medical Journal **341**(c4862).

Bardsley, M., et al. (2012). "Overlap of hospital use and social care in older people in England." Journal of Health Service Research and Policy **17**(3): 133–139.

Barnett, J., et al. (2011). "Understanding innovators' experiences of barriers and facilitators in implementation and diffusion of healthcare service innovations: a qualitative study." BMC Health Service Research **11**(342).

428

Barriball, K. and A. While (1994). "Collecting data using a semi-structured interview: a discussion paper " Journal of Advanced Nursing **19**: 328-335.

BBC News (2011). "Extreme world: Dying." Retrieved 29.07.2013, from http://www.bbc.co.uk/news/world-12355802.

BBC News (2013). "Liverpool Care Pathway: 'They told my family I was dying'." Retrieved 04.11.13, from http://www.bbc.co.uk/news/health-23698071.

Bean, W. B. (1961). "Peace at the last. A Survey of Terminal Care in the United Kingdom; A Report to the Calouste Gulbenkian Foundation " Archives of Internal Medicine **107**(4): 631-632.

Bell, D. (2010). "GMC guidance on end of life care." British Medical Journal **340**(c3231).

Bergman, M. (2008). The Straw Men of the Qualitative-Quantitative Divide and their Influence on Mixed Methods Research. Advances in Mixed Methods Research: Theories and Applications. M. Bergman. London, Sage Publicatons.

Bhaskar, R. (1978). A realist theory of science. Brighton, Harvester Press.

Bhaskar, R. (1979). The Possibility of Naturalism: A philosophical Critique of the Contemporary Human Sciences. Brighton, Harvester Press.

Bhaskar, R., Ed. (2002). From Science to Emancipation: Alientation and the Actuality of Enlightenment. Thousand Oaks, CA, Sage.

Blaikie, N. (2007). Approaches to Social Enquiry. Cambridge Polity Press.

Bonk, V., et al. (2001). "Distraction Reduces Self-Reported Physiological Reactions to Blood Donation in Novice Donors With a Blunting Coping Style." Psychosomatic Medicine **63**: 447-452

Bookbinder, M., et al. (2005). "Improving end-of-life care: development and pilot-test of a clinical pathway." Journal of Pain and Symptom Management **29**(6): 529-543.

Bower, B., et al. (2010). "Improving integrated team working to support people to die in the place of their choice." Nursing Times **106**(32): 14-16.

Boyatzis, R. (1998). Transforming qualitative information: Thematic analysis and code development. Thousand Oaks, CA, Sage.

429

Braddock, C., et al. (1999). "Informaed Decision Making in Outpatient Practice: Time to Get Back to Basics." Journal of the American Medical Association **282**(2313-2320).

Bradley, J. and S. Cartwright (2002). "Social support, job stress, health, and job satisfaction among nurses in the

United Kingdom." International Journal of Stress Management **9**: 163-182.

Braun, V. and V. Clarke (2006). "Using thematic analysis in psychology." Qualitative Research in Psychology **3**(2): 77-101.

Breen, C., et al. (2001). "Conflict associated with decisions to limit life-sustaining treatment in intensive care units." Journal of General Internal Medicine **16**(5): 283-289.

Brennan, F. (2007). "Palliative Care as an International Human Right " Journal of Pain and Symptom Management **33**: 494-499.

Brower, V. (2005). "The squeaky wheel gets the grease." EMBO reports **6**(11): 1014-1017.

Brumley, R., et al. (2003). "Effectiveness of a home-based palliative care program for end-of-life." Journal of Palliative Medicine **6**: 715-724.

Buckman, R. (1984). "Breaking bad news: Why is it still so difficult? ." British Medical Journal **288**: 1597-1599.

Burns, F., et al. (2008). "Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK." AIDS **22**: 115-122.

Burt, J., et al. (2013). "Care plans and care planning in long-term conditions: a conceptual model." Primary Health Care Research & Development.

Caley, M. and K. Sidhu (2011). "Estimating the future healthcare costs of an aging population in the UK: expansion of morbidity and the need for preventative care." Journal of Public Health **33**(1): 117-122.

Campbell, D. and J. Stanley (1963). Experimental and quasiexperimental designs for research. Chicago, IL, Rand McNally.

Campbell, H., et al. (1998). "Integrated Care Pathways." British Medical Journal **316**: 133-137.

Campion, P., et al. (2002). "Patient Centredness in the MRCGP Video Examination: Analysis of a Large Cohort." British Medical Journal **325**(691-692).

Cardiff University (2013). "Festival of death to confront end-of-life taboos." Retrieved 31.07.2013, from http://www.cardiff.ac.uk/news/articles/festival-of-death-to-confront-end-of-life-taboos-10916.html.

Carter, B. and C. New (2004). Making Realism Work: Realist Social Theory and Empirical Work. . London, Routledge.

Cartwright, A. and R. Anderson (1979). Patients and their Doctors: 1977. London, The Royal College of General Practitioners. **8**.

Cattell, R. B. (1966). Anxiety and motivation: Theory and crucial experiments. . Anxiety and behavior. C. Spielberger. New York, Academic Press**:** 23-62.

Chan, R. and J. Webster (2010). "End-of-life care pathways for improving outcomes in caring for the dying (Review)." The Cochrane Library(11).

Charles, C., et al. (1997). "Shared decision-making in the medical encounter: waht does it mean? (or it takes at least two to tango)." Social Science & Medicine **44** (5): 681-692.

Charles, C., et al. (1999). "Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model." Social Science & Medicine **49** 651-661.

Chassin, M. and J. Leob (2011). "The Ongoing Quality Improvement Journey: Next Stop, High Reliability." Health Affairs **30**(4): 559-568.

Checkland, P. and J. Scholes, Eds. (1992). Soft Systems Methodology in Action Chichester, Wiley.

CINAHL (2013). "CINAHL with Full Text." from http://web.ebscohost.com/ehost/search/advanced?sid=ad9b8ae6-c658-4f3c-9c2c-3b75da59b722%40sessionmgr4001&vid=1&hid=4207.

Clark, D. (1998). "Originating a movement: Cicely Saunders and the development of St Christopher's Hospice 1957-67." Mortality **3**: 43–63.

Clark, D. (1999). "Cradle to the grave? Terminal care in the United Kingdom 1948-67." Mortality **4**(3): 225-247. .

Clark, D. (2004). History, gender and culture in the rise of palliative care. <u>Palliative care nursing. Principles and evidence for practice</u>. S. Payne, J. Seymour and I. Ingleton. Maidenhead, Open University Press**:** 39-54.

Clark, D. (2007). "From margins to centre: a review of the history of palliative care in cancer." <u>Lancet Oncology</u> **8**: 430-438.

Clark, D. and J. Seymour (1999). <u>Reflections on palliative care: sociological and policy perspectives</u>. Buckingham, Open University Press.

Clark, D., et al. (2005). <u>A bit of heaven for the few? An oral history of the hospice movement in the United Kingdom</u>. Lancaster, Observatory Publications.

Cohen, J. (1988). <u>Statistical power analysis for the behavioral sciences</u> Hillsadle, NJ, Lawrence Erlbaum Associates.

Collier, A. (1994). <u>Critical Realism: an Introduction to Roy Bhaskar's Philosophy</u>. London, Verso.

Costanzo, E., et al. (2009). "Psychosocial Adjusmtnet Among Cancer Survivors: Findings From a National Survey of Health and Well-Being." <u>Health Psychology</u> **28**(2): 147-156.

Coulter, A. (2002). <u>The Autonomous Patient: Ending Paternalism in Medical Care</u>. London, Nuffield Trust.

Coulter, A. (2006). <u>Engaging patients in their healthcare. How is the UK doing relative to other countries</u>. Oxford, Picker Institute Europe.

Coulter, A. (2010). "Do patients want a choice and does it work? ." <u>British Medical Journal</u> **341**: 973-975.

Creswell, J. (2003). <u>Qualitative, Quantitative and Mixed Methods Approaches</u>. London, Sage Publiactions.

Croucher, M. (2005). "An evaluation of the quality of integrated care pathway development in the UK National Health Service." <u>Journal of Integrated Care Pathways</u> **9**: 6-12.

Curtis, J. R., et al. (2002). "A measure of the quality of dying and death: initial validation using after-death interviews with family members " <u>Journal of Pain Symptom Management</u> **24**: 17-30.

432

Daily Mail (2013). "Revealed: How GPs are paid £50 bonus to put elderly on 'death lists'." Retrieved 04.11.13, from http://www.dailymail.co.uk/news/article-2468112/Revealed-How-GPs-paid-50-bonus-elderly-death-lists.html.

Dalkin, S. M., et al. (2012). "Understanding integrated care pathways in palliative care using realist evaluation: a mixed methods study protocol." BMJ Open **2**(e001533).

de Haes, H. and N. Koedoot (2003). "Patient centered decision making in palliative cancer treatment: a world of paradoxes." Patient Eduaction and Counselling **50**(1): 43-49.

De Luc, K. (2001). Developing care pathways - the handbook. Oxford, Radcliffe Medical Press.

Delvin, K. (2009). Controversial 'death' pathway. The Daily Telegraph.

Denning, J. and C. Verschelden (1993). "Using the focus group in assessing training needs: empowering child welfare workers." Child Welfare **72**: 569-579.

Department of Health (2005). "Mental Capacity Act."

Department of Health (2008). Advance Care Planning: A Guide for Health and Social Care Staff.

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.

Detering, K., et al. (2010). "The impact of advance care planning on end of life in elderly patients: randomised controlled trial." British Medical Journal **340**(c1345).

Doumit, G., et al. (2011). "Opinion leaders and changes over time: a survey." Implementation Science **6**(117).

Doyle, D. and R. Woodruff (2008). The IAHPC manual of palliative care Palliative Care in Clinical Practice. G. Zeppetella. London Springer.

Duke, G. and S. Thompson (2007). "Knowledge, attitudes and practices of nursing personnel regarding advance directives." International Journal of Palliative Nursing **13**: 109-117.

Earle, C. (2006). "Do Unto Others..." American Society of Clinical Oncology **24**(21): 3331-3332.

433

Ellershaw, J., et al. (1997). "Developing an integrated care pathway for the dying patient." European Journal of Palliative Care **4**: 203-207.

Ellershaw, J., et al. (2007). "Benchmarking: a useful tool for informing and improving care of the dying?" Supportive Care in Cancer **16**(7): 813-819.

Ellershaw, J. and D. Murphy (2005). "The Liverpool Care Pathway (LCP) influencing the UK national agenda on care of the dying." International Journal of Palliative Nursing **11**: 132-134.

Ellershaw, J. and C. Ward (2003). "Care of the dying patient: the last hours or days of life." British Medical Journal **326**: 30-34.

Ellershaw, J. and C. Ward (2003). "Care of the dying patient: the last hours or days of life." British Medical Journal **326**(7379): 30-34.

Elwyn, G., et al. (1999). "Shared decision-making in primary care: the neglected second half of the consultation." British Journal of General Practice **49**: 477-482.

Elwyn, G., et al. (2000). "Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices." British Journal of General Practice **50**: 892-897.

Elwyn, G., et al. (2003). "Shared Decision Making: Developing the OPTION Scale for Measuring Patient Involvement." Quality and Safety in Health Care **12**: 93-99.

Elwyn, G., et al. (2010). "Implementing shared decision making in the NHS." British Medical Journal **341**: 971-972.

Entwistle, V. and A. Cribb (2013). Enabling people to live well. Fresh thinking about collaborative approaches to care for people with long-term conditions. London, The Health Foundation.

Eve, A., et al. (1997). "Hospice and palliative care in the UK 1994-95, including a summary of trends 1990-95." Palliative Medicine **11**: 31–43.

Exton Smith, A. N. (1961). "Terminal illness in the aged." Lancet **5**: 305-308.

Eyre, S. (2010). "Supporting informal carers of dying patients: the district nurse's role." Nursing Standard **24**(22): 43-48.

Ferlie, E. and S. Shortell (2001). "Improving the Quality of Health Care in the United Kingdom and the United States: A framework for Change " The Milbank Quarterly **79**(2): 281-315.

Ferrer, R. and J. Gill (2013). "Shared Decision Making, Contextualized." Annuals of Family Medicine **11**(4): 303-305.

Finch, T., et al. (2012). "From theory to 'measurement' in complex interventions: methodological lessons from the development of an e-health normalisation instrument." BMC Medical Research Methodology **12**(69).

Forder, J. and J. Fernandez (2011). Length of stay in care homes, Report commissioned by Bupa care services, PSSRU Discussion Paper 2769. Canterbury, PSSRU.

Fowell, A., et al. (2004). "Cluster randomisation or randomised consent as an appropriate methodology for trials in palliative care: a feasibility study [ISRCTN60243484]." BMC Palliative Care **3**(1): 1.

Froggatt, K. and L. Hoult (2002). "Developing palliative care practice in nursing and residential care homes: the role of the clinical nurse specialist." Journal of Clinical Nursing **11**: 802-808.

Gardiner, C., et al. (2011). "Exploring the transition from curative care to palliative care: a systematic review of the literature." BMJ Supportive and Palliative Care **1**: 56-63.

Gattellari, M., et al. (1999). "Misunderstanding in cancer patients: Why shoot the messenger?" Annals of Oncology **10**: 39-46.

Gattellari, M., et al. (2001). "Sharing decisions in cancer care." Social Science & Medicine **52**: 1865-1878.

General Medical Council (2008). Consent: Patients and Doctors Making Decisions Together. London

General Medical Council (2010). Treatment and care towards the end of life: good practice in decision-making.

Gillies, C., et al. (1995). "Balancing proactive and reactive care." Royal College of General Practitioners **71**: 15-18.

Gillon, R. (1994). "Medical ethics: four principles plus attention to scope." British Medical Journal **309**: 184-188.

Glaser, B. and A. Strauss (1968). Time for dying. Chicago, Illinois, Aldine Publishing.

Godolphin, W. (2009). "Shared Decision Making " Healthcare Quarterly **12**(Special Issue): e186-190.

Gomes, B., et al. (2011). Local preferences and place of death in regions within England. Cicely Saunders International.

Gomes, B. and I. Higginson (2006). "Factors influencing death at home in terminally ill patients with cancer: systematic review." BMJ Support Palliative Care **332**(7548): 1012.

Gomes, B. and I. Higginson (2008). "Where people die (1974-2030): past trends, future projections and implications for care." Palliative Medicine **22**(33).

Goodrich, J. and J. Cornwall (2008). Seeing The Person in The Patient: The Point of Care. London., The King's Fund.

Gordon, R. (1975). Interviewing: Strategy, Techniques and Tactics. Illinois, Dorsey Press.

Gott, M., et al. (2011). "Transitions to palliative care in acute hospitals in England: qualitative study." British Medical Journal **342**(d1773).

Graham, H. and B. Livesley (1983). "Dying as a diagnoses: difficulties of communication and management in elderly patients." The Lancet **322**(8351): 670–672.

Graham, N. (1995). Quality in health care Aspen, Aspen Publishers.

Grande, G. and G. Ewing (2008). "Death at home unlikely if informal carers prefer otherwise: implications for policy." Palliative Medicine **22**: 971–972.

Grande, G., et al. (2009). "Supporting lay carers in end of life care: current gaps and future priorities." Palliative Medicine **23**: 339-344.

Grande, G., et al. (1997). "Support needs in the last year of life: patient and carer dilemmas." Palliative Medicine **11**(3): 202-208.

Grau, R., et al. (2001). "Moderator effects of self-efficacy on occupational stress." Psychology in Spain **5**(1): 63-74.

436

Greenhalgh, T., et al. (2004). "Diffusion of Innovations in Service Organizations: Systematic Review and Recommendations." The Milbank Quarterly **82**(4): 581-629.

Groer, G. (1955). "The Pornography of Death." Encounter: 49-52.

Guba, E. and Y. Lincoln (1989). Fourth generation evaluation. Newbury Park, CA, Sage.

Guba, E. and Y. Lincoln (1994). Competing paradigms in qualitative research. Handbook of Qualitative Research. Thousand Oaks CA, Sage.

Hales, S., et al. (2010). "The quality of dying and death: a systematic review of measures." Palliative Medicine **24**(2): 127-144.

Hall, S., et al. (2011). "Implementing a quality improvement programme in palliative care in care homes: a qualitative study." BMC Geriatrics **11**(31).

Hansford, P. and H. Meehan (2007). "Gold Standards Framework: Improving Community Care." **1**(3).

Hanson, L., et al. (1997). "What is wrong with end-of-life care? Opinions of bereaved family members." Journal of the American Geriatrics Society **45**: 1339-1344.

Hanson, L., et al. (1997). "Can clinical interventions change care at the end of life? ." Annals of Internal Medicine **126**: 381-388.

Harre, R. (1978). Social Being: a Theory for Social Psychology. Oxford, Blackwell.

Harris, J., et al. (2012). "Drawbacks and benefits associated with inter-organisational collaboration along the discovery-development-delivery continuum: a cancer research network case study." Implementation Science **7**(69).

Hedstom, P. and R. Swedberg, Eds. (1998). Social Mechanisms: an Analytical Approach to Social Theory. Cambridge, Cambridge University Press.

Hibbard, J., et al. (2004). "Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers." Health Service Research **39**: 1005-1026.

Higginson, I. (1997). Palliative and terminal care: health care needs assessment. Abingdon, UK, Radcliffe Medical Press.

Hockley, J., et al. (2010). "The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an indepth evauation " <u>Palliative Medicine</u> **24**(8): 828-838.

Hoffman, J. C., et al. (1997). "Patient Preference for communication with physicians about end-of-life decisions." <u>Annals of Internal Medicine</u> **127**: 1-12.

Hotchkiss, R. (1997). "Integrated care pathways." <u>Journal of Research in Nursing</u> **2**(1): 30-36.

Hughes, J. and L. Robinson (2004). "General practice perspectives: coordinating end-of-life care. ." <u>Nursing Residential Care</u> **6**: 601-604.

Hulbert, N. and V. Morrison (2006). "A preliminary study into stress in palliative care: Optimism, self-efficacy and social support." <u>Psychology, Health and Medicine</u> **11**(2): 246–254.

Humphreys, C. (2001). "Waiting for the last summons: the establishment of the first hospices in England: 1878-1914." <u>Mortality</u> **6**: 146-166.

Hunter, D. (1983). "Promoting innovation in the NHS." <u>British Medical Journal</u> **286**: 736-738.

Innes, A., et al. (2006). <u>Promoting Person-centred Care at the Front Line</u>. York, Joseph Rowntree Foundation.

Institute of Medicine (2001). Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC

Izumi, S., et al. (2012). "Defining end-of-life care from perspectives of nursing ethics." <u>Nursing Ethics</u> **19**(5): 608-618.

Jagosh, J., et al. (2013). "Critical reflections on realist review: insights from customizing the methodology to the needs of participatory research assessment." <u>Research Synthesis Methods</u>.

Jansen, S., et al. (2001). "Patients' preferences for adjuvant chemotherapy in early-stage breast cancer: is treatment worthwhile?" <u>British Journal of Cancer</u> **84**: 1577-1585.

Johnson, B. and A. J. Onwuegbuzie (2004). "Mixed Methods Research: A Research Paradigm Whose Time Has Come." <u>Educational Researcher</u> **33**(7): 14-26.

438

Joos, S., et al. (1993). "Outpatients' attitudes and understanding regarding living wills." Journal of General Internal Medicine **8**: 259-263.

Joosten, E., et al. (2008). "Systematic Review of the Effects of Shared Decision-Making on Patient Satisfaction, Treatment Adherence and Health Status." Psychotherapy and Psychosomatics **77**: 219–226.

Justice (2007). "Mental Capacity Act.". Retrieved 12.01.13, 2013, from http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

Kelner, M. and I. Bourgeault (1993). "Patient control over dying: responses of health care professionals." Social Science & Medicine **36**: 757-765.

Kitchiner, D. and P. Bundred (1996). "Integrated care pathways." Archives of Disease in Chidhood **75**: 166-168.

Kitzinger, J. (1995). "Introducing focus groups." British Medical Journal **311**: 299-302.

Koffman, J. (2012). Social Inequalities at the end of life. A Public Health Perspective on End of Life Care. J. Cohen and L. Deliens. Oxford UK, Oxford University Press**:** 183-194.

Kon, A. (2012). "Difficulties in judging patient preferences for shared decision-making." Journal of Medical Ethics **38**: 719-720.

Konrad, T., et al. (2010). "It's about time: physicians' perceptions of time constraints in primary care medical practice in three national healthcare systems." Medical Care **48**(2): 95-100.

Länsisalmi, H., et al. (2006). "Innovation in healthcare: A systematic review of recent research." Nursing Science Quarterly **19**(1): 66-72.

Lee, R. (2008). "Modernity, Mortality and Re-Enchantment: The Death Taboo Revisited." Sociology **42**(4): 745-759.

Légaré, F., et al. (2010). "Interventions for improving the adoption of shared decision making by healthcare professionals." The Cochrane Library **5**.

Leming, M. and G. Dickinson (2010). Understanding dying, death, & bereavement. Wandsworth, Cengage Learning.

439

Levinson, W., et al. (1997). "Physician-patient communication: the relationship with malpractice claims among primary care physicians and surgeons." Journal of the American Medical Association **277**(553-559).

Ley, P., et al. (1973). "A method for increasing patient recall of information presented to them." Psychological Medicine **3**: 217–220.

Lincoln, Y. and E. Guba (1985). Naturalistic inquiry. Beverly Hills, CA, Sage.

Little, P., et al. (2001). "Preferences of patients for patient centred approach to consultation in primary care: observational study." British Medical Journal **322**: 1-7.

Locality North East Clinical Commissioning Group (2012). Final Report. The new Palliative Care Pathway in (locality).

Locock, L., et al. (2001). "Understanding the role of opinion leaders in improving clinical effectiveness." Social Science & Medicine **53**(6): 745-757.

Luhrs, C., et al. (2005). "Pilot of a pathway to improve the care of imminently dying oncology inpatients in a Veterans Affairs Medical Center." Journal of Pain and Symptom Managment **29**(6): 544-551.

Lunney, J. R., et al. (2003). "Patterns of Functional Decline at the End of Life." Journal of the American Medical Association **289**: 2387-2392.

Luptak, M. and C. Boult (1994). "A method for increasing elder's use of advance directives." Gerontologist **34**: 409-412.

Maddams, J., et al. (2011). "Levels of acute health service use among cancer survivors in the United Kingdom." European Journal of Cancer **47**(14): 2211-2220.

Manley, K, et al. (2011). "Person-centred care: Principle of Nursing Practice D." Nursing Standard **25** (31): 35-37.

Markson, L., et al. (1994). "Implementing advance directives in the primary care setting." Archives of Internal Medicine **154**: 2321-2327.

Martin, D., et al. (1999). "A New Model of Advance Care Planning: Observations From people With HIV " Archives of Internal Medicine **159**: 86-92.

440

Matsuyama, R., et al. (2006). "Why Do Patients Choose Chemotherapy Near the End of Life? A Review of the Perspective of Those Facing Death From Cancer." American Society of Clinical Oncology **24**(21): 3490-3496.

Maxwell, S. and H. Delaney (2004). Designing experiments and analyzing data. Mahwah, NJ, Lawrence Erlbaum.

May, C. and T. Finch (2009). "Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory." Sociology **43**(3): 535-554.

Mayor, S. (2008). "UK audit shows need for greater caution with chemotherapy in very sick patients." British Medical Journal **337**(a2498).

McCall, K. and A. Rice (2005). "What influences decisions around the place of care for terminally ill cancer patients? ." International Journal of Palliative Nursing **11**(10): 541-547.

McCormack, B. and T. McCance (2010). Person-centred Nursing: Theory and Practice. Oxford.

McCormack, L., et al. (2011). "Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach." Social Science & Medicine **72**: 1085-1095.

McCusker, J. (1984). "The terminal period of cancer: definition and descriptive epidemiology." Journal of Chronic Diseases **37**(5): 377-385.

McEvoy, R., et al. (2014). "A qualitative systematic review of studies using the normalization process theory to research implementation processes." Implementation Science **9**(2).

McLaughlin, C. K., AD (1994). Continuous quality improvement in health care. . Aspen, Aspen Publishers

Mead, N. and P. Bower (2000). "Patient-centredness: A conceptual framework and review of the empirical literature." Social Science & Medicine **51**: 1087-1110.

Meier, D., et al., Eds. (2010). Palliative Care: Transforming the Care of Serious Illness San Francisco, Jossey-Bass.

Miles, S., et al. (1996). "Advance end-of-life treatment planning." Archives of Internal Medicine **156**(1066).

Miller, S. (1980). When is a little information a dangerous thing? Coping with stressful events by monitoring versus blunting. <u>Coping and health</u>. S. Levine and H. Ursin. New York, Academic Press**:** 204-256.

Miller, S. (1987). "Monitoring and blunting: validation of a questionnaire to assess styles of information seeking under threat." <u>Journal of Personality and Social Psychology</u> **52**: 345-353.

Miller, S. M. (1995). "Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. ." <u>Implications for cancer screening and management</u> **Cancer**(76): 2.

Miller, S. M., et al. (1996). "Applications of the Monitoring Process Model to Coping With Severe Long-Term Medical Threats." <u>Health Psychology</u> **15**(3): 216-225.

Miller, S. M., et al. (1994). "Effects of coping on psychological reactions of low income minority women of colposcopy." <u>Journal of Reproductive Medicine</u> **39**: 711-718.

Mills, M., et al. (1994). "Care of dying patients in hospital." <u>British Medical Journal</u> **309**: 583-586.

Mirando, S., et al. (2005). "Introducing an integrated care pathway for the last days of life." <u>Palliative Medicine</u> **19**(1): 33-39.

Morgan, D. (1996). "Focus Groups." <u>Annual Review of Sociology</u> **22**: 129-152.

Morrison, D. and F. Mair (2012). "Telehealth in practice: using Normalisation Process Theory to bridge the translational gap." <u>Primary Care Respiratory Journal</u> **20**(4): 351-352.

MSN News (2013). "'Death Café' events: Tackling a taboo topic over tea." Retrieved 31.07.2013, from <u>http://news.msn.com/pop-culture/death-caf%C3%A9-events-tackling-a-taboo-topic-over-tea</u>.

Mulley, A., et al. (2012). Patients' preferences matter: Stop the silent misdiagnosis. K. O'Neill. London, The King's Fund.

Muris, P., et al. (1995). "Monitoring, imagery and perception of threat." <u>Personality and Individual Difference</u> **18**(6): 749-759.

Muris, P., et al. (1994). "Coping style, anxiety, cognitions and cognitive control in dental phobia." <u>Personality and Individual Difference</u> **17**: 143-145.

442

Murray, E., et al. (2006). "Shared decision-making in primary care: Tailoring the Charles et al. model to fit the context of general practice." <u>Patient Education and Counseling</u> **62**: 205-211.

Murray, E., et al. (2007). "Clinical decision-making: Patients' preferences and experiences." <u>Patient Eduaction and Counselling</u> **65**(2): 189-196.

Murray, E., et al. (2010). "Normalisation process theory: a framework for developing, evaluating and implementing complex interventions." <u>BMC Medicine</u> **8**(63).

Murray, S. (2005). "Palliative care in chronic illness." <u>British Medical Journal</u> **330**(7492): 611-612.

Murray, S., et al. (2008). "Editorial: Palliative care research in the community: it is time to progress this emerging field " <u>Palliative Medicine</u> **22**: 609–611.

Murray, S., et al. (2005). "Illness trajectories and palliative care." <u>British Medical Journal</u> **330**: 1007-1011.

Murtagh, F., et al. (2004). "Patterns of dying: palliative care for non-malignant disease." <u>Clinical Medicine</u> **4**: 39-44.

Nagel, T. (1986). <u>The view fom nowhere</u>. New York, Oxford University Press.

National Cancer Research Institute (NCRI) (2004). Supportive and palliative care in the UK: report of the NCRI strategic planning group on supportive and palliative care. London.

National End of Life Care Intelligence Network (2013). "Data Sources: Place of Death." from http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death.

National End of Life Programme (2011). "Talking about end of life care: right conversations, right people, right time. ." from http://www.endoflifecareforadults.nhs.uk/publications/talking-about-eolc.

Neuberger, J., et al. (2013). More Care, Less Pathway: A Review of the Liverpool Care Pathway

NHS Choices (2013). "What end of life care involves ". Retrieved 13.08.2013, from http://www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx.

443

NHS North East (2012). "Deciding Right - an integrated approach to making care decisions in advance.". Retrieved 30th April 2013, from http://www.cnne.org.uk/uploads/doc/vid_14439_Deciding%20Right-%20full%20document%20v15-%203Feb12.pdf.

Norton, S., et al. (2007). "Proactive palliative care in the medical intensive care unit: Effects on length of stay for selected high-risk patients." Critical Care Medicine **35**(6): 1530-1535.

Nutley, S., et al. (2010). "Evidence and policy in six European countries: diverse approaches and common challenges." Evidence Policy **6**(2): 131-144.

O'Leary, A. (1985). "Self-efficacy and health." Behavior Research and Therapy **23**: 437-451.

Office for National Statistics (2013). Deaths Registered in England and Wales, 2012.

Okon, T., et al. (2004). "Palliative educational outcome with implementation of PEACE tool integrated clinical pathway." Journal of Palliative Medicine **7**(2): 279-295.

Omega: the National Association of End of Life Care (2010). National Snapshot 2009.

Palda, V., et al. (1997). "Breast cancer patients' attitudes about rationing post lumpectomy radiation therapy: applicability of trade-off methods to policy making." Journal of Clinical Oncology **15**: 3192–3200.

Pallant, J. (2010). SPSS Survival Manual New York Open University Press.

Parry, R. (2013). "Communiaction and compassion need time and support: Indights from end of life care." International Journal of Therapy and Rehabilitation **20**(10).

Pawson, R., Ed. (1989). A Measure for Measures: a Manifesto for Empirical Sociology. London, Routledge.

Pawson, R. (2006). Evidence-based policy: a realist perspective. London, SAGE.

Pawson, R. (2013). The Science of Evaluation: A Realist Manifesto. London, SAGE

Pawson, R., et al. (2005). "Realist review - a new method of systematic review designed for complex policy interventions." Journal of Health Services Research & Policy **10**(1): 21-34.

Pawson, R. and N. Tilley (1997). <u>Realistic evaluation</u>. London, SAGE.

Payne, S., et al. (2004). <u>Palliative Care Nursing: Principles and Evidence for Practice</u>. Maidenhead, Open University Press.

Pellett, C. (2009). "Provision of end of life care in the community." <u>Nursing Standard</u> **1**(24(12)): 35-40.

Penson, J. (2000). "A hope is not a promise: fostering hope within palliative care." <u>International Journal of Palliative Nursing</u> **6**(2).

Petersson, L., et al. (2002). "Differential effects of cancer rehabilitation depending on diagnosis and patients' cognitive coping style." <u>Psychosomatic Medicine</u> **64**(6): 971-980.

Plowright, D. (2011). <u>Using Mixed Methods: Frameworks for an Integrated Methodology</u> London, Sage Publications.

Pooler, J., et al. (2003). "Dying at home: a care pathway for the last days of life in a community setting." <u>International Journal of Palliative Nursing</u> **9**(6): 258-264.

Popper, K. (1959). <u>The Logic of Scientific Discovery</u> New York, Routledge.

Pot, A., et al. (2009). "Utilization of acute and long-term care in the last year of life: comparison with survivors in a population-based study." <u>BMC Health Services Research</u> **9**(139).

Ptacek, J. T. and T. L. Eberhardt (1996). "Breaking bad news: A review of the literature." <u>Journal of Clinical Oncology</u> **19**: 4160-4164.

Ptacek, J. T. and J. J. Ptacek (2001). "Patients Perceptions of receiving bad news about cancer." <u>Journal of Clinical Oncology</u> **19**: 4160-4164.

Putnam, H. and J. Conant (1990). <u>Realsm with a Human Face</u>. Cambridge, MA, Harvard University Press.

Quill, T. (2000). "Initiating End-of-Life Discussions With Seriously Ill Patients: Addressing the "Elephant in the Room" " <u>Journal of the American Medical Association</u> **284**(19): 2502-2507.

Radawski, D. (1999). "Continuous Quality Improvement: Origins, Concepts, Problems and Applications." <u>Education</u> **10**(1): 12-16.

445

RAMESES (2014). "RAMESES Home Page." Retrieved 17.01.14, 2014, from https://www.jiscmail.ac.uk/cgi-bin/webadmin?A0=RAMESES.

Reymond, L., et al. (2011). "A residential aged care end-of-life care pathway (RAC EoLCP) for Australian aged care facilities." Australian Health Review **35**(3): 350-356.

Richardson, S., et al. (1965). Interviewing. New York, Basic Books.

Riley, K. (1998). "Paving the way." Health Services Journal **108**(5597): 30-31.

Robbins, H. and M. Finley (1995). "Why teams don't work." Executive Book Summaries **17**(4): 25-31.

Robinson, L., et al. (2010). "Patient preferences for future care - how can Advance Care Planning become embedded into dementia care: a study protocol." BMC Geriatrics **10**(2).

Robinson, L., et al. (2005). "End-of-life care and dementia." Reviews in Clinical Gerontology **15**: 135-148.

Rogers, E. (1995). Diffusion of Innovations New York, The Free Press.

Rosenwax, L., et al. (2011). "Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care." Medical Journal of Australia **194**(11): 570-573.

Royal College of Nursing (2009). Measuring for Quality in Health and Social Care: An RCN Position Statement.

Saunders, C. (1996). "Hospice." Mortality **1**: 317-322.

Sayer, A. (1984). Method in Social Science: a Realist Approach London, Hutchinson.

Sayer, A. (1992). Method in Social Science: a Realist Approach. . London, Routledge.

Sayer, A. (2000). Realism and Social Science. London, Sage.

Schofield, P., et al. (2006). "'Would you like to talk about your future treatment options?' discussing the transition from curative cancer treatment to palliative care." Palliative Medicine **20**(397).

Schrag, F. (1992). "In defense of positivist research paradigms." <u>Educational Researcher,</u> **21**(5): 5-8.

Schwandt, T. (2000). Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructionism. <u>Handbook of qualitative research</u>. N. L. Denzin , YS. Thousand Oaks, CA, Sage**:** 189-213.

Schwartz, M. D., et al. (1995). "Coping Disposition, Perceived Risk, and Psychological Distress Among Women at Increased Risk for Ovarian Cancer " <u>Health Psychology</u> **14**(3): 232-235.

Searle, B., et al. (2001). "Helping people to sort it out: The role of social support in the Job Strain Model." <u>Work and Stress</u> **15**: 328-346.

Selkin, S. (2011). "End-of-Life Liability Issues." <u>Ethics, Law and Aging Review</u> **10**.

Seymour, J., et al. (2010). "Implementing advance care planning: a qualitative study of community nurses' views and experiences." <u>BMC Palliative Care</u> **9**(4).

Shields, C., et al. (2004). "Decision-making role preferences of patients receiving adjuvant cancer treatment. ." <u>Supportive Cancer Therapy</u> **1**(2): 119-126.

Shipman, C., et al. (2008). "Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups." <u>British Medical Journal</u> **337**(a1720).

Shortell, S., et al. (1998). "Assessing the Impact of Continuous Quality Improvement on Clinical Practice: What It Will Take To Accelerate Progress " <u>The Milbank Quarterly</u> **76**(4).

Silveira, M., et al. (2010). "Advance directives and outcomes of surrogate decision making before death." <u>New England Journal of Medicine</u> **362**: 1211-1218.

Simpson, M. (1987). <u>Dying, Death and Grief: a critical bibliography</u>. Philadelphia, University of Philadelphia Press.

Singer, P. A., et al. (1995). "Public opinion regarding end-of-life decisions: Influence of prognosis, practice and process." <u>Social Science and Medicine</u> **41**: 1517-1521.

Slevin, M., et al. (1990). "Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors nurses and general public." <u>British Medical Journal</u> **300**.

447

Smith, D. (2012). "Development of an end-of-life care pathway for patients with advanced heart failure in a community setting." International Journal of Palliative Nursing **18**(6).

Smith, H. (1975). Strategies of Social Research: methodological imagination. London, Prentice Hall International.

Smith, J. (1983). "Quantitative versus qualitative research: An attempt to clarify the issue." Educational Researcher **12**: 6-13.

Smith, J. (1984). "The problem of criteria for judging interpretive inquiry." Educational Evaluation and Policy Analysis **6**: 379-391.

Smith, R. (2009). More training needed following concerns about death pathway: cancer tsar. The Daily Telegraph.

Spence, J. (1960). The Purpose and Practice of Medicine. Oxford Oxford University Press for University of Durham Publications.

Steptoe, A. and J. O'Sullivan (1986). "Monitoring and blunting coping styles in women prior to surgery." British Journal of Clinical Psychology **24**: 143-144.

Stewart, M. (1995). Studies of health outcomes and patient-centered communication. Patient-Centered Medicine: Transforming the Clinical Method. M. Stewart, J. Brown and W. Weston. Thousand Oaks, CA, Sage.

Stewart, S. and J. McMurray (2002). "Palliative care for heart failure." British Medical Journal **325**: 915-916.

Stocker, R. and H. Close (2013). "Assessing the uptake of the Liverpool Care Pathway for dying patients: a systematic review." BMJ Supportive Palliative Care.

Straub, C., et al. (2008). "Translating research into practice: a German sickness fund supporting patient participation." Patient Education and Counseling **73**: 544-550.

Strecher, V., et al. (1986). "The role of self-efficacy in achieving health behavior change." Health Education Quarterly **13**: 73-91.

Sullivan, E. and G. Garland (2010). Practical Leadership and Management in Nursing. London, Pearson

448

Temel, J., et al. (2010). "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer " The New England Journal of Medicine **363**(8): 733-742.

The National Council for Palliative Care (2009). "Dying Matters." Retrieved 30th April 2013, from http://dyingmatters.org/.

The National Gold Standards Framework Centre (2009). Gold Standards Framework. N. W. C. Health.

The SUPPORT Principal Investigators (1995). "A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognosis and Preference for Outcomes and Risks of Treatment (SUPPORT)." Journal of the American Medical Association **274**: 1591-1598.

Thomas, K. (2003). "The Gold Standards Framework in community palliative care." European Journal of Palliative Care **10**: 113-115.

Thompson, G., et al. (2006). ""Changing Lanes": Facilitating the Transition from Curative to Palliative Care." Journal of Palliative Care **22**(2): 91-98.

Thoonsen, B., et al. (2011). "Early identification of and proactive palliative care for patients in general practice, incentive and methods of a randomized controlled trial." BMC Family Practice **12**(123).

Towle, A. and W. Godolphin (1999). "Framework for teaching and learning informed shared decision making." British Medical Journal **319**(7212): 766-771.

Towle, A., et al. (2006). "Putting Informed and Shared Decision Making into Practice." Health Expectations **9**(321-332).

Tuckett, D., et al. (1985). Meetings between Experts. An Approach to Sharing Ideas in Medical Consultations. New York, Routledge.

Van den Block, L., et al. (2007). "Hospitalisations at the end of life: using a sentinel surveillance network to study hospital use and associated patient, disease and healthcare factors." BMC Health Services Research **7**(69).

van Zurren, F. J. (1994). "Cognitive confrontation and avoidance during a naturalistic medical stressor." European Journal of Personality **8**: 371-384.

van Zurren, F. J. and G. J. F. P. Hanewald (1993). "Cognitive approach and avoidance in threatening medical situations: the development of a questionnaire." Gedragstherapie **26**(1): 33-48.

van Zuuren, F. J. and H. M. Wolfs (1991). "Styles of information seeking under threat: personal and situational aspects of monitoring and blunting." Personality and Individual Differences **12**(2): 141-149.

van Zuuren, J. F., et al. (1996). "Coping with medical threat: an evaluation of the Threatening Medical Situations Inventory (TMSI)." Personality and Individual Difference **21**(1): 21-31.

Veerbeek, L., et al. (2008). "Using the LCP: bereaved relatives' assessments of communication and bereavement." The American Journal of Hospice & Palliative care **25**(3): 207-214.

Veerbeek, L., et al. (2008). "The effect of the Liverpool Care Pathway for the dying: a multi-centre study. ." Palliative Medicine **22**: 145-151.

Vissers, K., et al. (2013). "Palliative Medicine Update: A Multidisciplinary Approach." Palliative Medicine **13**(7): 576–588.

Wagner, E., et al. (2005). "Finding Common Ground: Patient-Centeredness and Evidence-Based Chronic Illness Care." The Journal of Alternative and Complementary Medicine **11**(1).

Walshe, C., et al. (2008). "Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three primary care trusts." Public, Environmental and Occupational Health **22**(6): 736-743.

Walter, T. (1991). "Modern Death: Taboo or not Taboo?" Sociology **25**(2): 293-310.

Web of Knowledge (2013). "Web of Knowledge Service for UK Education." Retrieved 14.11.2013, 2013.

Weissman, D. (2003). "Champions, Leaders, and the Future of Palliative Care." Journal of Palliative Medicine **6**(5).

Williams, M. (2000). Science and Social Science. London, Routledge.

Wilson, A. and S. Childs (2002). "The relationship between consultation length, process and outcomes in general practice: a systematic review." British Journal of General Practice **52**: 1012-1020.

World Health Organisation (2014). "WHO Definition of Palliative Care." Retrieved 01.01.2014, from http://www.who.int/cancer/palliative/definition/en/.

450

Yalow, E. and J. Collins (1987). "Self-efficacy in health behavior change: issues in measurement and research design." Advances in Health Education and Promotion **2**: 181-199.

Yorkshire Post (2013). "Doctor who is determined to fight the last taboo by sharing her own death." Retrieved 31.07.2013, from http://www.yorkshirepost.co.uk/news/features/doctor-who-is-determined-to-fight-the-last-taboo-by-sharing-her-own-death-1-5787767.

Young, H., et al. (2008). "Physicians' Shared Decision-Making Behaviors in Depression Care." Archives of Internal Medicine **168**(13): 1404-1488.