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**How does English End of Life Care and the views of
stakeholders fit with the ambitions of national policy: insights
from a realist evaluation**

Rhiannon Barker

Submitted in accordance with the requirements for the degree of Doctor of Philosophy

Centre for Health Services Studies
University of Kent
November 2020

The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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This thesis is offered in memory of my father Ashley Barker, who died as I was completing the field work. His death provided me with a very personal insight into ways in which the dying process has become over medicalised, focussing on the transactional rather than the relational, reinforcing my initial motivation to embark on the study.

Finally, I am very grateful to the Centre for Health Service Studies at the University of Kent for supporting the work financially and for helping me to feel part of a wider team.

Abstract

Background

In England as in other European and North American countries people are living longer with more complex co-morbidities, requiring clearer guidance be given on the delivery of scarcer public resources to fund health and social care. The global rankings of End of Life Care (EOLC) put together by the Economist Intelligence Unit (EIU) rates English EOLC services more highly than any other country (EIU 2015). A key contributory factor, pushing England to this top ranking, is the existence of what is seen as a robust EOLC policy. Yet, whilst there is strong agreement in most policy documents as to what determines good practice around EOLC (Centre for Health and Social Care Research 2016), there is little analysis or discussion as to how policy contributes to improved practice, both in terms of continual improvement of guidance and the process by which it is translated into practice.

Aims and Objectives

This study explores EOLC Strategy and Policy in England (both national and local). It asks to what extent national policy is effective in influencing and guiding local practice to help ensure that care is of a consistently good quality. Pivotal to gaining a clearer understanding of how policy works in practice was the interrogation of:

- i) the key contextual factors that needed to be in place in order for EOLC policy to be effectively enacted
- ii) how well aligned policy ambitions were with the differing priorities and perspectives of stakeholders.

Methodology

The study followed a Realist Evaluation (RE) methodology (Pawson and Tilley 1997) and was divided into two phases:

- i) Scoping study; comprising a literature review and 12 in-depth interviews with professionals involved in the creation of EOLC policy.
- ii) Case studies of three Clinical Commissioning Groups (CCGs); comprising documentary analysis, meeting observation and 96 in-depth interviews with 4 key stakeholder groups.

Results

This study reveals the key contextual factors which need to be in place if EOLC Policy is to be effectively implemented. In line with Pawson's (2006) conception of context these are located at the levels of: individual capabilities and characteristics, interpersonal relationships, organisational settings and infrastructural settings.

The findings provide insight into the rapidly changing policy environment, the rising local inequalities and the impact that ongoing NHS organisational change has on both commissioning and service provision. The sense of fragmentation and the way services have built up, piecemeal, over the years is noted, as is the tendency to accept and replicate historical patterns of commissioning.

The narratives from different stakeholders offer insight into the degree to which their attitudes, opinions and needs align with those articulated in policy statements. It is in the areas of significant misalignment that the challenges lie. Particularly noteworthy was the division between the delivery of clinical/transactional care on the one hand which was generally felt to be of high quality and relational/social care on the other – which, though seen as a priority by patients and relatives, was undervalued and overlooked at a system level.

Discussion

This piece of research was ambitious in its scope and revealed the huge levels of complexity involved in implementing effective EOLC policy. EOLC operates across multiple settings and sectors and findings reinforce the impossibility of arriving at a neat set of conclusions, where inputs can be causally linked to outputs.

The aspirations of EOLC policy, in as far as it lays out an acceptable vision of what good patient centred care looks like at the end of life, were largely found to be acceptable. Yet within the different contextual landscape of each case study there was evidence of disparities in the scale of local provision, leading to increasing inequalities. Whilst examples of excellent practice prevail, running alongside these are instances where the needs of individuals and communities are marginalised and overlooked. At the core of this dislocation is the lack of rigorous planning and strategy in the way services are prioritised and valued. At the end of life (EOL) two key priorities are signalled. The first is the clinical imperative to ensure that patients are pain free and have their symptoms controlled and the second relates to relational care - to ensure that patients are treated with kindness, compassion and dignity. Whilst most respondents in the research were confident that

good clinical care was generally received there was considerably less assurance that adequate levels of relational care could be guaranteed. Redressing the imbalance between health needs on the one hand and social care needs on the other is a major task and one which urgently needs to be addressed.

Recommendations

Meeting the challenge to establish closer alignment between health and social care will involve input at multiple structural levels including policy change, structural alignment of services, public education, improved training and staff support - particularly for social care staff.

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List of Abbreviations

ACP – Advance Care Plans
ACO – Accountable Care Organisations
AD – Advanced Directives
BAME – Black and Minority Ethnic
CCG – Clinical Commissioning Groups
CMC – Coordinate my Care
CMO – Context Mechanism Outcome
CDF – The Cancer Drug’s Fund
CQC – Care Quality Commission
DH – Department of Health
DHSS – Department of Health and Social Security
DNAR – Do Not Attempt Artificial Respiration
EIU – Economist Intelligence Unit
EOL – End of Life
EOLC – End of Life Care
EMIS – Egton Medical Information Systems
EPaCCS - Electronic Palliative Care Coordination Systems
5YFV – Five Year Forward View
GDPR – General Data Protection Regulations
GSF – Gold Standard Framework
HPSR – Health Policy System’s Research
ICSs - Integrated Care Systems
ICPs – Integrated Care Partnerships
KPI – Key Performance Indicator
MCPs – multi-speciality community provider
NEOLCIN – National End of Life Care Intelligence Network
NHS – National Health Service
NHSE – NHS England
NHSI – NHS Improvement
NIHR – National Institute of Health Research
NICE – National Institute for Clinical Excellence
OT – Occupational Therapist
PACS – Primary and acute care systems
PC – Palliative Care
PHB – Personal Health Budget
PHE – Public Health England
PPI – Patient and Public Involvement
QI – Quality Improvement
QoF – Quality Outcomes Framework
RCTs – Randomised Controlled Trials
RPT – Revised Programme Theory
ReSPECT – Recommended Summary Plan for Emergency Care and Treatment
STP – Sustainability and Transformation Plan
SPA – Single Point of Access
SPA PONS – Single Point of Access Palliative Overnight Service
STP – Sustainability and Transformation Plans

Glossary of Terms

Term	Description
Advance Care Plan (ACP)	An ACP is a written statement that sets out an individual's wishes, beliefs, values and preferences about future care. An ACP provides a guide to help healthcare professionals and anyone else who might have to make decisions about care and are particularly valuable if a patient is too unwell to make decisions or to communicate them.
Best practice	Practice based on the best available evidence.
Case study	An empirical inquiry that investigates a phenomenon within its real-life context. The investigation only includes a small number of cases but studies these in significant depth.
Clinical Commissioning Groups (CCGs)	CCGs were created following the Health and Social Care Act in 2012 and replaced Primary Care Trusts on 1 April 2013. They are clinically led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. From April 2020 CCGs across the country face 'constitution change, merger or dissolution' (NHS England, 2019). By 2021 the intention is that integrated care systems (ICSs) will be rolled out 'growing out of the current network of sustainability and transformation partnerships (STPs)'.
Commissioning	The concept of commissioning was introduced into the NHW in the 1990s when reform separated the purchasing of services from service delivery, creating an internal market. Commissioning in the NHS comprises a range of activities including: assessing need, planning services, procuring services and monitoring quality.
Configuration	Patterns of context-mechanism-outcome, 'if-then', propositions that vary in degree of abstraction and specification (Pawson & Tilley 1997; Pawson 2013).
Conjecture	Hypothesised or inferred propositions.
Context	Complex layered conditions which influence the success or failure of different interventions or programmes (Pawson, 2013).
Continuing Health Care (CHC)	NHS continuing health care funding is the name given to care and support which is arranged and paid for by the NHS. It is intended for people who have ongoing health care needs and may include social care costs which would normally be paid for by an individual or the council. Fastrack CHC is assigned to individuals with a rapidly deteriorating condition that may be entering a terminal phase.
Coordinate My Care (CMC)	CMC is a clinical service that holds patient care plans. These are electronic forms completed by a patient with their healthcare professional. It records the patient's wishes and preferences for their treatment and care to allow them to live well in their last stages of life. There are a wide range of Electronic Palliative Care Coordination Systems used nationally though at the time of fieldwork (2019) CMC

Critical realism	A philosophy of science which distinguishes between the 'real' world and the 'observable' world (McEvoy & Richards, 2006) and presents an interface between the 'natural' and the 'social' world.
End of Life Care (EOLC)	Refers to the health and relational (social) care provided for a person with a terminal condition that has become advanced, progressive and/or incurable. Within the NHS it is often used to refer to what clinicians suspect to be the last 12 months of life.
Hypothesis	A starting point in an investigation which posits how something works. In realist terms a hypothesis describes, "what might work for whom in what circumstances" (Pawson & Tilley, 1997).
Mechanisms	Mechanisms are the 'engines of explanation' (Pawson 2006) – they explain how contextual factors work to trigger particular outcomes and focus on the things that influence the behaviour or people ('the agents of change').
Middle-Range Theory (MRT)	Middle-Range Theory provides a limited set of assumptions from which specific hypothesis may be logically derived and confirmed by empirical investigation. They demand a certain level of abstraction yet remain close enough to observed data to allow for them to be incorporated into propositions that permit empirical testing (Merton, 1967 p.39).
Outcomes	In realist terms if the right contextual factors are in place to trigger identified mechanisms then outcomes will result which indicate the perceived success of the programme. Realism allows for a range of levels of impact, covering intermediate outputs and longer-term outcomes.
Palliative Care (PC)	Palliative care encompasses end of life care but is more holistic, focussing on improving the quality of life and quality of care for patients, families and carers. The focus is on: the prevention of relief and suffering; communication about goals of care; early identification and assessment; attention to physical, psychological, environmental and spiritual aspects of care.
Proposition	A statement that can be tested to affirm or dispute how something works.
Realist Evaluation (RE)	A theory-driven approach which "supposes that regularities in the patterning of social activities are brought about by the underlying mechanism constituted by people's reasoning and the resources they are able to summon in a particular context" (Pawson & Tilley, 1997:220).
Sustainability and Transformation Partnerships (STPs)	In 2016, NHS organisations and local councils joined forces in every part of England to develop proposals for improved health and care. They formed new partnerships – known as sustainability and transformation partnerships (STPs) – to run services in a more coordinated way, to agree system-wide priorities, and to plan collectively how to improve residents' day-to-day health. Typically, each STP is made up of CCGs, local authorities and other voluntary organisations.

Outputs

Publications:

Barker,R., Wilson,P., Butler,C (2020) Does national policy in England help deliver better and more consistent care for those at the end of life? *Journal of Health Services Policy and Research*.

Conference posters/presentations:

Barker,R., Wilson,P., Butler,C (2018) How does End of Life Care and the views of stakeholders fit with the ambitions of national policy? *Hospice UK National Conference*

Chapter 1: Introduction and overview

Reports from researchers, regulators, journalists, patients and their carers suggest that for many, End of Life Care (EOLC) continues to be delivered reactively rather than proactively, particularly in the acute hospital setting (Wollaston 2015). Stories of intrusive medical intervention being delivered to frail patients, at the end of life, are all too common. The impact of poor experiences of end of life care is profound, not just for the dying person, but on the families, carers and professionals around them. Whilst a string of strategy reports (Department of Health 2008; NPELCP 2015; Department of Health 2014; Wollaston 2015) over the last decade have laid out aspirations for good care, responsive to individual needs and preferences, at the End of Life (EOL), Care Quality Commission (2016) data reveal huge variability in provision. This study will explore EOLC strategy and policy in England (both national and local). It will ask to what extent national policy influences and guides local practice to help ensure that care is of a consistently good quality. Through case studies of local practice based around three CCGs, the research will examine what good EOLC means to a variety of stakeholders (policy, clinicians, patients and carers) and will look at the role national policy has in shaping outcomes at a local level.

This chapter provides an insight into the motivation behind the study, it presents an overview of the thesis, introduces the key themes and reflects on how findings can inform better EOLC in the future.

A comment on the language and style

This dissertation is written, in parts, in the first person. Although this sets it apart from much academic writing, there is a recognised tradition within qualitative approaches of using this style of writing (Gilgun 2005). In my role as a qualitative researcher carrying out in-depth interviews with vulnerable people I believe that using the first person is a necessary device to allow me to authentically and legitimately represent my views along with the perspectives and the experiences of my respondents. All participants have been anonymised – with fictional names used to refer to patients and carers.

1.1 Motivation for the study

I have spent thirty years working in health-related social research and for a number of these was a non-executive director on East Sussex Downs and Weald Primary Care Trust. In this capacity, one of

my responsibilities was to sit on the 'Exceptional Case Funding Review Panel' which was charged with considering applications for drugs and interventions that were not approved by the National Institute of Clinical Excellence (NICE) and would often involve requests for considerable sums of money. Typically, we were asked to consider funding for cancer drugs costing something in the region of £50-80K, for treatments where the expectation was that life may be extended by a few months. In the criteria used to assess the validity of the application age was not a consideration. Instead we reviewed 'quality of life' alongside a rather opaque and poorly articulated value for money metric. Often funding would be agreed and ethical and moral questions around probity and equity remained unvoiced. At the same time in 2004, following a car accident, I found myself recovering in a hospital bed on a general orthopaedic ward in an East Sussex Hospital. Nursing a head injury and broken bones I lay, idly observing life on the ward. During this period of enforced ethnographic study, my attention was drawn to an old woman who lay in the bed opposite. Neither of us were able to get out of bed so conversation was never a possibility, she had no visitors and her presence seemed to be little felt on the ward. But in my waking hours I would watch as the trolley with her meals was put in front of her. Her frail hand would reach out and grapple to get leverage on the spoon, followed by painful and shaky manoeuvring towards her mouth. Occasionally small quantities of food would safely reach their target, but typically after a number of false starts, the spoon would fall from her hand onto the bed and a small shudder would signal her resignation that the meal was over.

When one morning the nurses appeared to draw the curtains around her dead body, I remember the huge sense of indignation that so little attention should be paid to someone at the EOL. Where is the equity, I asked myself, in a system which on the one hand carelessly agrees to the funding of hugely expensive drugs to possibly extend life by a few more months, but on the other hand pays no attention to basic social/relational care for a frail dying old lady? Whilst this story is clearly no more than anecdote and I do not claim that ethnographic evidence offered by someone suffering a head injury should be used to tell a wider story – it highlighted the disparities, commented on by other observers (Barker et al. 2014), between health and social care and the way that curative medicine is at times privileged over social and relational care (Heath 2016; Barker et al. 2014). The experience led me to ask how national policy could be used to begin to provide a clearer framework and guidance through which all stakeholders can be made more aware of the impact that one funding decision has on another and through this can begin to play a more informed and active part in planning for EOLC.

I have also been influenced in my thinking by literature. For example, Atul Gawande's (2014) beautiful and moving book, *Being Mortal*, explores 'the modern experience' of mortality. Gawande steers his reader through the tensions of being a surgeon at a hospital in Boston, USA. As a doctor trained to save and extend lives he talks of the cultural tensions that arise around preference and choice at the EOL. He refers particularly to his grandfather in India, enabled to ride out on his horse into his old age, who he compares with his American grandmother-in-law, Alice, confined to an old people's home where he suggests her independence and dignity were stripped from her. In the industrialised West, he contends, our elderly are cosseted by a culture that abhors risk and consequently takes away independence in its drive to reduce slips and trips.

Iona Heath, a London based former GP highlights the tensions that society faces in its attempts to grapple on the one hand with what technology and science enables us to do, to heal and extend life, and on the other the need to nurture and share our common humanity (Heath 2016). The human experience, she argues, must be seen in all its unique complexity and not obscured by the reductive nature of evidence-based medicine. The body is a lived subject, rather than a passive object and is not necessarily compliant with a set of standard solutions (Heath 2016).

In addition to clinical skills clinicians must also be able to listen to and respond on a human level, to give hope and sometimes simply to be a witness to the courage and endurance shown by their patients. Such thinking was mirrored in the findings of the Francis Inquiry (Francis 2012). The summary of the inquiry into the failings of care provided (largely to older people) at Mid Staffordshire hospital between 2005 and 2009, described a crisis in compassionate care where system pressures and lack of staff support, created a stressed system where malpractice was hidden from view and some staff lost sight of the value of empathetic, kind interactions with their patients.

Heath (2016) lays down a strong challenge to medics, encouraging them not to live exclusively in the realm of the rational but to engender humanity in the way they communicate with patients:

Today, evidence-based medicine is used to drive definitions of clinical quality that involve insufficient doubt, and this has become difficult to question because the aim is so worthy. Nonetheless, such unidimensional means are damaging because they propagate an intensely normative and objectifying view of what it means to be healthy and of what human life and healthcare should be. We need more breadth, more balance, and more doubt and only then will our consultations cohere (Heath 2016 p.3).

Many of the themes emerging here are mirrored in the aspirations of EOLC policy which contends services need better integration across health and social care with a rebalancing of resources and support across the acute and community sectors, bolstering primary and community care and taking some of the pressure from acute hospitals. The growing complexity and increasing resource implications of EOLC mean that ensuring the elderly receive good quality, empathetic care, delivered in a timely fashion must be the responsibility of all.

1.2 Research questions and rationale

The intention to focus on the relevance and impact of policy is prompted by the supposition that there is a lack of analysis in the literature exploring these issues. The global rankings of EOLC put together by the Economist Intelligence Unit (EIU) rates English EOLC practice more highly than any other country. A key contributory factor, pushing England to this top ranking, is the existence of what is seen as a robust EOLC policy. Yet, whilst there is agreement in most policy documents as to what determines good practice around EOLC (Centre for Health and Social Care Research 2016), there is little analysis or discussion of how policy contributes to improved practice, both in terms of examination of the content of policy and the process by which policy is transferred into practice.

Although a number of commentators have looked at issues of resource allocation in relation to ethics and justice (McMillan et al. 2006), little attention has been paid to the influence of government policy and how this impacts on the way different services are funded and accessed. If increasing amounts of the health care budget are spent on drugs and interventions to prolong life, does this mean less money is available for example, for relational care provided by nurses and health care assistants? How does the size of one pot of funds influence another? Although such considerations may be valid, the methods and processes used for allocating funds remain obscure.

In the UK as in other European and North American countries people are living longer with more complex co-morbidities, requiring that clearer guidance be given relating to the delivery of scarcer resources. The average age of death in the UK continues to increase; two thirds of deaths now occur at over 75 years, with male life expectancy from birth averaging 79.3 years and females 82.9 (Office for National Statistics 2019). Gomes (2013b) predicts that between 2012-2030 the number of deaths in England will rise by 17% to nearly 600,000. Such figures mean that the issues confronted in EOLC, particularly in the light of the 2020 Covid-19 epidemic, are likely to intensify over the next two decades and the importance of clear policy to support growing demands on national resources and infrastructure will intensify.

In the light of increasing pressures faced by the UK health system a 'step change in thinking and action is urgently needed' (Alderwick et al. 2015). The call to action articulated in the NHS five year forward view (NHS England 2014a) identified £22billion of productivity improvements by 2020/21. Making change happen will require a fundamental shift in approach at all levels.

Through an exploration of literature, a deep dive into local EOLC practice, and interrogation of the perspectives of different stakeholders, this study will ask how closely aligned national policy is with local practice and interrogate the different perspectives of those most closely involved in the delivery of services and receipt of care.

Primary research question:

How does English national policy and strategy and the way it is interpreted by the key stakeholders, help guide and determine local practice in EOLC and bring about equitable delivery of good quality care?

Secondary research questions:

- What are the enablers and challenges to enacting national EOLC policy?
- How is policy arrived at and is there any explicit or implicit theory behind the policy?
- How are decisions around cost and benefit variously understood and assessed by the key stakeholders (patients, families and carers, clinicians, commissioners and policy makers)?
- How do the perspectives and priorities of the key stakeholders vary (policy, clinicians, commissioners, patients, family/carers)?
- What more could be done at national level to drive and guide good practice?

1.3 Organisation of the study

The thesis is organised into eight chapters

Chapter 1: Introduction. Provides an overview and context to the thesis and presents a personal perspective sharing my motivation to get involved in this area of work. The research questions are introduced.

Chapter 2: An overview of the literature. This chapter begins with a look at definitions of EOLC, palliative care and policy. It considers the key barriers and enablers to providing good EOLC as

presented in UK and international literature. The narrative is structured through interrogation of the different system levels: macro, meso and micro.

Chapter 3: EOLC Care in England. Chapter three explores the development of English EOLC policy over the last two decades and looks critically at policy content and the response to policy both from researchers and practitioners. It considers how policy enactment has been facilitated by resource and infrastructural alignment and reflects on the challenges in determining budgets, particularly in relation to their relative allocation across health and social care.

Chapter 4: Methodology and method. This chapter examines the theoretical underpinning of the work, seeking to justify the veracity of locating the work within a realist evaluation (RE) framework using case studies as a means of gathering in-depth context related data. The second part of the chapter looks at the research governance process and details the method of selection of case study sites.

Chapter 5: Findings from phase one. Phase one of the study was based on interviews with professionals instrumental in the development of English EOLC policy. Findings from the scoping study are used to put together a conjectured theory which forms the basis for further testing in phase two.

Chapter 6: Findings from phase two (case studies). Chapter six looks at findings from case studies conducted in three London based CCGs (each located in a different sustainability and transformation plan (STP) footprint). It compares the experiences and views of commissioners, service managers, clinicians, patients and carers across different services and settings. Discussion is framed within the conjectured context, mechanism, outcomes (CMOs) developed following the scoping study; seven revised CMOs are presented at the conclusion of chapter six.

Chapter 7: Discussion. This chapter develops a revised programme theory (RPT) exploring the underlying mechanisms within each of the revised CMOs and proposes three mid range theories (MRTs) to support conceptualisation of the data.

Chapter 8: Conclusion Here the research questions are reviewed and the key findings summarised. A reflexive account of the methods used is provided and recommendations for policy, practice and research are made.

1.4 Chapter Summary

This chapter has presented an overview of the study and provided a personal insight into my motivation to research the subject. It has articulated the research questions and described the organisation of the thesis. Whilst it appears there is broad agreement within policy documents as to what good care looks like, evidence put forward by CQC (2016) and a number of other government

enquiries (Francis 2013; Berwick 2013; Keogh 2013) suggests that making sure these crucial building blocks are routinely in place remains a challenge.

Chapter 2: Overview of literature

This chapter begins with a look at definitions of EOLC, palliative care and policy. It will then consider the key barriers and enablers to providing good EOLC as presented in English and international literature. The narrative is structured through interrogation of the different system levels; meso, macro and micro. A method of narrative review (Greenhalgh et al 2018), presented in section 4.2.1.1, was used to explore the literature with the intention of highlighting the key themes relating to the use of EOLC policy since the introduction of the first national policy in 2008. A narrative review, like a realist review, is naturally broader than traditional Cochrane type reviews. Rather than looking for sweeping generalisations of what works in any circumstance the focus is on evaluating context, mechanisms and outcomes at mid-range level (Gough, 2013). The aim of the review was to provide the building blocks that would lead to a more complete understanding of the body of knowledge around the effectiveness of interventions to support patients at EOL, with specific reference to the role of policy.

2.1 Definitions

2.1.1 End of Life Care

The definition of EOLC used throughout this thesis is taken from the 2008 End of Life Strategy (DH 2008) which states that EOLC is that which:

Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (DH 2008. p.47).

EOLC care aims to help people to live for as long as possible and may include clinical treatment, however the relative clinical benefits of treatment are measured against the importance of maintaining dignity and respect; psychological/emotional side effects should be considered alongside the patient's wishes. The way patients are treated, and the kind of clinical or social care they receive will vary depending on how much longer the patient is expected to live – a question which is often hard to predict. The issue of whether or not to put a time frame on EOL is widely debated (Marie Curie 2018; Hui et al. 2014). Care needs and requirements will inevitably vary depending on whether death is anticipated to be years, months, days or hours away.

As modern medicine develops in sophistication sudden death is less common, particularly in the more economically developed nations. The three leading causes of death are related to serious progressive illness: cardiovascular disease, cancer and respiratory disorders (Murray et al. 2005). Looking at the most common causes of death in terms of illness trajectories can help patients, carers and professionals to understand and plan for the last phase of life, combining appropriate levels of active and palliative care. Three typical patterns of illness trajectories preceding death have been identified (Murray et al. 2005):

- i) a steady progression with a clear terminal phase – often exhibited in cancer
- ii) conditions arising from organ failure including respiratory disease and heart failure are often characterised by a gradual decline, interspersed with acute deterioration with some recovery, leading to sudden (or less predictable) death
- iii) a prolonged gradual decline exhibited by the frail elderly, suffering a number of minor co-morbidities including dementia.

For the purposes of this study and particularly in terms of identifying the patient sample, a standard definition which included an anticipated amount of time remaining was seen to be important and therefore EOL is taken to refer to those, who in the opinion of clinicians, were expected to die within 12 months.

2.1.2 Palliative Care

The definition of PC is more holistic than EOLC, focussing on improving the quality of life and quality of care for patients as well as their families and carers. The focus is on the prevention of relief and suffering; communication about goals of care; early identification and assessment; attention to physical, psychological, environmental and spiritual aspects of care. PC may cover a range of diseases and conditions including those with complex illness who need their symptoms controlled.

Table 1 **Definition of Palliative care**

<p>Definition of Palliative care</p> <ul style="list-style-type: none">• improves quality of life• gives relief from pain and other distressing symptoms• supports life and keeping people as healthy as possible, regarding dying as a normal process• does not quicken or postpone death• combines psychological and spiritual aspects of care• offers a support system to help people live as actively as possible until death• offers a support system to help the family cope during a person's treatment and in bereavement• uses a team approach to address the needs of the person who is ill and their families• also applies to the earlier stages of illness, alongside other therapies that are aimed at prolonging life• can take place in hospitals, hospices but also in people's homes. <p>Marie Curie (2018)</p>
--

A range of models of palliative and EOLC exist, implemented both across in-patient units in hospices and acute trusts, and in the community where they are supported by a network of skilled clinicians and carers. These models, backed by varying levels of research evidence to demonstrate their effectiveness, are discussed in more detail in section 2.2.2.

2.1.3 Policy: What is it and what does health policy set out to achieve?

Policy constitutes the guidance and 'rules' around how services should be delivered with the aim of achieving collective health goals and is inextricably enmeshed in health systems and the broader determinants of health (Gilson 2012). In this sense policy may be viewed as a social agent which determines the shape and form of service delivery and helps in the articulation of how experiences of the service can be evaluated (Borgstrom 2016). Policy and systems together provide the knowledge base and mechanisms to bring about effective outcomes.

Through understanding the nature of policy and the processes of policy change, we gain new insights that help to explain how health system actors, and the relationships of power and trust among them, influence health system performance (Gilson, 2012 p.24).

Health policy aims to ensure that resources made available from the public purse achieve the greatest benefits for the greatest number – in other words it is founded on the values of

utilitarianism, establishing a framework which should bring about equal access to all, indeterminate of age, class, ethnicity, disease or geographical location (Borgstrom 2016). Adherence to these principles have been important in highlighting inequities in current end of life provision. The ongoing anomalies in the provision of cancer services compared to services offered those suffering conditions such as dementia at EOL has been widely reported (Marie Curie and Alzheimer's Society 2014; Martinsson, Lundstrom and Sundelof 2018). Today patients with cancer are still much more likely to receive palliative care than those dying from other diseases, and evidence also suggests that there are inequalities relating to age, ethnicity, geographical location (Wollaston 2015).

The links between policy and the achievement of broad societal goals are hard to define, with a tension often emerging between the needs of the individual on the one hand and those of society on the other (Heath 2016).

2.1.3.1 Policy analysis

Attempts to define how policy should be analysed with a view to articulating a replicable method or to define parameters for measuring the effectiveness of the policy, often become obfuscated by inherent complexities. The challenges are multifarious, starting with often ill-defined policy boundaries, unclear aims and objectives together with accusations that policy analysis cannot compete either with the 'hierarchy of evidence' that favours RCTs, or that the process is wrought with inevitable tensions around exposing the often antagonistic and intractable views of the various stakeholders. Harrison identified three central planks to policy analysis: the policy making process; its context; the use and development of theory. Within this, five stages are identified which commonly form a part of the policy process including:

- agenda setting
- defining the problem and determining possible improvements
- outlining the causal mechanisms which have led to the problem
- identify and appraise options for intervention and how to bring about positive change
- implementation, evaluation, and feedback

Harrison (2001) suggests that policy analysts are often reluctant to make assumptions about logic or rationality – yet, in order for a policy to be effective, it must be based on an understanding both of why the 'problem' which the policy sets out to improve has come about and how the intervention is

going to improve it. Without this articulation of cause and effect any interventions lack focus and become impossible to monitor and evaluate.

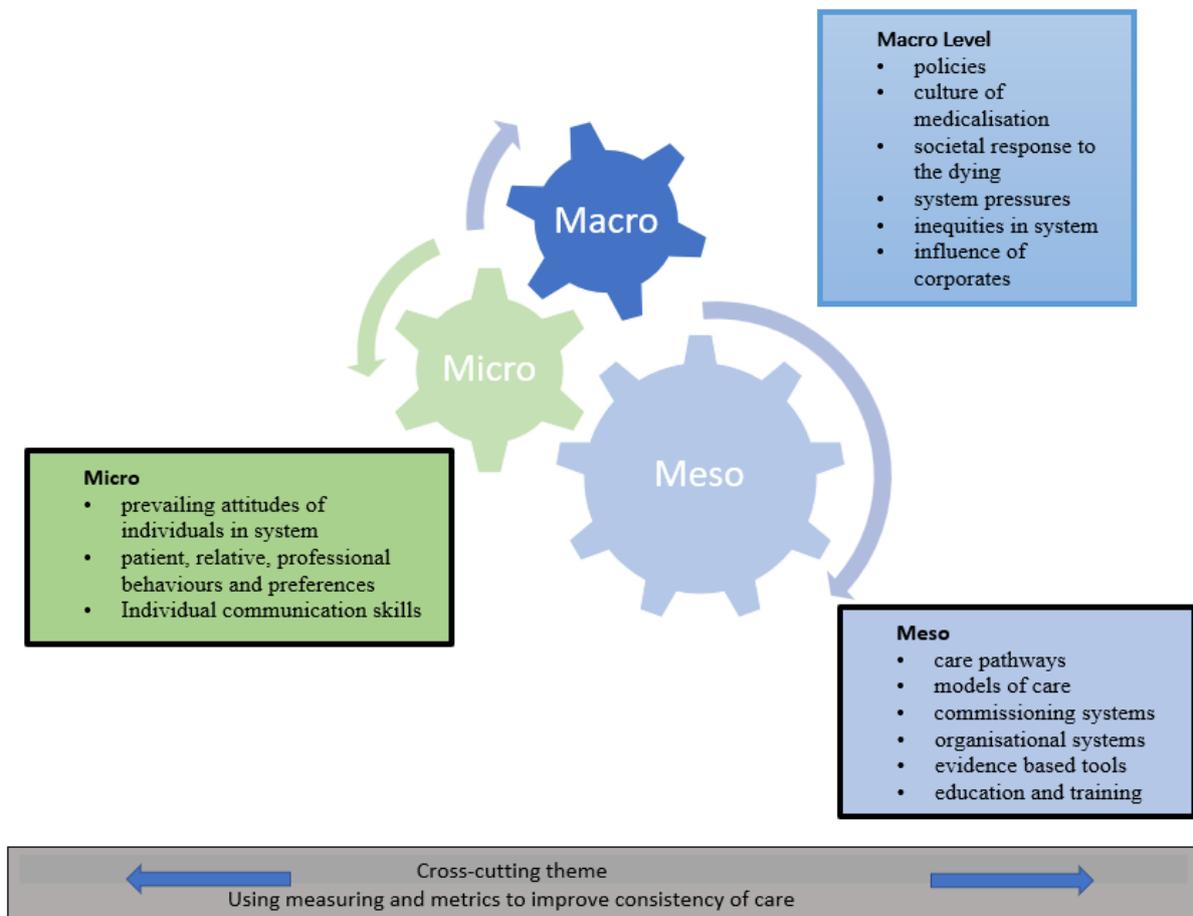
Making theory explicit permits, and indeed encourages us to question the taken-for-granted: to consider, for instance whether our facts could be interpreted in other ways or whether our assumptions are out of date (Harrison 2001, p.92).

Harrison's (2001) rationale of policy fits well with the Realist Evaluation method used in this study to interrogate policy and is discussed further in chapter three.

2.2 Barriers and facilitators to the provision of end of life care

The determinants impacting on the type and quality of EOLC are complex and located at different system levels. For the purposes of this contextual overview determinants and challenges relating to achieving more consistent outcomes in EOLC are stratified by the level of the system where the determinant is located (though this demarcation is not always precise and at times particular factors may straddle different levels of the system) – represented in figure 1 below. The items listed do not exist as isolated factors but interact with each other both within and between system levels. The list presented here is a summary of some of the key determinants dominating the literature.

Figure 1 Factors influencing EOLC at different system level



The relative influences of each factor will be considered in turn in the next section.

2.2.1 At the macro Level

2.2.1.1 National/local policies

Although policy is generally seen as something that helps guide good practice there is little research evidence in EOLC literature that looks at the associations between policy and practice. Indeed, as a discipline EOLC studies are still in their infancy with the UK being one of the first countries to develop a robust EOLC policy as recently as 2008. For this reason, literature examining the form and effectiveness of EOLC policies is thin on the ground and there is little consistency in the way that policy is seen to help define or guide practice. The Economist Intelligence Unit (EIU) (2015) notes that only a handful of countries internationally recognise EOLC in their healthcare and medical education policies. Whilst there are pockets of good practice around the world the overall picture is

far from uniform. The existence of robust policy however does not, in itself guarantee good practice. To be effective policies must clearly be backed by service delivery.

There's a lot of interest in the symbolic language of getting palliative care into ... high-level statements of policy... but it also has to get into the bloodstream of policy, and into the funding and reimbursement programmes—and most countries are struggling to move forward from high-level statements to real action and investment on the ground (EIU 2015 p.31).

A comparative study of progress on PC policy in both EU and non-EU countries (Woitha 2014) suggests that while things are improving there is still scope to further align policy with system building blocks, i.e. policy must be linked to practical steps enabling service provision. Moreover, quality control supported by realistic measures and financial backing needs to be in place. Commentators also warn of the need for policy alignment – so that policies in one sector (e.g. social care) do not impact deleteriously on another sector (e.g. health) – as has been seen to be the case in the UK following dramatic cuts in social care (Buck 2018).

In a Hong Kong based study looking at the facilitators and barriers to EOLC (Threapleton et al. 2017) found that a key concern at the macro level was inadequate policy and guidelines. The latest 'quality of death' ranking of global EOLC by the EIU (2015) includes consideration of national policy as a key factor linked to effective outcomes. According to the EIU national policies play a vital role in extending access to palliative care and in unifying local practice to ensure consistent access to services. As a result, the presence and effectiveness of government policies equates to a 10% weighting of the overall Quality of Death score. In order to score the full 10% countries were asked to demonstrate that:

There is a comprehensive strategy for the development and promotion of national palliative care. It has a clear vision, clearly defined targets, an action plan and strong mechanisms in place to achieve targets...These mechanisms and milestones are regularly reviewed and updated (EIU 2015 p.27).

A policy analysis conducted by May (2013) looked at how the practice of PC in Ireland had developed since they published a dedicated national PC policy in 2001 (DoHC 2001). They found that whilst recommendations that PC should be made available to all patients 'wherever and whenever' were accepted by the government, the policy was slow to be implemented and six years into the period of implementation funding was only 50% of that required. Despite this, policy was seen to provide a road map for future direction which was both valued by the government and helped to set markers

against which progress could be measured. Although the pressure of competing policies within ringfenced national budgets was a barrier to progress, the policy did help legitimize EOLC as an area worthy of investment. Despite this, resources required to fund staff and services to facilitate the meeting of targets were not made available. Moreover, differences in opinion remained between, for example, those advocating for specialist or generalist investment. Whilst it was acknowledged that a specialist-led service is optimal for treating a relatively small number of patients with complex needs, a larger group of patients have simpler needs which can be met with more generalist resources. The report concludes that PC is a relatively new field with limited capacity for rapid expansion and there are significant challenges in competing for resources with more established areas of the health care system – however policy formation was seen to encourage development of clearer plans, objectives and monitoring indicators. In order to generate widespread motivation to implement a national plan, inter-disciplinary working is advantageous, yet challenging to achieve (May 2013).

In Andalusia, Spain, following a 'Death With Dignity Act' passed in 2010 a study was conducted to assess the effectiveness of the act on EOLC practice (Sanchez et al. 2014). Using data from deaths over three years in one acute hospital in Spain the authors concluded that there were few significant differences in most of the areas addressed by the new law. The adjustments necessary to bring about positive change, they argue, are rooted in social, ethical and moral values, and rely therefore on a cultural change which goes deeper than simply modifications to the regulatory framework.

The U.S. spends a disproportionate amount on health care compared to Europe and offers an interesting point of comparison in relation to EOLC practice. Macpherson (2017) contends that despite spending \$3.4 trillion annually, health outcomes in the US are no better than counterparts in OECD (Organisation for Economic Co-Operation and Development) counterparts; a third of care is deemed inappropriate and a small minority of patients receive disproportionate levels of spending. Using seven quality indicators to determine quality of care at EOL they highlight significant variations in practice and provide a list of the 'best' and 'worst' places to die according to these scores. Looking at US EOLC legislation it is evident that the key areas providing challenge are similar to those in the UK. Namely the need to: strengthen physician–patient communication; return the focus of care to the person; build coordination of care across sectors and settings. Sustainable improvements, MacPherson (2017) advises not only demand changes to policy and legislation, but also require concerted cultural change together with support to the wider community, caregivers and professionals.

Still focussing on the US (Tilden and Thompson 2009), look at interventions introduced to help reduce 'futile' treatments. These include nurse led discussions sparked after a patient has been on a ventilator for 72 hours in ICU and 'ethics rounds' where patient treatment is reviewed by multi-professional panels. Such initiatives can, it is argued, begin a thoughtful dialogue and raise awareness of EOLC issues. The authors call for incremental changes such as these to be the starting point of more widespread change and larger research studies.

In Canada, Wilson et al (2017) show how deaths in hospital have seen a dramatic decline, from 78% in the mid 90's to 43.7% between 2014/15. Nonetheless given that most of the deaths still taking place in hospital were palliative in nature, it was concluded that there was still room for a substantial shift in services from acute settings into the community.

EOLC in lower income countries is not well documented, though one system that stands out as particularly worthy of mention is the community model developed in Kerala, the Southern State of India. India ranks at the bottom of the EIU ranking table, yet Kerala, with 3% of India's total population provides two thirds of the country's PC services (EIU 2015). It is the only Indian State with a PC policy in place and was the first to relax narcotics regulations to enable the legal use of morphine in PC. The model implemented, known as the Neighbourhood Network in Palliative Care (NNPC), relies on a core of peer trained volunteers that deliver services to patients who are largely able to remain in their own homes. The project is run and operated by the community and largely funded through a system of local 'micro-donations'. The volunteers provide social, psychological and spiritual care that supports the work of the state's local palliative care units and whilst they do not themselves provide medical care they are able to signpost those in the community who do (Sallnow, Kumar and Numpeli 2010; Government of Kerala 2019).

The UK's position as leader on the EIU tables is linked in part to its achievement as one of the first Western countries to produce a formal, coherent EOLC policy. A fuller analysis of the development and content English EOLC policy will be considered in chapter four.

2.2.1.2 The rise of 'medicalisation' and cultural attitudes to dying

Ivan Illich (1976) a Catholic priest turned social commentator, laid down a challenge to the rise of medical technology in the 1970's. His hypothesis, controversial then, as it is now, was that modern medicine has gone too far, staging an omniscient battle to eradicate, death, pain and sickness and in

doing so turning people into consumers or objects of its treatment and care, rather than active purveyors of their own health. He sees three levels of iatrogenesis operating in the system. The first, clinical iatrogenesis is the injury caused to patients by unnecessary medical intervention. The second, social iatrogenesis, results from a broader level of organisational thinking where pharmaceuticals and medical interventions are increasingly seen as the solutions to conditions that would previously have been dealt with in other ways. Third, and perhaps most pernicious according to Illich, is cultural iatrogenesis which refers to the destruction of dealing with and making sense of the body's decline into pain, sickness and ultimately death.

Culture makes pain tolerable by interpreting its necessity; only pain perceived as curable is intolerable...Duty, love, fascination, routines, prayer, and compassion were some of the means that enabled pain to be borne with dignity (Illich 1976 p. 133-134).

Callahan and Wasunna (2008) talk about a dominant culture of medicalisation resulting in what is seen as an imperative to extend life, often using aggressive medical interventions which can jeopardise a peaceful end of life. As technology grows in sophistication, the stakes on all sides get higher. The challenges that doctors face in balancing technology with a humanistic approach when treating the dying, grow more complex and Clark (2002) identifies an emerging paradigm shift in EOLC literature, towards an ethos embracing a more pro-active fight to ease suffering. Commentary on PC over the last few decades Clark (2002) observes has become more evidence based and less anecdotal and presents new concepts of dignity and respect in dying. The principles of hospice care, espoused by Cicely Saunders are more widespread and propose a more holistic concept of care. There is greater acceptance that mental distress runs alongside physical distress and that care of the dying must tend to the spiritual, social, cultural and psychological side of the individual as well as the physical body. Karkauer (2016) describes the phenomena as a global moral failing asserting:

Modern medicine's focus on mastering each part of the human body and the diseases that make them malfunction has generated remarkable power to sustain life. But this focus, shared by governments and health-care planners, has neglected the dying and their suffering, as if repressing a shameful secret (Karkauer 2016, p.445).

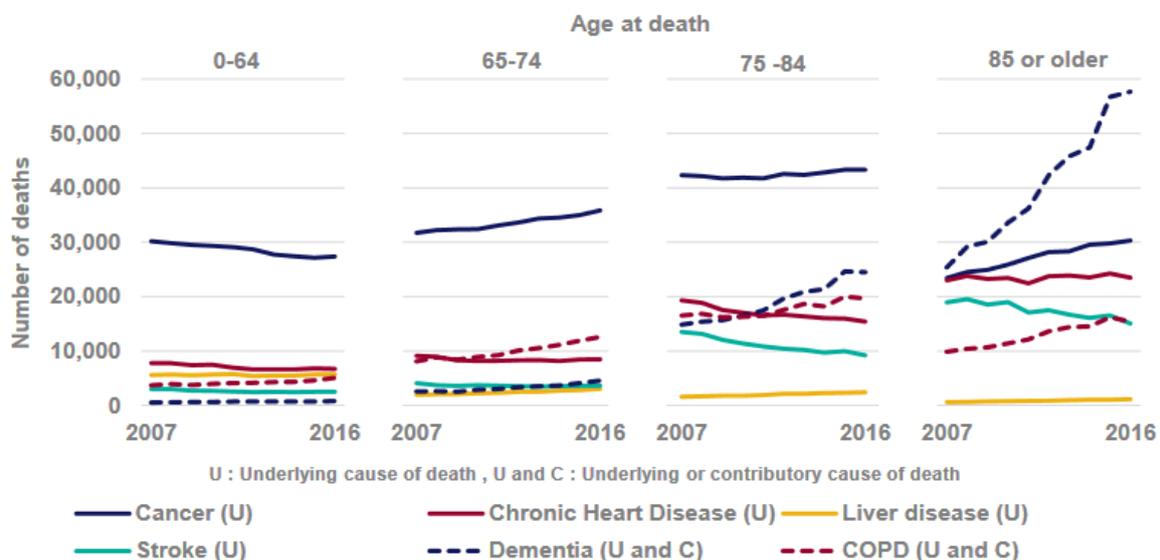
Running alongside advances in technology, there are concerns that the level of dignity, respect, safety and one to one contact from statutory caregivers in the UK is on the decline (Care Quality Commission 2011). Different funding and governance systems for health and social care, built up over the years, reflect a value system where medical interventions are often privileged over the

provision of care and have exacerbated the unequal treatment experienced by people at the end of life. The Barker Commission (Barker et al. 2014) highlighted the extent of some of the disparities in the health and social care arrangements in England, exemplified by the complexities of the Continuing Healthcare funding system whereby a patient, dying at home with dementia, is not entitled to a package of home nursing support, whilst a cancer patient receives full support. In the current system, the method of determining allocation of funds both within the health system (for example in dividing funds between clinical interventions and nursing care) and between health and social care, is both complex and lacks transparency (Barker et al. 2014).

2.2.1.3 System pressures funding decisions and resource allocation

Figure 2 shows how deaths in the 75-84 age group and 85+ have risen between 2007-2016 with a particularly fast rise in dementia.

Figure 2 Number of deaths by selected cause of death by age at death, England 2007-2016

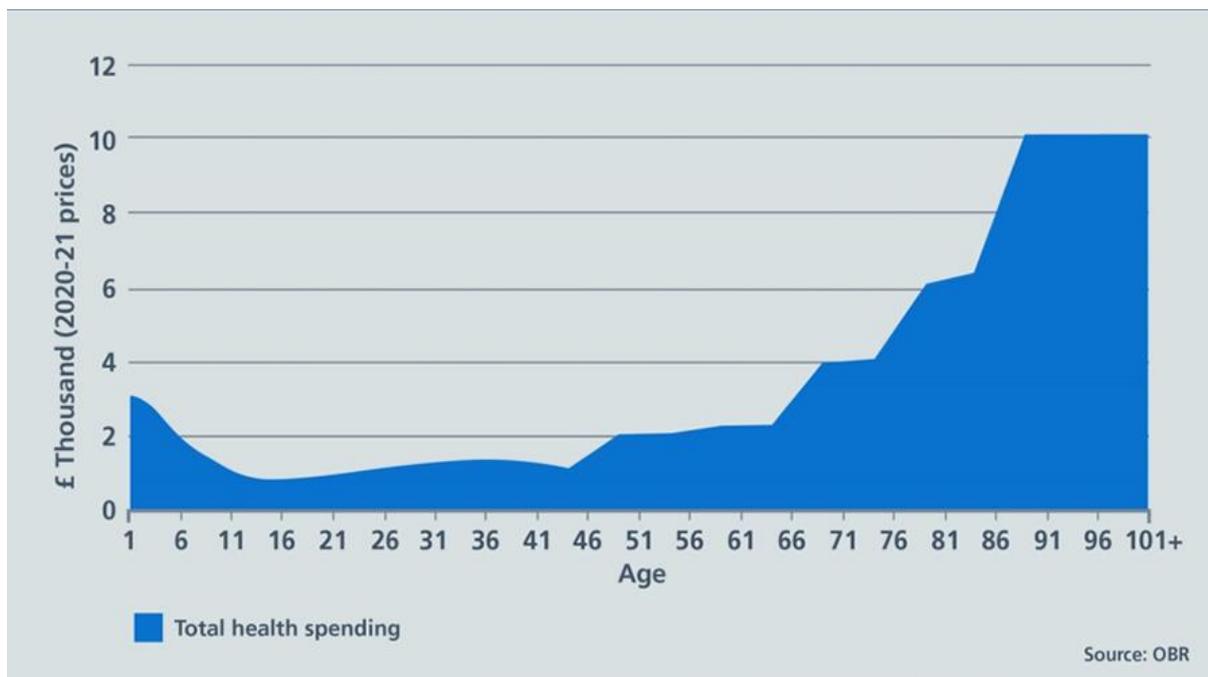


Taken from PHE (2018) p.11

Commentators are united in the view that the UK health system is under increasing pressure and that if funding gaps are to be realised a 'step change in thinking and action is urgently needed' (Alderwick et al. 2015). The call to action articulated in the NHS five year forward view (NHS England 2014) identified £22billion of productivity improvements by 2020/21. Making change happen, both at an individual and cultural level, will require a fundamental shift in approach at all levels of system

(government, leaders, policy, commissioners, providers, clinical teams, individual staff and patients). In June 2018 a real spending increase, for the NHS, of 3.4% was announced which whilst enough to address some of the current pressures, did not cover a number of key areas including capital investment (Charlesworth 2018). This funding boost represents a larger increase than has been seen in the last eight years but remains below the historical average of 3.7% (Stoye 2018). There is a need to shift the debate and revise expectations; the question of how to set boundaries on what public services can realistically provide needs to be urgently addressed.

Figure 3 Showing how health care spending rises sharply with age



Taken from 'The NHS at 70' <https://www.england.nhs.uk/five-year-forward-view/next-steps-on-the-nhs-five-year-forward-view/the-nhs-in-2017/>

Figure 3 shows the rise in total health spend by age in England. Whilst the upward incline shifts dramatically with age, putting an accurate figure on the amount of money spent on older people in the last year of life is problematic, both in terms of knowing what data to compare and being able to access required data. Unresolved issues include:

- i) should costs from both health and social care be included?
- ii) should money paid by both private and public funds be included?
- iii) which settings should be included; private homes; care homes; nursing homes; hospitals?

Despite these uncertainties what is clear is that the current demographic pressures described in Chapter 1 will lead to an unprecedented rise in public expenditure. Cracknell (2011) predicts that by 2050 25% of the population will be over the age of 65, compared to 18% in 2017 (ONS 2017). However, whilst it appears an increase in spend on English health and social care is inevitable in the light of the aging population – the scale of the increase is hard to predict (Gruenberg 2005). In a study using data from 40,000 individuals Howdon and Rice (2018) found that it is not age per se but time to death, particularly in the last year of life, that has the biggest impact on health care spending. The important link here is that Time to Death (TTD) is a proxy for morbidity – and it is the number and severity of conditions suffered that impact on health spend.

An increasingly high proportion of the NHS budget is spent on technologies and drugs, with these costs rising significantly at the end of life (Imison et al. 2011). Until recently NICE has had little leverage to determine how the impact of high costs drugs they approve may affect the rest of the system. In April 2017 new guidance was published (NICE 4th April 2017) advising that all drugs priced at £20million or more per year would be reviewed to see how they could ‘reasonably introduce them but in a way that does not take money away from other priorities and areas of clinical need’. The new proposed ‘budget impact test’ will trigger discussions between NHS England and the drug company to:

Find an approach that will not distort the NHS’s ability to pay for other important things. (NICE 4th April 2017).

NICE issued supplementary guidance (2009) suggesting that a different threshold be applied to (some of) those with EOL conditions. The recommendation was that if certain criteria were met, and there was robust evidence that the treatment would add an additional three months to life expectancy, then it may be appropriate to recommend such treatments even if they would not normally be considered ‘cost-effective’. Some consider this guidance unjustified (Shah 2014) and there is a growing literature exploring societal values on this issue (Coast 2014). Interviews with a sample of the general population conducted by Shah et al (2014), concluded that whilst there was some evidence to support giving priority to patients with shorter life spans, a sizeable minority expressed the opposite preferences, and there was a ‘substantial preference’ for improvement in quality of life rather than life extension.

Although a number of commentators have looked at issues of resource allocation in relation to ethics and justice (McMillan et al. 2006) little attention has been paid to the influence of government policy and how this impacts on practice. If increasing amounts of the health care budget are spent on drugs and interventions to prolong life – does this mean less money is available for example, for relational care provided by nurses and health care assistants? How does the size of one pot of funds influence another? Although such considerations may be valid the methods and processes used for allocating funds remain obscure.

2.2.1.4 Pressures on staff and staff support

As demand in the system grows so too does pressures on staff. The decade between 2010-20 has seen significant shortages of clinical staff in certain positions including GPs, nurses and palliative care consultants. NHS Digital (2019) reports there are currently 100,000 staff vacancies across the system with numbers of staff leaving the NHS between 2011-12 and 2018-19 nearly trebling (Buchan, Gershlick and Charlesworth 2019). Understaffing leaves staff feeling isolated and strained, subjected to increasing stress and anxiety.

A series of enquiries into hospital malpractice have all recognised that the greater the burden put on staff the more likely patients are to receive sub-optimal care. The link between patient and staff experience grows stronger as does the call for improved staff welfare (Francis 2013; Keogh 2013; Berwick 2013).

Another important factor that has been shown to be linked to the ability of staff to deliver good compassionate and relational care is the welfare of staff themselves. Maben et al (2012a) found in their study of acutely ill older people that patient experience of care was directly affected by staff welfare, indeed good staff experience is the forerunner to good patient experience. If staff are treated better in terms of ward culture and management style, patients report feeling better cared for by staff.

2.2.1.5 Inequities in the system

EOLC is not accessed equally across population groups with commentators showing that service provision is influenced by a range of factors including: level of deprivation; ethnicity; type of condition; cognitive ability (Lau and O'Connor 2012; Adshead and Dechamps 2016; PHE 2018).

A number of studies have shown that Black and Minority Ethnic (BAME) patients have reduced access to PC, appropriate pain and symptom relief, and are less likely to be able to die at home or in a hospice (Siriwardena and Clark 2004; Calanzani, Koffman and Higginson 2013). The reasons for such inequalities are complex and a number of suggested causal factors are shown in table 2.

Table 2 Factors linked to reduced access to palliative care in BAME communities

- Cultural and religious differences, for example, family oriented decision making
- Mistrust of the medical profession
- Language and communication barriers
- Financial constraints
- Transportation difficulties
- Perception of racial bias
- Local/national policies enabling more resources to be spent on particular groups or conditions
- The desire from some ethnic groups for more aggressive care

(Siriwardena and Clark 2004; Calanzani, Koffman and Higginson 2013, Koss and Baker 2017)

A review of services for BAME communities by CQC (2016) reinforces earlier findings suggesting a national picture of iniquitous service provision and highlighting the need for improved training and awareness particularly in relation to communication, cultural sensitivity and proactively supporting better access. Siriwardena and Clark (2004) emphasise how the differences within cultural and religious groups are often as big as the similarities between them and the focus for improvement should be on the patient centred approaches guided by a menu of different offers.

Deprivation is linked causally with a number of outcomes. Dixon's review of PC (2015) found a statistically significant link between quality of experience of GP care and indices of deprivation. Similarly there was a correlation in the National Survey of Bereaved people between quality of care and area deprivation. Inequalities in care were also found with age (older people receiving poorer care), the existence of a spouse/partner and disease type. Recommendations made to improve care offered to BAME groups include the provision of appropriate literature, interpreter services, liaison

services, equal opportunity strategies staff training, systematic referral and equality audits (CQC 2016).

2.2.1.6 Influence of corporate business (pharmaceuticals, care providers, insurance) on EOLC provision

Issues concerning the way the market influences access to and availability of EOLC, whilst perhaps more pertinent to countries without a national publicly funded health service, are worthy of consideration - though an in depth analysis of this area is largely beyond the scope of the current study. Whilst in the UK the NHS remains the dominant provider of care at EOL, there are growing numbers using private, voluntary and charitable providers. Despite the UK's publicly funded health service, death it appears, is big business; with all aspects of the sector (including undertakers, bereavement counsellors, health providers and academics) all developing their own professional portfolios. Callahan (2011; 2008), a philosopher and bio-medical ethicist, is a vociferous voice from the States who highlights the anomalies presented within a highly commercialised health care system, where the contrast between private and public systems are particularly stark. Americans, he asserts, have an incontrovertible belief in the benefits accrued by progress and technological innovation – as a result, he suggests, a situation has arisen where there are 'excessive financial rewards for providing often excessive EOLC' (Callahan 2012 p.462). American physicians are for the most part paid on a fee-for-service basis, and on the whole receive better financial rewards 'for the use of technology than for talking with patients' (p.459). The hospitals where their patients are based tend to find that having the latest and best technology gives them an edge over competitors, pushing costs ever higher (Callahan 2012 p.459). The drive to keep patients alive longer, not perhaps cured of disease but living with increased medical needs, is, according to this paradigm, economically appealing. Whilst the costing models of American and UK healthcare are fundamentally different, it remains the case in the UK that perverse incentives still exist where hospitals may be given financial incentives to carry out interventions, even towards the EOL, regardless of clinical need (Mears 2014).

2.2.2 At meso level:

2.2.2.1 Care pathways, models of care and related tools

There is an incomplete but evolving evidence base around new care models, pathways, and EOLC tools. Evaluation and dissemination of new models is variable and there is concern that traditionally respected research methods such as the gold standard for RCTs (Sullivan 2011) and systematic

reviews (Dixon-Woods et al. 2006) may be too rigid for most ongoing ‘real-life’ research rendering results unhelpful and invalid.

Some of the best-known tools and models used nationally are shown in table 3 below and will be discussed in more detail throughout this chapter.

Table 3 Examples of models and tools used in EOLC

Examples of models, pathways and tools being developed in End of Life Care
<p>Enhanced Health in Care Homes Vanguards (NHS England 2018)</p> <p>A number of national vanguards provided learning to improve NHS partnerships with care home providers and local authority services. Guidance is provided on new evidence-based models of care and support for older people.</p>
<p>The Gold Standards Framework Prognostic Indicator (Royal College of Physicians 2016)</p> <p>The Gold Standards Framework (GSF) provides training for generalist frontline staff in health and social care, to enable the provision of ‘gold standard’ care for all people nearing the EOL.</p>
<p>Amber Care Bundle (Guy’s and St Thomas’ NHS Foundation Trust 2018)</p> <p>An approach used in hospitals when clinicians are uncertain whether a patient may recover and suspect that they may only have a few months left to live. It encourages staff, patients and families to continue with treatment in the hope of a recovery, while talking openly about patient’s wishes and putting plans in place should the worst happen.</p>
<p>The Daffodil Scheme. RCGP and Marie Curie (2018).</p> <p>A free, evidence-based, structured approach to help general practitioners to consistently offer the best EOLC for patients.</p>

2.2.2.1.1 Integrated models of care

There is recognition within the development of new models and ways of thinking that more joined up, integrated care is needed with more emphasis on the community. Staff need better support and leadership, with EOLC approached more consistently and given greater priority across the system (National Council for Palliative Care 2015). Hashem et al (2020) applied a realist logic of analysis to a systematic literature review of hospice services and found that structural and organisational factors emerged as a key theme, influencing the manner in which care was coordinated; either obstructing or facilitating provision of good care. Inter-professional collaboration was found to be a key enabler

of effective seamless practice, yet the considerable range of different staff, across organisations and settings means that *'providing seamless care is challenging'* (Hashem et al 202, p.28)

Ongoing work developing Integrated Care Systems (ICSs) and Accountable Care Systems (ACS) will no doubt impact on the future delivery of EOLC and important learning is promised from the devolved models of care currently being tested. The Greater Manchester Health and Care Partnership, for example, (Walshe et al. 2018), is trialling a system wide health and care partnership enabling pooled budgets and joint commissioning. Early reports from Devo-Manch, as it is known, suggest that whilst there is the potential to reduce gaps in quality and funding in health care, as yet progress is hampered by the fact that there are no new regulatory powers – with health ultimately remaining the responsibility of a government department rather than the combined authority or the mayor – creating barriers to any real joint accountability (Quilter-Pinner and Antink 2017). The assumption is that the lack of real decentralisation might make it harder for local areas to unleash the creativity and transformative thinking needed to bring about real change.

Like the STPs from which the ICSs evolved, new systems and partnerships seek to make sense of the complex and fragmented organisational arrangements resulting from the Health and Social Care Act (2012). A 2018 briefing paper on EOLC in England identified the need for improved integration of health and care commissioning and the need to shift the focus of care from acute to primary (Hunter and Orlovic 2018). Yet a number of barriers have been identified undermining efforts to join up commissioning including fiscal constraints together with severe cuts to social care over the last decade (Charlesworth 2019).

[2.2.2.1.2 Assessment and prognostication](#)

Identification of the EOL is complex and nuanced. A range of tools exist but staff support and training is needed to promote effective understanding (Cardona-Morrell 2015). Whilst it may be impossible to predict exactly when someone may die, clinical experience and understanding alongside the question 'would you be surprised if this person dies in the next year?' provide a reasonable indicator. In addition recent indicators of frailty and decline (Stow, Matthews and Hanratty 2018) may be used to provide guestimates. The Gold Standards Framework (GSF) Prognostic Indicator Guidance (table 4) pulls together tools which provide indicators for a range of different conditions (GSF 2011).

Table 4 Tools to identify End of Life

Three indicators that suggest patients are nearing the end of life
1. The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?
2. General indicators of decline - deterioration, increasing need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.

Taken from The Gold Standards Framework (2011)

The Supportive Palliative Care Indicator Tool (SPICT) (University of Edinburgh 2017) is another prognostication tool which is gaining traction amongst health professionals. The SPICT is a collaborative programme, running since 2010, which provides guidance on a range of clinical indicators with the aim to identify people whose health is deteriorating and to help assess their unmet supportive and palliative care needs. An evaluation of the programme (Highet et al. 2014) concluded that SPICT can support multidisciplinary teams identifying patients at risk of deteriorating and dying, particularly those with multiple, unmet needs.

In primary care good practice requires GPs to identify patients on their lists who are approaching EOL and are likely to die within the next 12 months. Guidance suggests these patients be included on a register which should detail a care plan and record patient choices. On average it is anticipated that within any one GP practice, 1% of recorded patients will die per year and the goal is therefore to have a register consisting of 1% of patients. The GSF guidance paper on palliative care (GSF 2006) suggests that using GSF tools and templates every practice should:

- Identify patients in need of PC – including non-cancer patient
- Set up a PC register using GSF template
- Meet regularly as an MDT to discuss, review and plan and care for these patients.

Practices that achieve these criteria are awarded up to six extra points on the quality outcomes framework (NHS Digital 2018).

The National Audit of EOLC (RCP and Marie Curie. 2016) suggests that 93% of patients in hospital, whose death was predictable, had documentation to show that they would probably die. In 76% of

these cases a senior doctor had been involved in prognostication. The length of time before death at which point prognostication was offered varied – for half of those with documentation it was created less than 24 hours before death. Of those recognised as being likely to die only 25% had documented evidence that a discussion had taken place with a health care professional, however discussions with relatives were much more common and were documented in 95% of cases.

2.2.2.1.3 Advance Care Plans (ACPs) and Advance Directives (ADs)

ACPs are a way of facilitating early conversations about what people want at EOL before a crisis is reached at which stage patients may no longer be in a position to make a choice. Encouraging patients and family to have open and honest conversations about death helps ensure that patients wishes are more likely to be met, securing, what for them, is a 'good death' (Macmillan 2018). ACPs also help ensure that patients have understood the legal options available to them, promoting assurance over financial and medical decision making. Hashem et al (2020) identified the potential value of ACPs in enabling patient's wishes, yet highlight issues around lack of clarity as to whose role it is to initiate ACPs as well as challenge in electronic recording of data.

The National Audit of EOLC (RCP and Marie Curie. 2016) found that of the 9302 patients in the study only 415 (4%) had a formal, written ACP which was made prior to admission to hospital. Yet, despite these low numbers for those in possession of an ACP evidence of benefit is strong. A review of three RCTs (Nice 2018) found that ACPs result in less visits to A&E, reduced inpatient admissions and increased family satisfaction. In addition to improved patient and family experience data (CMC 2013) also suggests that on average having a plan in place may save the NHS an average of £2,100 per patient. Coordinate My Care (CMC) data suggests that 75% of those with a care plan die in their place of choice (Chill 2016) . Of those patients with a plan 18% die in hospital, compared to a national figure of 54%. However, the percentage of people admitted to hospital with a plan remains small. A study analysing secondary data in England (Dixon, King and Knapp 2016) found that of 22,661 patients, only 15% had a preferred place of death recorded by health care staff. Of that 15%, those with a cancer diagnosis had significantly higher odds of having a preference for location of death recorded, as did those living in more affluent communities and those with partners.

The Amber Care Bundle (Guy's and St Thomas' NHS Foundation Trust 2018) is a key enabler used to support communication with patients and family and promote good planning when recovery is uncertain. The tool has the potential to improve the care of patients with an uncertain prognosis at

EOL, its benefit comes about from supporting patients to recognise their condition and prompt discussion about their preferences around treatment and care (Carey et al. 2015).

Technology is increasingly being harnessed to share care plans electronically across different providers and settings, in an effort to ensure that information pertaining to the patient's wishes accompanies them on their journey through the care pathways – these systems are known as Electronic Palliative Care Co-ordination systems (EPaCCS).

2.2.2.1.4 Electronic Palliative Care Co-ordination Systems

EPaCCS aim to improve communication and coordination relating to patient's preferences at EOL. One of the most joined up national EPaCCS exists in London, where a system called Coordinate my Care (CMC) is funded by 32 London based CCGs. CMC is a platform designed to hold information about patients including the choice of treatment and care that they have specified for EOL. The electronic plan may include the individual's preferred place of death or care, helping to ensure they are not taken to busy and stressful hospital environments, when they do not need to be, particularly in cases where there may be a community team to support them at home. Early data suggests that the system is well received by patients and professionals - although there are the inevitable obstacles presented by GDPR, confidentiality and compatibility of different IT systems across settings - it appears that use of such systems is gaining traction. In London 50,000 CMC plans have been created (Wrigley 2018) representing only a tiny fraction of its 8.6 million population. However, of those in possession of an EPaCC positive outcomes are reported. In London 77.8% of patients with a CMC plan die in their preferred place (PHE 2014). Petrova et al (2016) report on the challenges around implementation of EPaCCS, particularly in terms of integrating data with established systems, which has resulted in many projects folding or be continuously in development.

2.2.2.1.5 Training and education

Since the Francis Report (2013) revealed the endemic scale of neglect within a number of acute trusts, there has arguably been greater importance attached to the delivery of compassionate care. Despite this, there are warnings that training and education, have not kept up with changes in political imperatives (Abel and Kellehear 2018). Death remains a taboo subject riddled with stigma and sensitivity and a reluctance to tackle sensitive conversations around EOL is confounded by a poor understanding of EOL processes both on the part of staff, patients and carers/relatives.

The need for training to improve communication between clinicians and patients is commonly referred to in the literature, but many barriers remain underexplored (Wollaston 2015). Obstacles include time and resource pressures, unclear roles and responsibilities, attitudinal barriers, models for referral and forward care, poor multi-disciplinary working, patient and public expectations and possible perverse organisational or professional incentives (Dixon et al. 2015).

Evidence suggests that more time spent communicating about options available to patients at EOL may both improve patient experience and reduce costs. Indeed, a study of 396 advanced cancer patients in the US found that self-reported quality of life was better in those patients who avoided admission to the intensive care unit and the consequent interventions resulting from such a course of action (Zhang, Nilsson and Prigerson 2012). Proactive communication from the point of first diagnosis was welcomed by both patients and carers (S. A. Murray et al. 2008; Kendall et al. 2007; Kendall et al. 2006; Hashem et al 2020) and a randomised study in the US found that the presence of advance directives, including decisions to refuse treatment, was linked to improved patient satisfaction (Engelhardt et al. 2006).

Studies also support the finding that when patients are presented with clear information about the choices available to them at EOL they will tend to opt for less invasive options which not only supports the personalisation agenda, conferring greater autonomy in decision making, but may also present an overall cost saving to the health system (De Silva 2012).

One reason attributed to the fact that the majority of individuals continue to die without an ACP in place is that professionals working with those who are dying lack the skills, knowledge and confidence to be able to initiate EOL conversations (Macmillan 2018, De Vleminck et al. 2016). There is considerable dissonance between the strategic ambitions of ACP and how older people actually want to discuss their end of life (Godfrey 2015). EOL discussions are emotionally charged, requiring not only well-honed skills from those involved but also the luxury of time and space, something that health professionals, working in highly charged and pressured environments, often do not have. The consequence is that professionals avoid initiating difficult conversations (Galushko, Romotzky and Voltz 2012). Interdisciplinary work can be beneficial though often structural barriers obstruct effective team-work. The Royal College of Physicians (Bailey and Cogle 2018) suggest that earlier conversations with patients, suffering from either a progressive or terminal condition, including frailty, would be welcomed.

Qualitative research commissioned by Public Health England (PHE) (Solutions Research 2016) recommended that conversations with patients about EOL should be conducted early in the patient pathway, when the individual is more likely to have insight and full capacity. However, the report acknowledges that the topic is hard to introduce, may sometimes be viewed as premature and is easier to raise once the person is in the later stages of an incurable illness. Supporting staff in initiating often difficult, EOL conversations, is an area increasingly viewed as a priority by service providers. The 2016 EOLC Audit (Marie Curie and RCP 2016) found that of trusts surveyed 49% had offered formal training in EOL communication to allied health professionals, 63% to medics and 71% to nursing staff.

A critical review by Abel et al (2018) evaluates the syllabus for training of palliative care doctors in the UK and concludes that it currently places too much attention on the clinical concerns of harm reduction, whilst glossing over key public health and social concerns which have become more pertinent particularly in the light of changing demographics over the last two decades. The central tension in constructing an appropriate syllabus echoes the debate presented in section 2.2.1.2 around the primacy of the medical model for education and its acknowledgement (or lack) of the social determinants of health. Indeed, Abel et al (2018) note that only a fraction of the current syllabus is devoted to psychosocial care and to public health concerns. The authors conclude:

The current UK syllabus inadequately prepares its trainees for the main social and public health challenges of living while dying, or living with long-term caregiving, grief, and bereavement (Abel and Kellehear 2018. p.2).

Whilst the current policy context for palliative and EOLC puts increasing emphasis on the importance of continued social connections and networks for the dying, as well as support for those offering care, it appears that such policy is not yet backed by a consistent educational approach. The Palliative Medicine Syllabus, produced by the Joint Royal College of Physicians Training Board (2014), is seen to largely neglect the public health component of PC. Abel and Kellehear (2018) suggest that future revisions of the curriculum should incorporate:

- i) a wider process of consultation with those involved in geriatric medicine (both professionally and in the community) and should cover a broad range of age-related conditions in addition to cancer (neurological disorder, organ failure, dementia and frailty)
- ii) A review of academic literature on health promoting PC and examination of PC policy

- iii) Epidemiological insights backed by practical learning from public health projects, particularly through recognition of the importance of community support and how this can enhance well-being – rather than the current over-emphasis on symptom control

The call for more rigorous, routine training for health professionals, both in communication about and identification of EOL, together with better familiarisation with EOL tools and pathways is strongly made in a range of policy and strategy reports (Thoosen et al. 2016; Neuberger 2013; NHS England 2014b; Wollaston 2015; Hunter and Orlovic 2018; Deloitte 2014; Hashem et al 2020).

2.2.2.1.6 Commissioning tools

A number of EOLC modelling tools are available on the National End of Life Care Intelligence Network (NEOLCIN) website intended to help commissioners answer questions relating to:

- i) modelling the number of deaths each year in the locality alongside a calculation of the number of EOL bed days in hospital
- ii) calculations to show how early recognition impacts on the last days/weeks of life
- iii) the financial implications of the numbers in each area dying in hospital and how a shift in resources from acute to community may impact on the tariff
- iv) an analysis of the main five cohorts which characterise the way people die (sudden death 14%, cancers 21%, other terminal disease 4%, organ failure 19%, frailty 42%) and what this means in terms of resource distribution
- v) how changes simulated in these models impact on the health and care workforce and what this means in relation to resources and budgets

In addition a number of toolkits are available for use by commissioners, including for example, 'Commissioning Person Centred End of Life Care' (NHSE 2016) and 'RCGP Commissioning Guidance in End of Care' (RCGP 2013) together with a summarised check list produced by London Clinical Network, 'Commissioners' checklist (RCGP 2016). All these resources acknowledge the huge complexity involved in commissioning and recommend following the steps outlined below.

Table 5 Recommended steps in the commissioning process

<p>Develop a local vision and strategy - using national guidance, resources, local knowledge and networks to agree aims and goals. Integral to successful strategy development is the need to establish, from the start, clear governance and leadership structures including senior people across each setting (NHS trust, CCG, adult social care, primary care, lead GPs) who are assigned responsibility for EOL (London Strategic Clinical Networks 2016)</p>
<p>Gather information - from national and local data sources with a particular focus <u>on</u>: reducing hospitalisation; long term conditions; care for the elderly; frailty and those with dementia. Identify local policies and procedures. Assess what services are in place and identify gaps</p>
<p>Plan and specify - Identify the services needed to meet the needs and wishes of people approaching the EOL and develop the necessary service specifications. All service specifications need to state what acceptable outcomes will look like and how they will be identified and should, to this end, include key indicators and quality outcome markers. All organisations should plan a monitoring system, detailing how outcomes for EOLC will be prioritised and fed routinely to the board. In line with the quality improvement agenda there should be a focus on improving quality and reducing costs. Guidance includes a call for innovative, cross sectoral, partnership working between health, social-care and the third sector. Moreover, each service must be considered in relation to the five domains of care; right person, right care, right place, right time, every time.</p>
<p>Procurement. Work with local health and social care providers to develop contractual arrangements for effective commissioning.</p>

Sources: NHSE (2016), RCGP (2013 and 2016)

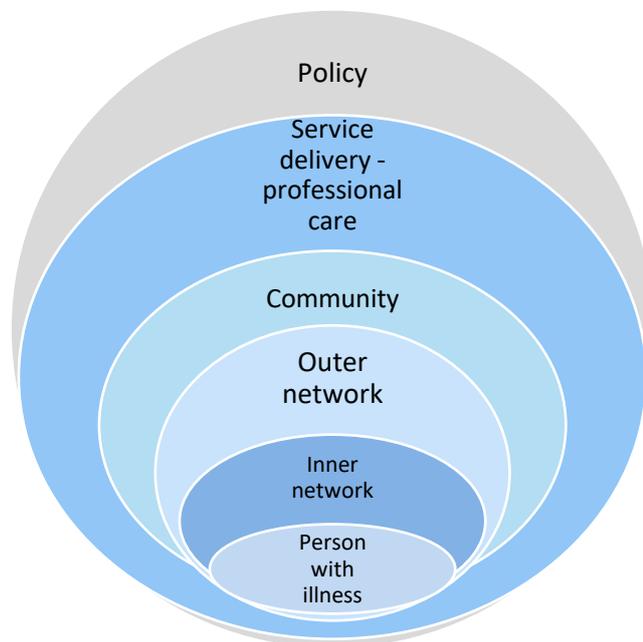
In 2015, PHE commissioned a programme of work to enable CCGs, local authorities, and other decision makers to better understand the health and economic case for increasing investment in prevention and early intervention. The work culminated in the publication of 'Cost-effective commissioning of EOLC' (PHE 2017), and related tools aimed to support programme leads and commissioners who were involved in the planning of health and social care interventions for patients at EOL. The guidance specifically explores the trade-offs associated with shifting care from an acute setting to a primary, community and/or social care setting. Tools produced as a result of the work have created a model for assessing the relative financial outlay of different EOLC interventions estimating costs to both acute and community settings. Whilst data around costs can never be 100% accurate, the aim is to provide a ball-park figure, presenting the user with an assessment of the potential net financial implications of a shift in activities. If the numbers of acute hospital beds for those at EOL are cut and more resources diverted to the community,

commissioners are able to input local data to model projected costs and in this way facilitate service planning.

2.2.2.1.7 Compassionate Communities

Focussed work around non-medical forms of support is being developed, one example being that of ‘compassionate communities’ which endeavours to create supportive local environments. Whilst community initiatives supporting the dying are on the increase they are reported to be poorly signposted and knowledge about and access to community-based support is variable (Solutions Research 2016). There is a sense that community-based initiatives may feel less integrated than medical services, with no clear roadmap for how they can be accessed. Abel (2018) presents a new way to conceptualise the compassionate community, presenting a model that focuses not just on the patient, but on the main carer and the caring network. He conjectures that failure to engage with and trust the caring network around the patient not only misses an important opportunity to fully connect and add value to the patient/carer relationship, but may actually cause significant harm which can exacerbate bereavement reactions.

Figure 4 **Circles of Care in compassionate communities**



Source: Abel (2018)

2.2.3 At micro level:

2.2.3.1 *Prevailing attitudes/dominant cultures: Patient, carer and staff behaviours*

A range of individual characteristics and types of behaviour are reported in the literature which have been found to impact on the way care is provided and received (Findik, Unsar and Sut 2010). Character traits, behaviours, beliefs and preferences inevitably affect the interaction and experiences of both staff and patients. Whilst literature pertaining to the behaviour of elderly patients at EOL and its impact on outcomes is scant, more generic studies suggest that patient characteristics have an important causal link with experience and outcomes. Maben (2012) found that patients on a geriatric ward, perceived to be easy to care for (referred to as 'poppets'), may be favoured by nurses over more complex patients who were made to feel like 'parcels', particularly in stressed environments. The easier patients, the 'poppets', report better patient experience. A review of literature exploring the importance of the therapeutic relationship between patient and professionals looked at factors that may interfere with positive social interactions, a number of which are likely to face patients at EOL including for example, excessive use of technology, increased staff workloads, lack of staff training and confidence (Kornhaber et al. 2016).

Attitudes and preferences of clinicians have also been linked to patient outcomes. Davidson (2013) suggests that physician age, race, religion, attitude to risk and personality are all factors which influence EOL decisions they make for their patients. He coins the term 'physician roster lottery', highlighting discrepancies in treatment as a potential ethical problem. Campbell et al (2015) in a Zimbabwean study found that amongst patients with HIV needing antiretroviral treatment, those whose behaviour was construed as 'good', were better treated by the nurses than those who did not live up to the accolade. For the latter group, good care and continued access to treatment was called into question and their health jeopardised. The benefits of clinicians being open and transparent in discussions with patient are frequently cited and tensions are reported when clinicians have conflicting approaches. One study investigating nurses working in intensive care units found a tendency for nurses to become frustrated when they were asked to operationalise medical plans which conflicted with their views particularly when they felt that messages given were overoptimistic or the treatments futile (Cox, Handy and Blay 2012; Coombs and Long 2008).

Notably the type of care clinicians say they would choose at EOL, does not always align with public perceptions of good EOLC. A letter sent to the Daily Telegraph (06/11/2012), following the furore over the Liverpool Care Pathway (LCP) and its subsequent withdrawal from standard practice, signed

by 1300 health professionals who had worked with dying patients, states that practice recommended under the LCP is *'how we would wish to be cared for at the end of our lives and our patients deserve to be offered nothing less'*. Indeed, an American study (White 2014) found that an overwhelming percentage of doctors (88.3% from a sample of 1081 physicians) said that they would choose do-not-resuscitate orders for themselves.

2.2.4 Measures used to improve consistency of care

Monitoring and evaluating outcomes at EOL are incorporated here as a cross cutting theme, used at all system levels to assess the effectiveness of different types of care and treatment offered. Although the quality of data collected in England has recently improved due to the efforts of NEOLCIN to provide a central data base, rigorous research evidence relating to the effectiveness of PC is said to be lacking (Wollaston 2015). This is in part due to the lack of agreed indicators to measure effectiveness, particularly in relation to patient experience at EOL (The National Council for Palliative Care 2014). Knowledge about the way strategies are delivered locally rely largely on self-report, proxy feedback from carers and review of documentation; meaning that is difficult to assess how effective policies are. Moreover, the gathering of robust outcome data relating to EOLC is collected inconsistently across the UK, meaning that clear baselines and comparisons are hard to come by. National surveys such as the VOICES survey in England conducted with bereaved relatives (Department of Health 2012) have proved invaluable in providing more sensitive data, as has the 'profiles section' of the NEOLCIN website which has provided English data since 2016. However, gaps remain, particularly in the collection of micro-level data from patients and service evaluations looking at integrated, community-based systems of EOLC provision are hard to come by, particularly those relating to public health and Compassionate Communities (Marie Curie 2016). STPs, charged to develop new models of care, are likely to begin to provide findings linked to EOLC. However early indications are that inconsistent attention will be paid to EOLC. Findings from a survey conducted by the End of Life Care Coalitions (2017) show that of the 44 STPs 18 have no mention of EOLC in their strategy documents, 15 have specific actions to improve EOLC, and 11 have embedded EOLC as a strategic priority (End of Life Care Coalition 2017).

Strategies used to measure effectiveness of EOLC interventions:

Complexity, it is said, defines health (WHO 2010) and monitoring the success of interventions and programmes to promote good health, or in this case 'a good end' is bound up in a confounding web of variables and uncertain levels of causation. Health agendas vacillate between an emphasis on technology based medical care on the one hand and public health interventions focussing on

individual behaviour and cultural norms on the other. This apparent duality in the approach to health is reflected in methods used to measure outcomes at EOL with a huge range of different measuring systems coming into play. Each measuring system is focussed on recording different types of outputs using different theoretical frameworks.

Economic Evaluation

Economic evaluations use value for money or economic indicators. They tend to be used as an integral part of a broader evaluation where weighting systems are in place to assess the relative importance attributed to different outcomes with a unit price attached to each outcome.

Coast (2014) highlights the lack of consensus for economic indicators used to evaluate EOLC and identifies three theoretical approaches, illustrated in appendix 2.1.

National Audit and validated measures for quality at the EOL

The complexity of incorporating suitable measures to provide assurance of the effectiveness of EOLC programmes is acknowledged and there has been a significant shift in emphasis towards softer measures of patient and carer experience, following the bad publicity emerging from the harrowing stories shared by bereaved friends and relatives in the Neuberger Enquiry (2014). Drawing on the failings of the Liverpool Care Pathway a new approach was proposed for looking after the dying referred to as achieving five 'priorities of care' (2014 LACDP). Under this model of care the dying person took a more central position as the focus of care and this is reflected in the outcomes determining the achievement of these priorities (table 6).

Table 6 Achieving five priorities of care

Outcomes linked to five priorities of care when it is recognised that a person is likely to die within the next few days/hours:
<ul style="list-style-type: none"> • That this information is recognised and communicated and that everything is then done to ensure decisions and actions comply with the person’s needs and wishes and these are regularly reviewed
<ul style="list-style-type: none"> • That sensitive communication takes place between staff, the dying person, and those identified as important to them
<ul style="list-style-type: none"> • That the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
<ul style="list-style-type: none"> • That the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
<ul style="list-style-type: none"> • That an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

Data taken from LACDP (2014)

Using these outcomes as a focus, a national audit conducted in 2018/19 (HQIP 2019) looked at how well these priorities were being achieved in English hospitals and community providers.

Results found practice was inconsistent. Although the number of patients with an ACP is on the rise (7% of patients were reported to have ACPs) for half of patient’s death is only recognised less than one and a half days before they die and 22% of relatives reported concerns about communication with professionals.

The ICEPAC project (University of Birmingham 2018) has developed capability instruments, notably the Supportive Care Measure (ICECAP-SCM), a tool for use in evaluations conducted in EOL settings. The attributes included in ICEPAC are shown in table 7.

Table 7 ICEPAC measures for Supportive Care at the End of Life

ICEPAC Supportive Care Measures
Choice 'Being able to make decisions about my life and care'
Love and affection 'Being able to be with people who care about me'
Physical suffering 'Experiencing significant physical discomfort'
Emotional suffering 'Experiencing emotional suffering'
Dignity 'Being able to maintain my dignity and self-respect'
Being supported 'Being able to have the help and support that I need'
Preparation 'Having had the opportunity to make the preparations I want to make'

Source: University of Birmingham (2018)

Early feasibility studies (Bailey et al. 2016), of ICECAP-SCM demonstrate that it is a valid tool to measure the quality of life among patients receiving supportive and palliative care, assessing attributes that are important to people at EOL. Further testing is needed in a wider variety of settings with a range of ethnic groups. Work by Huynh et al (2017) to determine the relative value assigned to capabilities should help give clearer insight into what aspects of EOLC are most important to a variety of stakeholders and ultimately provide a quantified estimate of the gain (or loss) in benefit from interventions provided. Cost data can then be applied to these outcomes to help determine efficiency and inform future policy and decision making.

Commissioning advice (table 8) provided to CCGs (RCGP 2016) provides recommendations for key indicators and measures at EOL.

Table 8 Recommendations for data to be collected at EOL

<ul style="list-style-type: none"> • Patient/carer feedback through VOICES, locally collected user experience data or public engagement events
<ul style="list-style-type: none"> • Independent quality assessment/assurance for example through accreditation from organisations such as the Gold Standards Framework
<p>Key outcome measures including for example:</p> <ul style="list-style-type: none"> • Numbers of identified patients on GP end of life or palliative care registers against the number of anticipated deaths • Number of patients on GP EOLC register with a non-cancer diagnosis • Number of carers offered assessment and care in bereavement • Numbers with recorded ACP • Numbers of patients able to live and die where they wish • Patients receiving timely proactive anticipatory care • Evidence of consistency or patient outcomes through regular audits

Adapted from RCGP (2016)

Who to collect data from and how to collect it?

Collecting data from patients at EOL is problematic (Addicot 2010) both ethically, given the sensitivity of the subject matter, and practically on account of patients often being too sick, frail or cognitively impaired. Yet the reliability of data collected from a proxy (often the relative or carer) and the impact of time lapse between the episode of care/dying and data collection inevitably impacts on data reliability. Data is routinely collected from clinicians and recently more effort has been made to collect data directly from patients and relatives (Department of Health 2012). The question of to what extent assessment by staff or caregivers agrees with patient self-assessment remains controversial (Pastrana et al. 2010) – yet given the high numbers of patients receiving palliative care who are not in a position to self-assess, some degree of assessment by others remains inevitable.

The Voices survey (Department of Health 2012) and NHSE are currently involved in developing more patient centred measures for EOL. In addition to data collected with specific research purposes in mind, considerable amounts of data are collected routinely across the NHS and Davies et al (2016) highlight the potential value of using this data more creatively to help improve EOLC. Table 9 shows

some of the possible sources of routinely collected data which could be used to better interrogate outcomes.

Table 9 **Routinely collected data at EOL which may contribute to more effective monitoring**

Sources of routinely collected data relevant to the EOL
Death registry data including place of death
Hospital activity data – record information on diagnosis and treatment
Primary Care Data – The Clinical Practice Research Datalink (CPRD) contains longitudinal medical records on a sample of 10% of the UK population
Social Care Data – significant gaps here. Recent project by Nuffield Trust and NEoLCIN collected data from seven local authorities and linked it individually to secondary healthcare data
NHS national surveys including Views of Informal Carers – Evaluation of Services (VOICES), The Carers Survey and Adult Social Care Survey
NEoLCIN provides local level data relevant to EOLC.

Adapted from Davies et al (2016)

Literature looking at measuring the effectiveness of interventions at EOL suggests that the indicators or instruments used are frequently inadequate (Gomes 2013). Place of death is often used to represent quality in performance of EOLC, yet whilst evidence suggests that community care at EOL is cheaper than acute hospital care, as an indicator of ‘quality of death’ or patient experience, ‘death in usual place of residence’ is at best a crude indicator of quality of outcome. Data suggests that more people would like to die at home or in their usual place of residence than in hospital, though this appears to change the closer the individual gets to death and data may be more heterogenous than some assume (Gomes et al 2013). Other more nuanced measures including a recent focus on ‘number of emergency admissions in the last three months of life’ may prove a better indicator of the responsiveness of the broader system to patient need (Shah 2013).

2.3 Chapter summary

This chapter began with defining key terms pertinent to the thesis; EOLC, PC and policy. It moved on to examine the scant literature, both national and international, exploring the impact that EOLC policy has on practice – the intention being to identify key factors impacting on EOLC outcomes. Analysis of relevant literature was divided into the structural levels at which related contextual

factors reside; micro, macro and meso. This framework fits with Pawson's proposition that outcomes are impacted by a number of contextual layers which he refers to as the 'four I's', relating to the individual, interpersonal relationships, the institutional setting and wider infrastructural factors. This schema is used throughout the thesis.

At the macro level, although policy is generally considered to support improved outcomes there was a dearth of literature evaluating the impact of EOLC policy on outcomes. The influence of broad government policies around the structuring and funding of the health and care system was considered and the English context, characterised by reductions in funding to social care between 2010-20 resulting in a growing differential between health and social care, was noted. Perhaps not unrelated to this, is the concept of 'over medicalisation', often felt to be employed at the expense of empathetic, relational care (Heath 2016; Illich 1976; Gawande 2014; Callahan and Wasunna 2008). Other macro level issues arising in the literature relate to system pressures on staff and resources and growing levels of inequality (Marmot et al. 2020). At the meso level the literature focussed on care pathways and models of care and noted both the lack of integration across pathways and the incomplete and inconsistent research base from which evidence is sought. Provision of sufficient and consistent training for staff (both clinical staff, support staff and commissioners) was also addressed. Finally, at the micro-level, the potential impact of patient and clinician characteristics and preferences, on the care received, was discussed. The importance of identifying ways to monitor and measure outcomes ran through each of the structural levels, with recognition that measuring 'hard' outcomes was often easier than measuring qualitative patient perceptions of the quality and the experience of dying.

The next chapter looks at the specific context of English EOLC policy and practice, and focuses on the development of EOLC policy in England since the first policy statement was introduced in 2008 (DH 2008).

Chapter 3: English end of life care Policy

This chapter begins with a contextual overview of EOLC in England. It then looks at the chronology of the development of policy, initially exploring how it has built up over the last two decades and moving on to take a more analytical look at its content. It considers how policy pledges have been funded and explores how the changing structure and governance framework of the NHS may impact on policy implementation. Whilst chapter 2 explored the barriers and enablers to providing good EOLC, this chapter focuses on the role of policy in guiding and shaping practice and specifically details how English EOLC policy has developed since the first strategy document emerged in 2008 (DH 2008).

3.1 NHS constitution

Although the NHS constitutes health services across the four nations (England, Wales, Northern Ireland and Scotland) since the referendums for devolution in Scotland and Wales in 1997 (Department of Health 2009), and the passing of the subsequent devolution acts, the way funding is allocated and how services are rolled out, is the responsibility of the separate nations. For this reason, the characteristics of the NHS across the four nations, with the divergence in structures and management approaches, and indeed with different relationships between health and social care (King's Fund 2013), grow increasingly distinct. This study will focus on EOLC care in England; in cases where the policy documents under review look more broadly at the UK rather than England, this will be made explicit.

Whilst the majority of deaths continue to take place in hospital, the role that social care and associated professionals play in death and dying should not be overlooked. Although the current study was primarily located in a health framework the need to acknowledge and work within a more integrated set of parameters became evident as the work progressed. In addition to policies developed within the NHS this section of the thesis will consider those staff and patients located in the social care sector, recognising the growing policy emphasis on the integration between health and social care.

3.2 Current context: How is current English EOLC rated?

A 2016 CQC report rated forty percent of acute hospitals in England as providing poor or inadequate care for the dying (CQC 2016). Inequalities in provision of EOLC care were experienced not only

across different settings (care in hospices was rated as more reliable than care provided in acute hospitals) but also varied with diagnosis, ethnicity, age and vulnerability. In 2008 the National Audit Office reported that 40% of patients who died in hospital over a three-month period had no clinical reason to be there (National Audit Office 2008). Yet, particularly for older patients, often suffering from a number of ongoing chronic conditions, when ill health looms and social care is unable to offer robust alternatives, it is to hospital that they are often taken - and once admitted it can be hard to escape the ethos geared towards aggressive, lifesaving interventions (Wollaston 2015).

The RCP and Marie Curie audit of EOLC (2016) examined data from 131 trusts, representing 6,580 data sets and found that of these only 21% had access to face to face PC services seven days a week. Mandatory training in care of the dying was only required for doctors in 19% of trusts and only 56% of trusts had conducted a formal audit of EOLC. Moreover only 47% of trusts had a formal process to capture the views of bereaved relatives or friends. Further insights are found in the National Survey of Bereaved People, VOICES (Office for National Statistics 2015) in England which reported that people being cared for in hospital are less likely to report high quality EOLC than people being cared for in other settings and are less likely to report being treated with dignity by hospital consultants and nurses.

Provision of PC in hospices in the UK is highly regarded, and creative models for accessing more patients in the community are being embedded – demonstrated by Hospice UK who suggest that more than 200,000 people with terminal and life-limiting conditions in the UK are treated by hospices each year (Hospice UK 2018). Despite this Hughes-Hallet et al (2013) estimate that 92,000 people per year in England, Wales and Northern Ireland have unmet PC needs and national data shows that less than six percent of the population die in a hospice in England (Public Health England 2019).

The Liverpool Care Pathway (LCP), introduced in the late 1990s, was intended to be a means of transferring best practice in PC into other settings, including hospitals. Yet in 2013 the LCP came under considerable criticism, fuelled by stories from carers that it had been used to hasten the death of loved ones and neglect basic needs. The furore resulted in suspicion and motives behind the initiative were questioned, eventually leading to its withdrawal (Neuberger 2013). In the void left by the LCP there has been a focus on efforts to better coordinate care, improve communication and record patient preferences at the EOL. There is a call for more rigorous research evidence to

demonstrate the effectiveness of EOL interventions from multiple perspectives; economic, clinical, social, cultural and individual (Wollaston 2015).

Despite improved knowledge and understanding of EOL over the last few decades there remains an underlying tension between the desire to cure and recognition that death is inevitable. The ability to recognise when the emotional and physical struggle outweighs the desire to stay alive presents ongoing challenges. Malhotra et al. (2015) consider the prevailing NHS culture where 'more is better' and highlight a system where diagnosis may lead to 'over treatment', debilitating side effects and high levels of anxiety. The authors recommend that doctors should provide patients with resources that increase their understanding about potential harms of interventions and help them accept that doing nothing can often be the best approach. This thinking may be particularly pertinent at EOL. Linked to this is the problem of over-investigation leading to over-diagnosis and over - treatment (Alderwick et al. 2015).

Yet, whilst the overall picture of EOLC provision in the UK is complex examples of excellent practice prevail. Indeed in 2015 the UK was ranked first among 40 countries for the quality of its EOLC – a measure derived from analysis of five weighted indicators: the palliative and healthcare environment, human resources, the affordability of care, the quality of care and the level of community engagement (Economist Intelligence Unit 2015). UK achievements are also attributed in part to the significant input and support that it has historically received from the charitable and voluntary sector. Of the various domains measured the UK scores lowest (18th out of 40) in the 'Basic End-of-Life Healthcare category'. Particular measures that bring down the UK rating include life expectancy; the number of hospital beds per 1,000 non-accidental deaths; the number of doctors and national spending on healthcare.

A further proviso relates to the quality of ranking data, whilst the UK scores highly on measured indices, there are a number of unmeasured indices which may be of particular importance to the patients, notably patient centred measures around their experiences in the weeks, days and hours before death. It may be that these 'softer measures' score more highly in countries which though poorer, have tighter community support structures and may provide better emotional/social support at EOL. NEOLCIN continues to prioritise the development of valid measures to record patient experience (personal communication with Director of EOLC, NHSE). More rigorous data providing such information should be available in the next few years.

3.3 Rise of localism and inequities in outcome

The advent of the Health and Social Care Act (DHSC 2012) with the introduction of CCGs assuming responsibility for commissioning (i.e. planning and purchasing) heralded a move away from centrism. Greater powers are held locally enabling providers to potentially respond to the needs of the local population – a move that was met with both optimistic approval and critical condemnation (Ham et al 2015). Enhanced local powers through devolution of health and social care – currently being trialled in various forms across the country, most notably in Manchester and Cornwall, will also have a significant influence on local service provision (see section 2.2.2.1). Greater Manchester has been offered the broadest deal to date, including powers over transport, planning and housing as well as uniting 38 different organisations as part of health and social care devolution plans (Walshe et al. 2018). Working together in this way promises a more joined-up, integrated response to individual needs. At the same time there are concerns that disparities between localities will become more noticeable. The spectre of the post-code lottery, where the quality and type of service provided depends on where you live in the country, looms large. As with all health provision there is a concern that the provision of consistent and equitable EOLC services will become harder to guarantee (Dixon 2015).

The Atlas of Variation for palliative and EOLC in England (PHE 2018) provides a map of ‘unwarranted variation’ and plots differences in service provision and outcomes, against 29 indicators.

Unwarranted variation is defined as ‘variation that cannot be explained on the basis of illness, medical evidence, or patient preference’. Although the report is careful to mention that the findings should be considered in relation to local need, which varies with population age profile and a range of socioeconomic and demographic factors including ethnic mix, as well as by local models of care, it would appear that the scale of the variation cannot be attributed to demographic factors alone, with a number of particularly significant findings highlighted in table 10.

Table 10 Showing outcome measures and magnitude of variation for a range of EOL and palliative care indicators in England

Indicator	Outcome measure. 2015 English data	Extent of variation across the 209 English CCGs
Percentage of patients who had 3 or more emergency hospital admissions during the last 90 days of life.	On average, 1 in 14 (6.9%) of all those who died.	Variation from 1 in 8 (12.6%) to 1 in 34 (2.9%) by CCG, a 4.3-fold difference.
Percentage of those with an individual plan of care documented in the last 24 hours of life. The plan should include food and drink, symptom control and provision for psychological, social and spiritual support.	65.7% of patients audited in acute hospital sites in England (and a median by acute hospital site of 71.4%) had documented evidence in the last 24 hours of a holistic assessment of their needs regarding an individual plan of care.	The variation between acute hospitals was 3.8% to 100.0%, which is a 26.7-fold difference.
Was there face-to-face access to specialist palliative care for at least 9am to 5pm, Monday to Sunday?	Of the 140 acute hospital sites included in the analysis, 38% replied yes, 61% replied no and 1% did not reply.	Variation from between nearly 1 in 4 to 1 in 6.
Percentage of patients whose death could have been anticipated on an end of life register.	In England during 2015/16 the average number of patients in need of palliative care/support recorded on GP disease registers was 39.6 per 100 deaths	The variation was between 13.1 per 100 deaths and 115.5 per 100 deaths by CCG, an 8.8-fold difference. The maximum value of 115.5 per 100 deaths indicates there is a CCG with more patients in need of palliative care/support recorded on GP disease registers than died in a single year. The median by CCG increased significantly from 25.4 per 100 deaths in 2012/13 to 35.6 per 100 deaths in 2015/16.
Percentage of deaths in usual place of residence (home and care home).	46.0% of deaths occurred in usual place of residence.	Variation by CCG from 28.5% and 56.9%; a 2.0-fold difference.
Percentage of deaths in hospital by CCG.	On average, just under half (46.7%) of all deaths occurred in hospital.	Variation of between two thirds (68.1%), and one third (36.1%) of deaths by CCG.
Percentage of deaths in hospice by CCG.	In England, the proportion of deaths in a hospice was 5.6% on average.	The variation between CCGs ranged from 0.2 to 13% constituting a 68-fold difference – explained largely by the uneven geographical distribution of hospices between CCGs.

Data taken from *The Atlas of Variation for Palliative and End of Life Care in England*, PHE (2018)

The extreme variation evidenced across England suggests that local strategies and policy may be an influencing factor. One likely contributory factor in determining EOLC outcomes may relate to the different ways' CCGs prioritise resources. The London Assembly Health Report (2016) noted sizeable variation in spend on EOLC across London with average spending varying across CCGs from £540 to £3,740 per death. Finlay (2019) reports a freedom of information request in which she asked 209 CCGs about palliative care commissioning. The disparity in spend between CCGs was huge, ranging from £52 to £2,330 per patient, with a poor correlation within this between spend and identified need.

The debate around localism continues to rage with ongoing discussion around how, in a nationally funded NHS such local discrepancies in provision can be justified (Dixon 2015). Also relevant are the many significant changes to the wider health and social care infrastructure which have impacted on the interface between national and local government over the last decade. England, for example, following the Health and Social Care Act (2012), has seen reforms which have removed critical central levers that were previously used to drive through national policy, notably responsibility for public health was taken from the Secretary of State for Health and conferred on local authorities (Marie Curie 2016).

The Access to Palliative Care Bill proposed in 2015 (Finlay 2019) sought to pass legislation that would ensure high quality care for all people who are dying, no matter what their geographical location within England. The bill argued that palliative care patients should have 24/7 'point of contact' assistance in their own homes or communities and that the training of employees in pain relief and communication skills should be improved. The Bill stipulated that CCGs should publish a strategy covering the expected needs of adults and children in its area, have a plan to demonstrate how these needs would be met, detailing the specialist services to be provided, with data collected to monitor progress. The intention was that guidance and learning from recent initiatives including 'Ambitions for Palliative and EOLC' (NPELCP 2015) and the work of Marie Curie/RCGP 'Daffodil Standards' (focussing on improving EOLC in GP practices) would be upheld. Yet, the Bill failed to pass its second reading in June 2019 and following the proroguing of parliament in late 2019 made no further progress.

3.4 Development of EOLC Policy in England

The emergence of UK EOLC policy was a response to a number of health debates being fuelled at the beginning of the new millennium, triggered both by a political will to increase patient choice and a growing awareness of changing demographics and increased pressure on health services. The result has been a focus on the need to create a clear road map for shaping EOLC in England which has driven a range of initiatives over the last two decades. Appendix 3.1 charts the various strategies, policies and documents produced by government together with charities and voluntary organisations over the last two decades which have been influential in shaping English EOLC.

In 2003 the Department of Health (DH) published a document entitled 'Building on the Best' (DH 2003) which laid out the policy direction towards increased patient choice in the NHS and pledged specifically that better EOLC would be delivered not just to cancer patients but to all those who were dying, irrespective of their diagnosis. A year later NICE (2004) issued guidance for Supportive and Palliative Care, and the EOLC Programme was launched by the DH which aimed to give patients more choice about where they died. Between 2004-2007 £12 million was invested in strengthening practice across a range of settings and pathways (DH 2003). On the basis of this improved resource base a number of programmes were developed, most significantly; the Gold Standards Framework (GSF) (Thomas 2003); the Liverpool Care Pathway (LCP) for the dying (Ellershaw and Ward 2003) and Priorities for Care (PPC) (Munday, Petrova and Dale 2009). Each of these initiatives set out a broad intent to make effective EOLC more systematic.

Building on ongoing projects and programmes such as these, in 2008, the first government 'EOLC Strategy' was published (DH 2008). The strategy backed by additional funding of £286 million over a two-year period, set out a whole systems approach which was endorsed by the 10 regional Strategic Health Authorities and elucidated a vision for achieving more informed choices and better outcomes at EOL. The intention was that through enhancing choice, quality, equality and value for money, people would be supported to have a 'good death'. The approach identified to achieve this in the strategy was to be enacted through raising awareness; better systems for monitoring and data collection; improved generic and specialist professional education; increased resources and a cultural focus on changing attitudes to dying. Following the strategy publication in 2008 there has been rigorous annual reporting on progress to achieve stated objectives and the NEOLCIN (2020) website now publishes data on-line accessible at the CCG level for a range of measures, including place of death.

Notably there was a strong emphasis in the 2008 strategy on extending choice, particularly around increasing the opportunity for those who want to die at home. The choice agenda was reinforced by a 2010 government document 'Equity and Excellence in NHS: Liberating the NHS' (DH 2010). In this document the coalition government set out reforms whose key objective was to both improve choice and create a system within which the position of patients was central – the mantra 'no decision about me without me' was coined. There was also a commitment to review payment systems at EOL including an option of 'per patient funding'.

During the same year the NHS Outcomes Framework highlighted the need to develop better indicators for measuring the quality of EOLC including crucial measures of patient experience. Another important marker in 2010 was the advent of a framework for social care at EOL; Supporting People to Live and Die Well (NHS Improving Quality, 2010), spearheaded by NEOLCIN presenting a vision, not only where services work around people, but where the major sectors of health and social care work together in a much more purposeful fashion than was contemplated previously.

2011 heralded more reviews and reports focussing on funding formulas and quality standards. A report commissioned by the DHSS 'Funding the Right Care and Support for Everyone' (Hughes-Hallett et al. 2011) set out a per-patient funding mechanism for PC. Pilot data was collected with a view to putting together a series of tariffs used to cost 'care episodes'. A King's Fund report (Imison et al. 2011) 'Transforming our Healthcare System' highlighted successful programmes where integrated systems of care were seen to potentially bring about cost savings by taking pressure from acute services. In the same year a series of quality statements were released by NICE (2011) laying out quality markers outlining what good EOLC looks like. There are now two standards one for EOLC, QS13 (table 11) pertaining to the last twelve months of life and the second, QS144 (table 12), pertaining to care in the last 2-3 days (NICE 2015). Both standards are supported and promoted by a range of organisations concerned with EOLC and NICE work to promote them to commissioners, service providers and regulators. The standards are wide ranging and rigorous in their scope, covering 15 quality statements:

Table 11 NICE quality standards for end of life care for adults (QS13)

Nice quality standards for EOLC for adults (QS13)	
1. Identification	People approaching EOL are identified in a timely way.
2. Communication and information	People approaching the EOL and their families and carers are communicated with, and offered information, sensitively and as required.
3. Assessment care planning and review	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
4. Holistic support – physical and psychological	People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
5. Holistic support – social, practical and emotional	Support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation.
6. Holistic support – spiritual and religious	– appropriate to current and changing needs.
7. Holistic support – families and carers	- appropriate to current and changing needs.
8. Coordinated care	Care should be coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
9. Urgent care	Available at any time of day or night, safe, effective and appropriate to needs and preferences
10. Specialist palliative care	Offered appropriately at any time of day or night
11. Care after death	The body of a person who has died is cared for in a culturally sensitive and dignified manner.

<p>12. Care after death – verification and certification</p> <p>Families and carers of people who have died receive timely verification and certification of the death.</p>
<p>13. Care after death – bereavement support</p> <p>People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.</p>
<p>14. Workforce training</p> <p>Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.</p>
<p>15. Workforce planning</p> <p>Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.</p>

Taken from NICE (2011)

Table 12 **Quality standard (QS144) clinical care of adults in last two to three days of life**

<p>1. Assessing signs and symptoms: close monitoring of further changes to assess if they are nearing death, stabilising or recovering.</p>
<p>2. Individualised care: patients and those important to them should be given opportunities to discuss, develop and review an individualised care plan.</p>
<p>3. Anticipatory prescribing: medicines for symptom control should be administered as required.</p>
<p>4. Hydration: Hydration status should be assessed daily along with discussion of the risks and benefits of different options.</p>

Taken from NICE (2015)

At the same time as these quality measures were being constructed to monitor progress, significant regulatory change was afoot. The Health and Social Care Act (2012) brought with it the most wide-ranging reform of the NHS since its founding. Following the harrowing findings of a number of hospital enquiries, particularly in relation to care of the elderly, (Keogh 2013; National Advisory Group on Patient Safety 2013; Francis 2013) quality regulation rose to the top of the agenda and a

strong emphasis was put on the importance of clinicians being central to the commissioning process. Arguments for the necessity of good compassionate, relational care came to the fore; clinical outcomes were in themselves no longer enough. The following year the RCGP published practical commissioning guidance (Thomas 2013) in an attempt to draw a line below the grim tales of patient mistreatment reported by Francis (2013). The RCGP commissioning guidance contains a multiplicity of tools and resources which can be used across different systems (health, social care, third sector). Running alongside RCGPs guidance were an influential set of recommendations made by Robert Francis QC (2013) which sought to ensure patients would no longer be left lying in soiled sheets with food and water left out of reach, victims of an overstretched system. A light was shone by Francis on the culture of the healthcare environment and a new, more open, honest and transparent culture was promoted where staff support was given higher priority.

When CCGs were founded in 2012 one specific service requirement related to continuing health care (CHC) fast track funding, a service intended to support those people identified as being at EOL. The 2018 National Framework for CHC (revised in 2018) provides no definite time scale for life expectancy, simply stating that an individual's rapidly deteriorating condition may be entering a terminal phase (DHSC 2018). The intention was to ensure that those entering this phase are supported in their preferred place of care as quickly as possible. Diagnosis is provided by an 'appropriate clinician' who is knowledgeable about the patient's needs and condition and should provide an assessment of why the individual meets the Fast Track criteria. CCGs are required to audit use of the Fast Track Pathway Tool carefully and discuss any concerns over its use with organisations, clinicians and teams as appropriate (Department of Health 2012a). Given the urgent nature of the patient's need, the CCG is under an obligation to agree and commission the care package within a 48-hour period from receipt of the completed Fast Track Pathway Tool.

Echoing some of the themes of earlier reports Simon Steven's Five Year Forward View (5YFV) (NHS England 2014a) set out a positive vision for the future of the NHS arguing that greater emphasis should be placed on prevention, service integration and putting patients and communities in control of their health. Guidance provided in the 5YFV sets out seven areas for specific focus though EOL is not singled out as one of these. Goals in the 5YFV for patient experience include 'significantly improved patient choice' for EOLC and long-term conditions alongside increasing the number of people with personal health budgets (NHS England 2015, p24). There was also particular mention of new care models which it was anticipated would enable frail, older people to stay healthy and independent for longer. There was emphasis on the need for greater integration of community,

mental health and hospital services as well as more joined up working with home care and care homes. Attention was paid to adapting existing services and working across systems. Rather than create further disruptions to existing structures it was suggested that 'diverse solutions' be found, where local leadership be supported, and flexibility was shown in relation to payments and regulatory requirements. New models of care have subsequently been tested across 50 'vanguard sites' a number of which focus particularly on EOLC.

In the same year as the 5YFP, The Barker Commission reported (Barker 2014), highlighting the extent of some of the disparities in the health and social care arrangements, exemplified by the complexities of the Continuing Healthcare funding system whereby a patient, dying at home with dementia, is not entitled to a package of home nursing support, whilst a cancer patient receives full support. In the current system, the method of determining allocation of funds both within the health system (for example in dividing funds between clinical interventions and nursing care) and between health and social care, is both complex and lacks transparency. Calls for needs based, integrated health and social care have been echoed in later recommendations made by the National Palliative and End of Life Care Partnership and more integrated working and funding arrangements are being tested in a number of the vanguard sites.

The Neuberger review (2013) has been influential in shaping new policy direction. It was evident that shortcuts in training and support of staff meant that there were repeated incidents where patients were treated with lack of care and dignity, communication was poor and transactions between patients and staff too rushed. The report concludes that many of the poor episodes of care result not only from staff shortages and rising pressures but also, fundamentally that communication skills of health professionals need to improve.

We believe there needs to be a proper National Conversation about dying. Otherwise doctors and nurses are likely to become the whipping-boys for an inadequate understanding of how we face our final days (Neuberger 2013.p.3).

Dying Matters, a coalition of organisations from across the NHS, voluntary and independent health and care sectors, has a mission to promote awareness of dying and have been particularly active in promoting the type of national conversation suggested by Neuberger. Recommendations in the final report (Neuberger 2013) focussed on creating strategic frameworks to provide broad based guidance on delivering better care and following on from this an alliance of 21 professional and

voluntary organisations was established. In 2014 this group published 'One Chance to Get it Right' (Leadership Alliance for the Care of Dying People June 2014) which articulates 5 key priorities for care (table 6, section 2.2.4) placing more emphasis on individual priorities over process, with personalised health plans taking new precedence over the earlier 'pathway' approach. The skill and time available to the clinician in initiating conversations in which care-plans were drawn up became key criteria for success (Ellis, Winslow and Noble 2016). Also significant at this time was the promotion of the 'House of Care' model for managing EOLC, with its particular emphasis on long-term conditions and acknowledgement of the importance of drawing on community assets (Coulter et al. 2016).

Perhaps the most significant policy development since the emergence of the initial strategy in 2008 has been the Ambitions Framework (NPELCP 2015), overseen by the National End of Life Programme and funded by the Department of Health. The document was produced through a broad partnership of national organisations working in England, whose aim was to improve the consistency and quality of EOLC. The ambitions framework proposes that the reason for inconsistent EOLC is not the result of lack of knowledge, rather it is about collective will, prioritisation of need and application of knowledge. The framework lays out six ambitions for achieving more consistent EOLC, these being to: individualise care; provide fair access; maximise comfort; coordinate care; ensure staff are prepared to care and facilitate community involvement. For each ambition the guidance identifies what is needed to achieve them in the form of foundations and building blocks.

Since 2015 there has been a flurry of further reports and guidance from both the government and voluntary sector looking, amongst other things at quality standards, education of the workforce, communication, ACPs, monitoring and reporting, data and indicators – much of it repeating well intended aspirations relating to what EOLC should look like and how it should be monitored and funded. The ambition to quantify the economic impact of new policies and models of care is gaining strength as system pressures become more intense. The National Audit of Care at EOL (HQIP 2019) represents an important step forward in routine national measurement of quality and outcomes of those at EOL within NHS settings.

3.5 How has English EOLC policy contributed to practice?

A review of national EOL policy documents conducted by Sheffield Hallam University (CHSCR 2016) concluded that their sheer volume, the fact that they are made available via a number of different routes, and that much information contained is repeated or re-crafted, means that there is a danger

that the focus becomes diluted. Uncertainty about the purpose and status of these documents adds to the confusion and increases the likelihood that they will be ignored or overlooked. Marie Curie (2016) stress that running alongside policy, what is needed is a concerted effort to resource and drive these policies through, measuring success against valid indicators and adapting practice to fit with evidence, particularly in relation to improved experiences of care. Looking at EOLC policy across the UK, the report (Marie Curie 2016) observes that whilst the majority of those dying will have some sort of PC need, there has been no robust attempt to provide a comprehensive overview of the scale of this need.

3.5.1 Policy framework and context

National policy can provide a useful framework that will ultimately improve patient experience (Coombs and Long 2008). At its best, policy will inform education, interprofessional learning and support, and resource management. Policy cannot be removed from context and must focus on the practical translation of guidelines and plans into practice – for this reason they stress, it must be informed and shaped with the involvement of clinicians who have everyday experience of patient care. Coombe and Long (2008), highlight how the stressful decisions that often have to be made in EOL can put disproportionate pressures and high levels of ‘personal stress’ on the staff involved – and that this may impact differently on nurses and doctors. Doctors on the one hand have responsibility for prognosis and determining treatment whilst nurses are more operational; administering treatments (futile or otherwise) and often facilitating treatment withdrawal. These different roles are likely to provoke different experiences, compounded by individually held beliefs and ethical views – and unless space is made to reflect on and communicate these differences, tensions are likely to arise (Puntillo and McAdam 2006). There appears to be a role for evidence-based protocols which can be used to reduce the pressure put on clinicians facing difficult EOL decisions. Coombs and Long (2008) stress that these tools must be practically applicable and not too onerous, to allow them to become a sustainable part of ongoing practice.

Whilst Harrison suggested (section 2.1.3.1) that a central component of policy analysis should be the use and development of theory, it is notable in the key national EOLC policy documents (DH 2008 and NPELCP 2015) that there is no reference, at any point in the combined 218’ pages, to the word ‘theory’.

3.5.2 Discourse of EOLC policy

Borgstrom (2015) is one of a small number of analysts who have interrogated the discourse of English EOL Policy, asking how its form and content may impact on outcomes. In her review of the 2008 EOLC Strategy she suggests discourses of 'choice' and 'compassion' have become detached from each other. Borgstrom asserts that in the policy discourse of EOLC, the strategies and guidance developed, which she terms 'managed care of the dying' are the response to the 'contemporary social problem of death'. She couches her analysis in Foucauldian terms highlighting the power that language has both in the construction and organisation of reality. Death becomes the problem and EOLC strategy, with its focus on the enactment of choice, the solution.

Borgstrom locates EOLC as a way of 'dealing with death and dying' by anticipating and planning for future care needs. The fact that death rates are on the rise and the changing demographic of the population presents a 'rapidly changing social context' which implies, that the 'previous political and medical ways of responding to death may no longer be appropriate' (Borgstrom 2016 p.9). New EOLC policies are presented as a solution suitable to manage long term complex pattern of illness that the elderly are more likely to face in the 21st Century; the problem in other words is 'death and dying' and the solution is managed deaths through ACPs and extension of choice.

'Choice,' Borgstrom (2015) contends, is presented as the dominant rhetoric and 'compassion' (or lack of it) which has been the recurrent theme in recent hospital scandals, is largely absent from the strategy. Indeed whilst 'choice' is mentioned 44 times in the DH (2008) strategy 'compassion' does not appear at all. The danger, of such a policy, Borgstrom asserts is that the focus on choice becomes a tick box exercise. Choices are recorded, often with a view to meeting targets, whilst potentially side-lining the relationships that are at the heart of good care. Choice she argues becomes a 'neo-liberal' bureaucratic exercise, whilst relational priorities; the time and space to be with someone is overlooked. The choice discourse may be set to reshape the way dying is experienced by changing narratives and shifting responsibility for care. To support her argument Borgstrom points to literature describing how Western society is moving towards an individualist, capitalist, culture, where individual autonomy is valued and the notion of 'informed choice' is privileged.

Enthoven, a Stanford economist, draws links between choice and the concept of an 'internal market' of health care (O'Hara 2013) where a plurality of providers supply medical services and patients are empowered to choose which services they will use. O'Hara (2013) claims that such models can bring about collective consumer action to assert control over the types of services provided. Supporting

the contention, that consumerism is not all about promoting self-interest, O'Hara posits that 'consumerism' and consumer groups have effectively fought for collective minimum standards, the prevention of professional mal-practice and the right to be heard. Indeed, going hand in hand with consumer power is the involvement of patients in helping to shape and co-produce services around a more patient-centred set of services. Politicians, from both right and left have embraced the language of 'patient power' extolling the increase in the individual choices assigned to the 'consumer' (O'Hara 2013).

The rise of choice and the consumer culture in the West, Borgstrom argues, contrasts with more cohesive cultures, particularly those in low- and middle-income countries which privilege relationships within the extended family more highly than personal autonomy (Borgstrom 2015). In Henry's 2015 report 'What's important to me?' in which the concept of choice is expounded she explains that if choice is to be meaningful, it must be supported by universally available high-quality care. Borgstrom (2015) examines the challenges of effectively translating concepts of 'choice' and 'compassion' into policies and persuasively suggests that the language can begin to frame and distort policy direction. Choice, moreover, cannot be separated from the complex network of relationships in which those at the EOL are located, yet rigid policies may leave little room for context. What people really want, it has been observed, rather than choice is simply good quality EOLC services (Addicot 2010).

Furthermore, evidence suggests that as people die older - with increasing co-morbidities their capacity to make choices and participate in decisions around care planning may be reduced (De Silva 2012). Patient choice as a driver for change in medicine relies on the notion that patients can make informed decisions, yet, particularly as the end of life nudges closer, this is evidently not always the case (Lloyd et al. 2016; Rolls et al. 2011; Ellis et al. 2016). For the frail elderly, suffering multiple morbidities, particularly dementia, issues of choice may be more complex than previously considered and must be looked at in relation to contextual factors. Being a competent consumer of health services demands levels of energy, experience and expertise which the frail elderly may not find easy to access (Rolls et al 2010). The focus on choice and control, rooted within an individualistic paradigm may subordinate the importance of dying as a relational process, negating the value that many old people place on networks and relationships (Ellis et al. 2016; Lloyd 2011; Borgstrom 2016). For such critics, an over-emphasis on the individual, and the privileging of choice and control, has meant that prevailing models of EOLC fall short of meeting the

needs of older people dying with complex co-morbidities, especially dementia.

3.6 Demographic considerations to inform EOLC policy

The ability of the elderly in England to access EOLC is influenced by a number of demographic variables including gender, ethnicity and level of deprivation (see appendix 3.2) which needs to be taken into account when developing policy. Analysis from the Institute for Fiscal Studies (Stove 2018) shows how the more deprived areas, with greatest need, had the greatest reductions in social care spending per head, demonstrating the importance of maintaining a national (as well as local) oversight of spending. The Marmot Review (2020) claims that cuts in social care funding between 2001-2017 have been regressive and inequitable and demonstrates how the greatest cuts have been in areas where need is highest, and conditions are generally worse. It is likely that the cuts have harmed health and contributed to widening health inequalities in the short term (Marmot et al. 2020).

A wide range of EOLC KPIs relate strongly to level of deprivation, with a particularly stark divide being life expectancy between the most and least affluent. In 2015–17, males living in the least deprived 10% of areas in England could live, on average, almost a decade (9.3 years) longer than males living in the 10% most deprived areas, and for females the gap was 7.5 years (Raleigh 2018). Also worth noting in relation to policy considerations for those nearing EOL, is the difference in the number of years lived in ‘poor health’ between those in the most and least affluent decile; with a gap of 19 years for both men and women. Those living in the most deprived areas spend nearly a third of their lives in poor health, compared with only a sixth for those in the least deprived areas (Raleigh 2018).

Gender is another significant variable for EOL with more women than men living into their nineties with the result that women in the older age groups are more likely to live on their own. Thirty four percent of men and 61% of women aged 75 years and over lived alone, a statistic that impacts on the higher number of women than men who ultimately die in care homes (Rolls et al. 2011).

Race and ethnicity have also been shown to be confounding variables in access to EOL services (Care Quality Commission 2016; Buck et al. 2018; Calanzani, Koffman and Higginson 2013). Issues including: culturally inappropriate practices; lack of appropriate information for different BAME groups and access to translated material, were all identified in the case studies and have been highlighted in the literature as factors contributing to disparities and inequities in practice (Calanzani, Koffman and Higginson 2013). The case studies identified challenges relating to cross-

cultural understanding, revealing instances where patients, both of BAME groups and from the white English majority, struggled in building positive relationships with carers, citing both language barriers and lack of familiarity with cultural preferences as being problematic. In London where 38% of the social care work force are of 'non-British' nationality (Skills for Care 2019) there is a greater likelihood than in other areas, that paid carers may not share a common cultural understanding, or even a common language with the person they are caring for.

3.7 Funding for EOLC in the UK

The amount of money spent by the UK Government on EOLC is hard to assess. Health systems are complex, with blurred boundaries and the way money is allocated to different services means that in organisations serving many different functions (acute, community and mental health trusts) money going into the system is allocated to staff wages, training, equipment, disease type etc. In such a system it is hard to break these figures down by type of patient or health condition – particularly as patients suffer increasing co-morbidities. The difficulties of distinguishing between a patient with a condition that needs treatment, and someone at EOL needing palliative care further compounds the problem.

Trials are currently being conducted in five areas in England (NHS England 2018) exploring the introduction of personal health budgets (PHB) which may potentially provide the opportunity for people in their final weeks and months of life to have more of a say in the type of care they receive. Early reports suggest that the experience for patients is positive though the project is ongoing and as yet no final evaluation available.

A study carried out by The Nuffield Trust (Georghiou and Bardsley 2014) concluded that given the finite resources available for health care an understanding of the costs involved would be propitious but concluded 'there is a stunning lack of good data surrounding costs for palliative care in England'. Adding another layer of complexity is the fact that the sector is unusual within the field of health care for its reliance on significant levels of voluntary/charity funding. Hospice UK report that of the 1.3 billion pounds spent by hospices in 2014/15 68% of this came from local communities, with only 32% from government.

When the End of Life Care Strategy for England (Department of Health and Social Services 2008) was published the government pledged that additional spending of £286m would be made available to support the strategy between 2009-2011. However, a follow up survey by NCPC found that 35% of

responding PCTs were unable to identify the amount they had earmarked for EOLC in 2009/10. Indeed many NHS providers also reported fears that resources were being cut (NCPC 2010) with only 28% of NHS providers reporting an increase in NHS EOL resources between 2008/09 and 2009/10. In the voluntary sector, where most specialist PC beds are provided, the picture was more positive with 75% reporting an increase in funding between 2008/9 and 2010/11 – though for just over 25% of these the increase was at the level of inflation/cost of living.

The importance of having good data illustrating how and where money for EOLC is spent is self-evident, not least because it is needed to help determine the cost effectiveness of care offered in different settings. Work by the Nuffield (Georgiou and Bardsley 2014) suggests that reduction in hospital admissions, with a refocus on provision of care at home and in the community (the preferred place of death for between 56–74% of patients) for those at EOL, would not only save money but would give the opportunity to redesign services more aligned with patient choice. Whilst the complexity of the data that needs to be input means that results are pitted with provisos, studies comparing care settings allude to the potential for overall savings from transferring care away from acute settings. An evaluation of the Marie Curie Nursing service for cancer patients at EOL, found a potential net saving of £487 per person, during their last three months of life, could be redeemed by shifting care from the hospital to the community (Georgiou and Bardsley 2014).

Yet despite evidence to suggest significant cost savings if care is re-directed to the community, the infrastructure available to support care in the community has been dramatically cut over recent years. The Royal College of Nursing cite district nursing, a specialism within community nursing which includes EOL nursing care in patients' homes, as one particular area of concern. Figures cited by the BBC (Hughes 2017) show a 46.4% drop in full-time district nurses working for the NHS in England from May 2010 to July 2017. Indeed a 2014 report from the RCN (Ball et al. 2014) warns that falling numbers and aging profile of existing district/community nurses means that they are now 'critically endangered'. Such anomalies appear to suggest that lack of joined up national policy results in siloed thinking and practice, where policy decisions in one area are made regardless of their impact on the wider system.

3.8 Chapter Summary

English EOLC policy is in its infancy as is any robust analysis of its effectiveness. Just as the policy process operates at a number of different levels so too does the interrogation or analysis of policy. This chapter has explored how English EOLC policy has grown and developed and considered the

economic, political and cultural context in which it operates. Whilst EOLC in England is recognised, at its best, to be world class – clear inequities and inconsistencies prevail (PHE 2018). The aim of the 2008 strategy was to develop a whole system approach to improve EOLC outcomes. The initial policy document was backed by significant funding and followed up with a raft of related policy and strategy. The content and language of the key policy documents are considered, particularly in relation to the presentation of ‘choice’ as being emblematic of a progressive free-market economy. Running alongside the development of policy, specialist units have grown up, most recently the NEOLCIN, which provides monitoring, data and related tools to facilitate local service provision and commissioning. Data is seen to be key to monitoring a range of indicators including quality, outcomes and cost – all of which are needed to inform policy development.

The following chapter will explore interviews conducted during the scoping study to interrogate how policy is implemented and the impact it has on local practice.

Chapter 4: Methodology and Methods

This chapter is divided into five sections, the first part outlines the methodology (philosophical paradigms) used to provide a framework for the study. The second part presents an overview of methods (tools and techniques) used to facilitate data collection and moves on to consider how this links to the development of theory. The final sections take a more detailed look at data collection and analysis and consider issues around reliability and rigour.

It has been my intention, as someone who has worked directly with health practitioners for many years, for my writing to be accessible and relevant to health service practitioners as well as academics. In the UK, a number of major national reviews of the 'public health sector' have noted the tendency of academically oriented researchers in relevant disciplines to investigate and publish excessively theoretical and impractical studies of little use in policy and practice (Wanless 2004; Haines 2004; Academy of Medical Sciences 2016). McAter et al (2018) suggest that the gap between research and practice may be compounded in the UK by fact that key 'actors' are situated in different locations with a research arm, based mostly in universities, and a practice and policy arm, based largely in public sector institutions and organisations. My choice of method has been purposefully influenced by a desire to find a design, and use a language, that is accessible to those working across health and social care.

4.1 Methodological Approach

4.1.1 Framing the research questions

This study has sought to provide results that are valid, feasible and useful. My aim, in line with this, has been to identify a methodology that is neither so abstract that it lacks empirical applicability nor so superficial and incongruent that it has little explanatory scope. Methods and sampling procedure are chosen to best answer the questions posed. Research methods and strategy must fit with what the study sets out to achieve and the development of relevant and well-framed research questions is key to effective outcomes. Health policy or more specifically EOLC policy, has been developed within a complex and multi-layered system influenced, as is discussed in the body of the thesis, by a myriad of macro, meso and micro level factors. A better understanding of how and why policies are

implemented (political, social, economic influences) will strengthen the ability of actors to influence policy for the better (Gilson 2012).

Exploring the challenges of policy implementation demands a deeper understanding of organisational dynamics of the health system and a method of working that acknowledges the multiple mechanisms which might be at play, the different contexts that will influence these causal patterns in different ways and the subsequent outcomes that result (Robson and McCartan 2016; Jagosh et al. 2015). Cause and effect in open complex systems are rarely linked in a linear fashion. Instead, multiple, interacting mechanisms will be influenced in a variety of ways by a range of circumstantial factors (Pawson 2005). As the health system grows ever more sophisticated and the required interventions more complex, the theoretical base on which services are built require underpinning by evidence gathered in a variety of ways from different sources. Strategies are required to demonstrate how interventions link across the system. Realism seeks to explain the way programmes work by theorising causal mechanisms within real-life contexts and thus provide a way of thinking that may be helpful in formulating strategy.

There is little current data that informs the questions that are central to this thesis and the intention is to generate exploratory research that will build a clearer picture of how English EOLC policy helps inform and guide good practice from multiple stakeholder perspectives. The intention is to explore both the outcomes and the processes that operate to produce them, from the perspectives of multiple stakeholders. Through generating new insights and asking new questions, the aim is to consolidate a holistic perspective of EOLC care, that encourages less siloed thinking and thus generates a more coherent and useful debate.

The theoretical framework chosen to guide the research is that of realist evaluation (RE), with two phases of data collection: phase 1 being a scoping review and phase 2 involving data collection from three case sites. Pawson and Tilley (2004), credited as the originators of RE suggest that it is particularly suitable for guiding policy makers, providing ideas and 'enlightenment' rather than 'political arithmetic'. Traditionally evaluation of interventions has been based on an experimental, outcomes - based approach where an intervention group is compared to a control group which has similar experimental parameters but receives no intervention. In complex environments, such as exist within healthcare, this approach has proved problematic. The multiple layers of interrelated and interdependent components mean that 'experimental controls' are difficult if not impossible to set up and causality therefore is hard to demonstrate. Focusing on outcome alone is unlikely to

provide sufficiently nuanced information to help determine the best pathway for the future direction of the intervention and in such circumstances, I will argue that RE offers a more appropriate method of enquiry.

A realist approach assumes that outcomes and impacts are driven by a combination of context and mechanism – nothing works everywhere for everyone. RE is based on assumptions from other forms of theory driven philosophies about the nature of reality and the way causation (how programmes cause change) takes effect. Pawson and Tilley (1997) provide a set of RE principles rather than methodological rules or steps to follow. RE is more about a logic of inquiry, rather than a set of prescriptions of how to undertake a study (Rycroft-Malone et al. 2010). The primary concern is to provide information and guidance to policy makers to help establish which guiding principles or theories will work best in which situations. This particular insight provided by RE is described as looking into the ‘black box’ of a programme – to help identify how and why interventions (in this case EOLC care programmes) are effective (or ineffective) and in what circumstances (McEvoy and Richards 2003).

The Liverpool Care Pathway (LCP) (Neuberger 2013), introduced in the 1990s as a means of making the hospice model of holistic care more widely accessible in non-hospice settings, is an interesting example of an intervention that did not meet with expected outcomes, demonstrating the value of methods of evaluation considering contextual factors as well as the mechanisms involved in an intervention. Despite being welcomed and approved at inception by a broad range of professionals, when the LCP was rolled out nationally, due to a series of unforeseen mechanisms and contexts converging to produce unanticipated outcomes, it met with broad public condemnation and was eventually withdrawn as a recommended service pathway (Neuberger 2013).

The next section of this chapter will look at the historical development of realism, the different perspectives presented within the broad realist framework and will set out why I believe it to be a suitable paradigm for the current study.

4.1.2 Realism: an overview

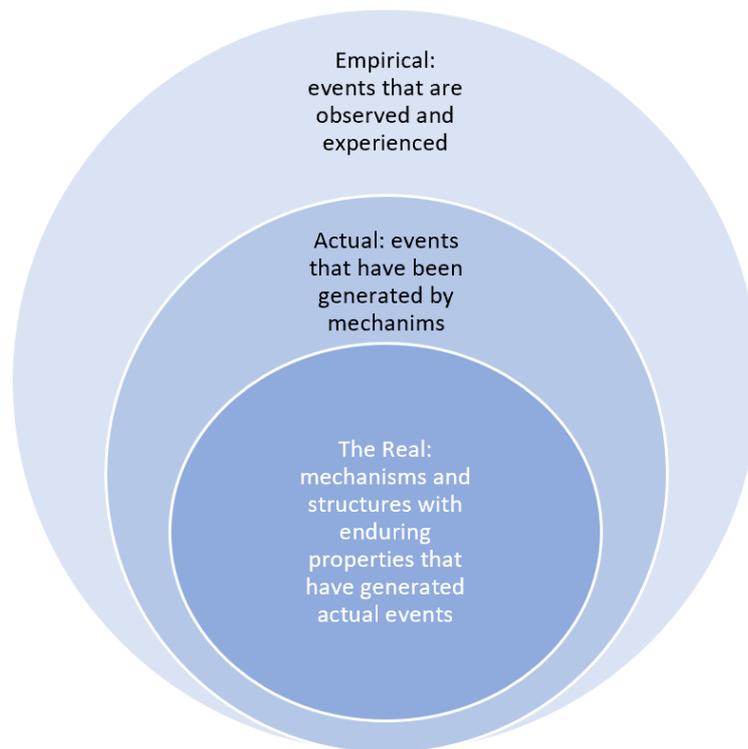
Whilst there are a number of philosophers who have contributed to the development of the critical realist paradigm it is largely attributed to the work of Roy Bhaskar (1989; 2010). Bhaskar’s contention was that neither empiricism nor idealism are in themselves sufficient to successfully explain real world occurrences which are stratified and emergent. Instead, he argued that a realist

ontology is required to bring in a third sphere, one that uses observations but in addition to this considers objects, entities and structures (even those that may not be directly observable) and asks how these mechanisms have given rise to an accepted happening or occurrence. What must the world be like in order for this to occur?

Realism, the school of philosophy from which critical realism originates, was developed to bridge the dualities between positivism on the one hand and constructivism on the other (Bryman 2008). Positivists contend that the real world can be directly observed in order to derive facts (deduction), whilst constructivists assert that all our observations are shaped and filtered through human consciousness and it is not possible therefore to know for certain what the nature of reality is, rather inductions are made. Realism provides an alternative paradigm on this continuum, contending that both the material (natural) world and social worlds are real in that both can bring about real effects (Mingers 2006). Observational evidence alone cannot establish causal uniformities from variables, rather it is necessary to establish the inner workings of a system; how the inputs and outputs are connected and what makes things work in the way they do. Protagonists of critical realism reject two key tenets of positivism (Archer et al. 2013). The first is the notion that only what can be seen or perceived is real – instead critical realism concedes that things can exist even if they cannot be observed (natural realism). Secondly, critical realists propose that all that is known cannot be looked at in isolation since the real world exists as an open system. Realist evaluators contend that causality is generative in nature, meaning that actors, by their very nature, have the power to bring about change (agency). Accepting the role of actors in change leads realist evaluators to the premise that structural and institutional features (such as policies and organisations) exist independently of actors and researchers (Pawson and Tilley 1997). Causal mechanisms may be located within social relations and contexts as much as individuals.

Bhaskar's interrogation of what is real led him to propose a vision of the world that was stratified into three distinct layers or domains, represented in figure 5 below:

Figure 5 Bhaskar's vision of the stratified world



Adapted from (Willcocks and Mingers 2004)

Old age, for example, can be experienced both physically (aching limbs, failing organs), and in relation to the social construction of what old age means; this construction may alter the way people think about and act towards older people as well as the way the individual perceives themselves. In this example the 'real' corresponds to cells in the body which have the potential to live and thrive or to break down over time, the 'actual' refers to a wide range of possible processes including for example the way the cells begin to break down as the body ages or an individual's psycho-social state. The 'empirical' refers to how these (sometimes invisible) processes manifest themselves – for example wrinkled skin, isolation, disability, depression. To push the analogy further at the domain of the 'real', cells within the body may or may not begin to break down and fail to work to their optimum depending on a range of external/contextual factors – in other words the mechanism bringing about the deterioration of cells/organs may remain dormant until a certain set of conditions are in place.

The same thinking can be applied not only to individuals but also to programmes and policies. Bhaskar (2010) acknowledges that policies and programmes are 'real' and can therefore have real

effects (both intended and unintended). Realism also acknowledges that social institutions and constructs (culture, class, gender, religion, political and economic systems) will have real effects on programme outcomes (Westhorp 2014).

All human actors and actions are embedded within a wide range of social processes which are part of a stratified social reality (Sayer 1992). Actions only make sense in relation to the built-in assumptions about the wider set of social rules and institutions on which they are based. Causal power resides not in particular objects or individuals but in the social relations and organisational structures in which they inhere. A programme theory will only work if subjects act as the theory anticipates – in other words if people choose to make them work and if the context allows (Pawson 2006). That interventions are theories is fundamental to the notion of RE. The approach is based on a hypothesis that postulates that if a programme is delivered it will bring about an outcome (some intended some un-intended) and that this is enacted within an existing and complex social system (Pawson and Tilley 1997). For social programmes, mechanisms are the cognitive or affective responses of participants to resources offered (Pawson et al. 2005).

Realism focuses on the generation of theories that help explain ‘what works for whom in which conditions’ (Pawson and Tilley 1997). This attention to explanatory theory, which comes from the natural sciences, gives more scope for generalisations and therefore assists in refining programme development.

The field of EOLC policy is broad and complex and includes a wide range of different proposed interventions, mechanisms and intended outcomes. RE is able to accommodate the explication of complex interventions resulting in multiple outcomes, through the development of programme theories, represented as conjectured CMO (context, mechanism, outcome) configurations. It is these theories of how the programme works which will be tested in this study. The various components and thinking behind this process of hypotheses generation are explored in the next section.

4.1.3 Components of realist thinking: complexity, context, mechanism, outcomes, cycles of evaluation

Realism as a philosophy adds valuable insights to complex interventions such as those operating within the health services. There are a number of key concepts integral to an understanding of RE and its particular value to the current study.

4.1.3.1 Complexity

Health programmes are based within complex real-world settings, where a myriad of different professionals from across sectors, settings and organisations, are involved in the care of patients. Each professional may follow their own sets of rules, professional values, organisational codes of conduct and ways of working, and will interact with patients who are correspondingly diverse in their culture, values, social class and genetic makeup. Social systems, in other words are open, complex and constantly changing, influenced not only by the individuals within them but also by broader sets of organisational and social relationships. Importantly, this means that outcomes cannot be attributed to a programme or policy alone but will be the result of how that programme or policy interacts with the complexity of factors it meets along the way. This interaction means that interventions are prone to modification as they are adapted and embedded into local systems (Pawson and Tilley 2004). Complexity also results from open systems where stakeholders learn to adapt and adjust behaviours as the intervention progresses. Pawson and Tilley (2004) give the example of performance measures and how once they are put in place and published, the different system players learn how to optimise the way they present their own scores, developers of measures in turn have to adapt the rules to ensure the process is not unfairly distorted. In EOLC care for example, it may be that increases in numbers of patients dying at home is a positive result of purposeful policies to encourage and support patients dying in their chosen place. Conversely, it may also be the result of staff being pressured to meet targets and therefore an unintended consequence of the policy is that staff may pressurise patients to return home; in other words, encouraging patients to make the choice that is favoured by the system.

4.1.3.2 Fallibility

Knowledge is viewed as fallible; all enquiry and observation are ultimately filtered through human perception and therefore there can be no final truth, only a contribution to a better understanding of how and why things work and in what circumstances.

4.1.3.3 Mechanisms

Bhaskar (1989) used the term 'generative mechanism' to explain how and why change happens. Often these causal pathways can only be identified by their outcome and are therefore not always directly obvious. For example, suppose a frail elderly person outlines on their Advance Care Plan (ACP) that they would like to die at home – this action can be recorded and documented. We can observe this decision and see how it is enacted (the domain of the empirical) and the person whose plan it is will experience their own involvement and participation in the decision (the domain of the

actual). However, the generative mechanism, i.e. the 'black box' which helps explain and describe how and why this event has taken place, is only accessible indirectly through the development of a related theory. In the case of patient choice this theory may relate to the level of patient education, knowledge and capacity which will influence the choices they make in relation to EOL.

Mechanisms, according to Pawson (2006), are the engines of explanation and it is through the identification of mechanisms that one is able to see how a programme tries to change behaviour. Realism offers an insight into how things work (causation) and in order to get a deeper understanding of this it is necessary to explore more than what is just visible to the eye. Weiss (1997) emphasises the distinction between mechanisms and programme activities and asserts that mechanisms are not an inherent part of the programme but a response to the programme parts and activities which are triggered in the stakeholders. In RE Pawson and Tilley (1997) present a slightly different conceptualisation of a mechanism, stating that mechanisms are a combination of the resources and interventions offered by the programme and the stakeholder's reasoning in response to the intervention on offer – in other words mechanisms are determined not only by the intervention but also the individual response to the intervention.

Jagosh (2015) provides helpful insight into mechanisms describing them as 'the intended or unintended resources created by an intervention and the response to those resources (cognitive, emotional, motivational) by participants' (p.2). Participants either choose (or choose not) to act in a way that the intervention directs (for example when a professional chooses to communicate openly with patients about their ACP. Importantly, mechanisms and strategies should not be conflated. A strategy is an intended plan of action whereas a mechanism involves a resource (developed by the strategy) and combines this with the participants' reaction or response to the intentional offer of incentives, disciplinary actions, information, education or other resources (Jagosh 2015).

Additional complexity emerges in the idea that mechanisms can remain dormant – that is their potential for change is always there but will only be activated if the conditions are right. Just knowing how mechanisms work is not enough to reliably predict outcomes since mechanisms exist as part of a whole system. For example, a patient at the EOL may be able theoretically to die in their preferred place but it will only happen (that is they will only use agency to enact this choice) if their relatives or responsible carers are confident and feel they have adequate resources to allow this to happen. A set of circumstances that brings about a good experience of death for some (for example being able to die at home) may not bring about similar experiences for others (for example if pain

relief is not available). If elements in the system are changed or removed the causal process is also liable to change.

Pawson and Tilley (1997) first explored the concept of 'mechanisms' for programme and policy evaluation and presented a method for exploring what the 'causal powers' of programmes might be. Mechanisms are not always immediately evident but are conjectured and tested through theory building. Given the complexity of systems in which interventions operate, different mechanisms will be pivotal in different circumstances and the interchange between the various players (management, clinicians, patients, relatives) will alter. The upshot of this is that interventions are likely to involve a number of mechanisms, each involving different players linked in a variety of ways.

To fully understand mechanisms we must consider the distinction between the notion of a 'reason' for human behaviour and a 'cause' as applied in a natural scientific sense (Winch 1958). This parallels the realist distinction between the ideas of 'successionist' causation and 'generative' causation (Pawson and Tilley 1997). The relevance of this debate relates to the issues of human agency and the causes attributed to human behaviour. Humans tend to attribute their actions to various paths of reasoning but the extent to which these are controlled internally by the individual or are structured and guided by external social contexts, power relations, cultural nuances remains open to debate and means that 'cause' can rarely be attributed to anything more than a 'probable' status.

4.1.3.4 Context

Mechanisms will only operate if the circumstances or 'context' are right; these may be social, economic and cultural. RE recognises the shaping influence of at least four contextual layers, referred to by Pawson(2006) as the 'four l's':

- The individual capacity of key actors
- The interpersonal relationships supporting the intervention
- The institutional setting
- The wider infra-structural setting

Context does not refer just to geographical or institutional location, but also to the prior set of social rules, values and interrelationships which are inherent and which can influence the efficacy of programme mechanisms. For this reason, as time goes by, many of the background features that make up the context may change. Jagosh et al (2015) in their work on community based

participatory research note that some of the initial characteristics labelled as 'context' (for example, initial levels of trust or mistrust with which community members engage) would transform through the course of the project and as trust between partners became more solid it was then relabelled as a 'mechanism' in a constantly flowing cycle of generative change. Jagosh (2015) refers to this phenomenon as the ripple effect. Similar findings from Shaw et al (2018) led the authors to conclude that mechanisms do not remain static; in other words, a mechanism in one CMO, can at a later stage be positioned as 'context'.

4.1.3.5 Outcome Patterns

Programmes operating in multiple contexts linking with a range of mechanisms will inevitably result in a variety of outcomes. Realism allows for a more nuanced approach to evaluation, than a single pass/fail verdict (Pawson and Tilley 2004). Instead it encompasses a range of levels of impact, covering both outputs (intermediate implementation targets) and outcomes (changes in the behaviour targeted).

4.1.3.6 Cycles of evaluation

RE utilises a 'research cycle' of hypothesis testing and refinement where there is no start or end point to the gathering of knowledge and refinement of theory. The process, instead, becomes an ever-repeating cycle where further analysis can be continued either within the same programme or same evaluation, or by addressing the same theory in subsequent evaluations. Pawson urges evaluators to build on what is already known rather than constantly re-inventing the wheel (Pawson 2013). It is arguably better to build on something that might not have firm foundations than not to build at all (Scriven 1994).

4.1.3.7 Stakeholder Involvement

RE requires the involvement of multiple stakeholders in order to explore how the different players in the system respond to the programme or intervention. To understand the mechanism, or the reasoning that participants in the programme apply to their actions, it is important that a range of views from key players located across the full complexity of social systems, organisations and institutions be sought; RE therefore privileges a pluralist method of enquiry (Pawson and Tilley 1997).

4.1.4 Divergence within realist paradigms

Although Bhaskar (1978, 1989) is credited with the early thinking around realism, the method has now come to be accepted to present a distinct spectrum of philosophical positions on a range of matters (ontology, causation, structure, persons, and forms of explanation). Archer et al (2016) suggest that realism represents a broad alliance of social theorists and researchers attempting to develop a 'properly post-positivist social science'. Despite differences in perspective within the various schools of thought, there are strong areas of commonality directed to a central goal of 'social betterment' (Pawson and Tilley 2004).

When one evaluates realistically one always returns to the core theories about how a programme is supposed to work and then interrogates it – is that basic plan sound, plausible, durable, practical and above all valid? (Pawson and Tilley 2004 p10).

Within the broad school of realism two major theoretical divergences emerge; 'critical realism' as advocated by Bhaskar (1989) and Pawson's (2013) 'scientific realism'. The point of divergence appears to focus on the argument around whether social science can create 'closed system' investigations. For Bhaskar the 'closed system' is ultimately not achievable in social research because of the 'unique and unceasing human capacity to change the circumstances in which they live'; referred to as 'emergent mechanisms' (Dalkin et al. 2015). Human actions therefore have to be critically evaluated. Pawson (2013), on the other hand, is more pragmatic and argues that neither physical nor social science depends on closed systems. There are no crucial experiments which will reveal ultimate social truths or laws (especially randomised controlled trials). Equally, Dalkin et al (2015) argue all natural science can do is contribute 'imperfect progress in gathering knowledge of the potentially infinite number of contingencies that can shape a physical system' (p.2).

A further anomaly between the different schools of realism relates to the precise point at which mechanisms bring about social change. For Bhaskar causal mechanisms are located within the power and resources that lie within institutions. For others such as Pawson and Tilley (1997) mechanisms are identified at the level of human reasoning. Interventions within health services tend, at some level, to involve the actions of people – so understanding why stakeholders act as they do in terms of their thinking and reasoning is essential to understanding the intervention.

4.1.5 Realist evaluation: strengths and weaknesses

4.1.5.1 Explanatory power

For the purposes of this thesis the framework that I suggest best fits my research questions is the realist evaluation approach, first proposed in 1997 by Pawson and Tilley and later developed by others (Henry, Julnes and Mark 1998; Pawson and Tilley 2004; Pawson et al. 2004). The premise in RE that the world of social interventions is complex and because of this complexity, specific interventions cannot be guaranteed to produce an outcome in all circumstances, fits well, I would argue, with the policy arena around EOLC. RE is a method that helps maximise learning across policy, practice and organisational boundaries. Its emphasis on pluralism encourages a range of information gathering tools which can cross boundaries, reduce siloed thinking and enfranchise stakeholders who may, in other forms of enquiry be side-lined. I believe RE fits with the government imperative to make better use of research and evidence in policy making and to question inherited ways of doing things – its fundamental purpose being to improve the thinking that goes into service building (Pawson et al 2004).

Another strength in terms of policy development is that as a form of explanatory evaluation RE brings weight and power to decision making and has been seen to assist the evaluation of complex interventions. Detailed assessment of the intermediate steps and processes between intervention and outcomes, backed by complementary quantitative data can improve attribution claims (Kernick and Mannion 2005). These characteristics in turn make findings more relevant to policy (Van Belle et al. 2010; Stame 2004). Moreover, decisions made based on an explanatory evaluation may be more easily guided than those directed by other sorts of data, for example the comparative statistical significance of a range of mediators and moderators in meta-analysis (Pawson et al 2004). Pawson (2006) suggests that the unit of analysis is shifted from a programme to a programme theory, thus helping resist the temptation to suggest that programmes may be viewed as treatments or dosages which have effects that can be averaged. Instead explanations of why things do or do not work are more nuanced, based on explicit or implicit theory around anticipated outcomes.

4.1.5.2 What determines quality in realist evaluation?

RE is used increasingly in health service evaluation of complex interventions and studies are carried out from different disciplinary perspectives using a wide range of methods. These endeavours have say critics, at times lacked transparency and discipline in failing to record clearly the steps taken to ensure they are replicable and robust (Wong et al. 2016; Welch and Tricco 2016). To address such concerns Wong et al have developed a tool to help ensure better quality reporting of REs (Wong et

al 2016) . The intention is to help practitioners to follow a more standardised procedure and so reduce previously reported misunderstandings and confusion among stakeholders. The tool (appendix 4.1) is made up of 20 items broken into six sections with explicit guidance given as to what each section should cover: title; summary of abstract; introduction; methods; result and discussion. Each step of this helpful tool was followed in this study (section 4.4).

In relation to perceived opacity in reporting mention has been made of lack of clarity around the process of analysis, particularly in the use of ‘retroduction’. This final stage in the analysis (explored in more detail in chapter eight), focuses on causal mechanisms attempting to identify the context necessary for the mechanisms to trigger. The importance of elucidating structure and agency is seen to be key to arriving at policy-based recommendations. Contemporary commentators have begun to address concerns by providing more transparent accounts to show the process of realist analysis (Fletcher 2017; Gilmore et al. 2019). Fletcher (2017), for example, uses a study looking at Saskatchewan Farm Women to describe the ‘deductive, yet flexible (i.e. directed) coding process that drew on existing theory and literature to arrive at the identification of demi-regularities. At the beginning of the research process a series of codes were conjectured which were then ‘changed, eliminated and supplemented with new codes’ as the research developed (Fletcher 2017, p.186). In this way she describes how the deductive codes were treated as a means to reformulate the existing model or theory from which they were drawn. Having initially used a deductive process to draw up a list of demi-regularities, the next step was a process of abduction, in which theory is applied to empirical data. This stage of analysis, the authors proposed, provided a route into allowing the researcher to engage with a range of ‘deeper causal mechanisms’ which may have influenced outcomes. In Fletcher’s study, for example, whilst women’s choice of ‘off-farm work’ may have been a simple matter of choice, abductive reasoning presented an alternative hypothesis in which the apparent loss of control women faced was considered at the macro-level in relation to neo-liberal changes in agricultural policy.

Jagosh (2020) adds clarification to the distinction between abduction and retroduction. Abduction, he says, is the starting point, a form of ‘imaginative thinking’ intended to lead to ‘new ideas for generating theories and testing possible mechanisms’ (Jagosh 2020, p.2). Retroduction, on the other hand takes these hunches to the next step, developing the theories further by testing the mechanisms. Darwin’s Theory of Evolution is cited as an example – where an initial hunch that some mechanism must be at play leading to changes which confer advantage is proposed, which then leads the theory to be further developed and the conjectured mechanisms are tested.

Despite greater attention to demonstrate consistency in method however RE is not without its critics (Marchal et al. 2012; Porter 2015; Rycroft-Malone et al. 2010; Astbury and Leeuw 2010); below I explore a number of the concerns raised.

4.1.5.3 Inconsistent use of defining variables

Porter (2015), Dalkin (2015) and Archer (2000) all argue that there are areas of confusion and inconsistency in the articulation of RE method, particularly around the lack of distinction between agency and social mechanisms. According to Porter (2015), the inclusion of human agency under the rubric of social mechanism is both unsustainable and erroneous, creating a situation where 'psychology is collapsed into sociology' (2015, p.243). The implication that agency is a component of structure means that individual action becomes deterministic, with the power of the individual rooted entirely within the social relations and organisational structures. Porter (2015) argues that greater clarification of the relationship between mechanisms, contexts and programmes is needed and suggests that the basic realist evaluation formula where $C+M=O$ be revised to include the additional component of 'A' for 'agency' on the left hand side (p.243). The formula becomes $C+(M+A) = O$. In other words, he suggests a revised method where the notion of a 'mechanism' includes: i) the strategies embedded in the planned intervention and its social context and ii) an additional component (A) which relates to experiences, interpretations and responses of the actors involved. Porter contends that the overt introduction of 'agency' in the formula will help correct the tendency of RE to conflate social structure and agency, meaning that it may be easier to tease out the relative contribution or reciprocal influence of each (Archer 2000).

Dalkin et al (2015) develop Porter's (2015) ideas along slightly different lines. They propose that the realist researcher's quandary lies in distinguishing between context and mechanism and clarifying how each feature contributes to the overall 'explanatory endeavour' (p.4). In an RE of a palliative care Integrated Care Pathway (ICP), the researchers aggregated a number of individual theories into one overall programme theory of the entire ICP. This process was reported to be challenging, specifically in distinguishing between context and mechanism and the resulting conflation of programme strategy (the intervention) with mechanism. Outcomes, they argue, are the most tangible and easily identifiable part of the $C+M=O$ formula yet identifying the context and mechanisms formula within complex environments is often not so straightforward. Reasoning (individual agency) and resources it is suggested may be conflated, and researchers have had a tendency to emphasise one at the expense of the other, often in the guise of a mechanism.

Moreover, the notion that the reasoning of professionals participating in the study could be conceptualised as a binary concept was deemed problematic. In other words, there is no precise point at which an on/off switch determines the course of action, rather 'there are varying degrees to which an individual can feel confident, angry or mistrustful leading in turn to a graduation of outcomes' (Dalkin 2015 p.6). To resolve this, in a similar vein to Porter (2015), they suggest that mechanism be separated into those, on the one hand, linked directly to the intervention (referred to as 'resources') and those on the other linked to individual agency (referred to as 'reasoning').

Whilst both reasoning and resources are constituents of a mechanism, by explicitly treating them as separate entities it can help highlight the difference in the way that mechanism and context operate (Porter 2015). Separating out the component parts of the mechanism (resources and reasoning) helps the researcher to consider both concepts, rather than privileging one at the expense of the other. The premise is that in order to bring about outcomes (anticipated or not), resources must be introduced into a specific context, and the interplay of these components results in individuals involved making decisions which results in an outcome. For further clarification Dalkin et al (2015) conceptualise an 'activation continuum' for participant decision making – rather than a binary trigger.

The important point is that context and programmes are both social formations in which mechanisms are embedded, the distinction being that contexts are pre-existing formations, whilst programmes are novel formulations designed to 'countervail against contextual mechanisms' (Porter 2015). Porter's (2015) main objection to Pawson and Tilley's work (1997) seems to be one of consistency, accusing them of asserting different things at different times and vacillating between voluntarism and determinism. At times, he suggests, their message is entirely consistent with realism, particularly in their argument that individuals always have choice, but these choices are always under elements of external influence. Programmes are met with 'constrained choices, located in pre-existing conditions' (Pawson and Tilley 2006, p. 25). Unpicking the role of structural determinism versus individual voluntarism should also help make more transparent the powers that reside at the level of the individual, allowing the researcher to be more cognisant of how this varies with relative position in the social hierarchy. Issues of power will be considered in more detail in the next section.

4.1.5.4 Interpretation of residual power within RE

Having dealt with criticisms targeted at lack of clarity around definition I turn now to a second major critique lodged against the absence of any real account of ‘power’ within RE (Rolfe 2016). Individuals are all endowed with different levels of power, inherent in the historical, socio-economic, political, institutional, religious and cultural frameworks within which they reside. Typically, these structures invest some players within the system with more power, authority and consequently more privileges than others. Bearing this in mind (Wittgenstein 1958) suggests viewing the gathering of information in research as ‘purposive activity’ – and reminds us of the need to retain an inquiring, critical attitude towards the value of data collection and its politically structured context. In other words, it is important throughout the study to interrogate a range of perspectives, paying attention to the voices that are seldom heard – in this case the voice of patients. Within this broad and often vulnerable group there are some who are more likely to be overlooked including those lacking cognitive capacity; the frail elderly lacking a clear clinical diagnosis; or those from a Black and Minority Ethnic (BAME) group, particularly whose first language is not English.

4.1.5.5 Concerns relating to the philosophical paradigm

Other concerns voiced against RE refer to misconceptions around the philosophical paradigm (Williams, Rycroft-Malone and Burton 2017; Greenhalgh, T. et al. 2015; Marchal et al. 2012), with the charge lodged that insufficient attention is paid to the philosophical roots of the paradigm and that researchers have misapplied or misinterpreted the theory as a result of thinking based on fundamentally different philosophical assumptions. Williams et al (2017) encourage researchers not overlook the value of delving ‘*underneath what is observable exposing values and beliefs and explaining relationships by methodologically exposing social roots and structures*’ (Williams, Rycroft-Malone and Burton 2017, p.6). Further criticism relates to a propensity to assert that interventions in and of themselves, cause outcomes (Greenhalgh et al 2015) and questions have also been raised about the validity of causal claims made in realist evaluation (Mayne 2012; Wimbush, Montague and Mulherin 2012).

The complexity of the realist evaluators endeavour and the deeply stratified social world under examination, means that the findings and recommendations can become so nuanced and so highly qualified as to render them of little value (Marchal et al 2012). To cope with the enormity of the task some REs may focus on mechanisms which explore a specific part of a complex programme. A solution suggested is to view findings from a realist evaluation as a set of building blocks which can be used to help determine what might work in what conditions.

4.1.5.6 Practical concerns

Another concern cited about RE is the absence of guidance to support the development of the programme theory (Marchal et al 2010) and may be particularly pertinent to this study. In the case of policy, particularly EOLC policy, whilst much of it sets aspirational goals, the suggested path through which these goals are achieved, both in terms of mechanisms and context are often notable in their absence from policy documents (see chapter three).

In addition to methodological and philosophical concerns about RE a number of more practical logistical issues have been raised around time, resource and lack of practical guidance (Wand, White and Patching 2010; Marchal, Dedzo and Kegels 2010; Rycroft-Malone et al. 2010). I was certainly aware in this study of the enormity of the task of evaluating EOLC policy and of the necessity to place limits on what was and was not realistic.

Finally, it should be noted that the breadth of study and fact that EOLC policy covers such a wide range of programme areas¹ means that the concept of ‘evaluation’ here will not relate to one particular policy area – but will represent a synthesis of information using a pluralistic methodology. Some of the information gathered will be retrospective, some concurrent and some prospective using data from audits, scoping studies and case studies – with the predominant themes throughout being the linking, testing and refinement of programme theory. Whilst this multi-method, flexible and iterative approach fits well with realist thinking it is likely that the broad scope of the enquiry will mean that, in order to provide an overall picture of the way policy is applied in practice, there will be little scope to look in detail at any particular area. Moreover, the wide range of tools utilised demands greater methodological expertise on the part of the reviewer.

In summary the research paradigm chosen to provide a framework for this study is realism. RE, as espoused by Pawson et al (2015), embraces multiple methods of data collection, combining quantitative and qualitative techniques, so that both processes and impacts can be explored. As can be seen from the challenges presented above, theory driven models such as RE are not a panacea, nor do they provide all the answers. It is nevertheless my contention that it is the method best

¹ The type of programme covered by EOL policy and strategy included, for example: promoting patient choice; reviewing culture, values and education; supporting commissioning for EOLC; using metrics and measures to compare and standardise practice; reviewing how EOLC fits within the broader health system issues; providing adequate and proportionate support to a range of health care settings.

suited to providing the means to help illuminate the central questions posed in this thesis. I found Porter's suggestion for revised CMO mechanisms useful (discussed in 4.1.5.3) and used this to guide my conjectured theories. Moreover, I was cognisant of the possible impact that the power vested in individuals could wield in relation to the research process (including design, implementation and analysis).

Having considered some of the strengths and weaknesses of RE and presented arguments to support my choice of method, the next two sections move on to discuss methods of data collection and how the different phases of the work inform the development of the theory.

4.2 Data Collection Methods: Overview

RE methodology will be used to frame the study which will be divided into two phases:

i) **A scoping study drawing on a methodology developed by Arksey and O'Malley (2005).**

Analysis of UK policy documents and interviews with key stakeholders explored how national policy and the way services are prioritised may influence the delivery of care. The scoping study was used to generate the hypothesis and theories subsequently tested in the case studies.

The final decision to use RE as the central paradigm to guide this work did not emerge until the scoping study was underway which is why Realist Synthesis (Rycroft-Malone et al. 2010) was not chosen as the method to inform this phase of the study. I would argue however that the methodology presented here is compatible with the method of realist synthesis (Pawson et al 2004). The one stage lacking in those outlined by Arksey and O'Malley (2005) (detailed below), which would be central to realist synthesis, is the explicit identification of CMOs and the articulation of these into conjectured programme theories. However, as the scoping study developed this stage of theory development was purposefully woven into stage 5 and became a part of the framework development.

ii) **Case studies carried out within three Clinical Commissioning Groups (CCGs).** The case study approach was used not as a theoretical paradigm but as a method to inform data collection design. This phase focused on how national policy is used to guide local practice, examining the delivery of EOLC care within three CCGs.

The study was rooted in a method that privileged depth of understanding over generalisability and reflected the real-life context of the fast-changing health system and policy environment.

4.2.1 PHASE 1: Scoping Study

A scoping review methodology is used to map the key concepts, clarify definitions and/or conceptual boundaries (Peters et al. 2015). Scoping reviews are helpful where the key objective is not to measure the quality of research, rather to develop a concept map, highlighting gaps in research and shedding light on how policy has developed. However, despite their potential to advance health care practice, policy and research, Colquhoun et al (2014) argue how their worth has been undermined by lack of clarity around terminology and method. Recognising the concerns which have been expressed around the rigour and validity of some scoping studies the methodology adopted here attempts to apply greater rigour. In a process developed by Arksey and O'Malley (2005) and refined by Levac et al (2010) six stages are proposed - outlined in table 13.

Table 13 **Six proposed stages for a scoping study**

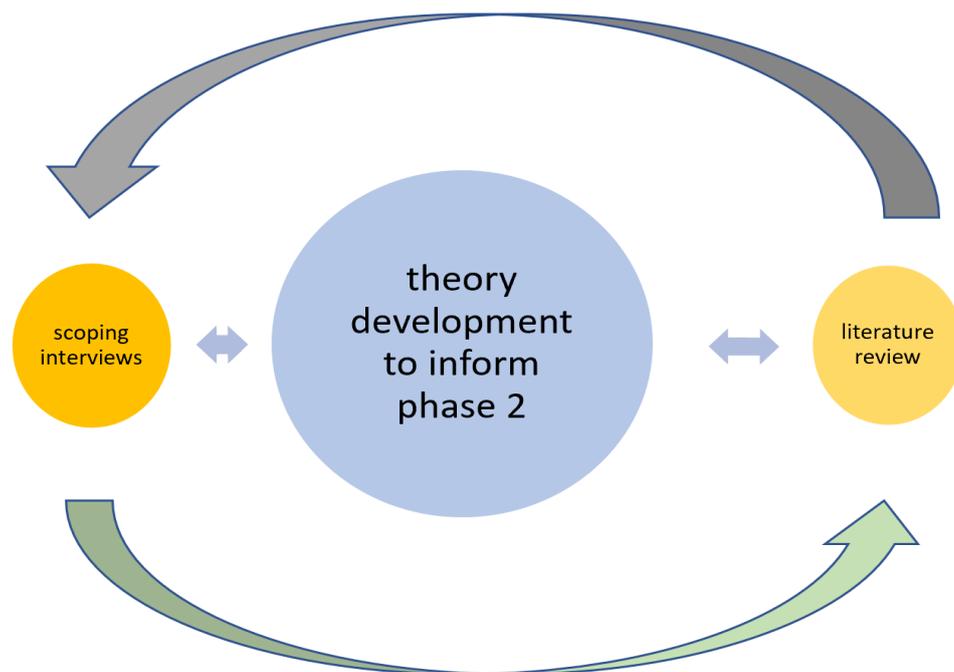
<ul style="list-style-type: none">• Stage 1: Clarifying and linking purpose and research questions; consideration of how to develop a feasible research strategy which maintains a broad scope without losing direction and clarity.• Stage 2: Considering how to manage breadth and comprehensiveness alongside practical and resource constraints.• Stage 3: Using an iterative approach to select studies – selection criteria will be influenced by growing knowledge of literature.• Stage 4: Extracting data. Challenges in remaining objective in selecting studies for inclusion are acknowledged. The process is iterative and to improve reliability should be done in consultation, with criteria being revisited and reviewed periodically in order to 'discuss challenges and uncertainties'. A 'narrative review' or 'descriptive analytical' method will be used that considers the importance of context.• Stage 5: Collating summarising and reporting results. An analytic framework helps to provide a view of the breadth of the literature. Clarity and consistency together with an indication of the weight of coverage of specific issues.• Stage 6: Consultation. This stage will allow for contributions from a range of stakeholders. The aim is to sense check and explicate findings against real life experience.
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Adapted from Arksey and O'Malley (2005)

The intention of the scoping study was to pull together existing knowledge around the impact of policy on EOLC - developing and framing the programme theory which was then developed and tested in the case studies. Pawson and Tilley (2004) suggest that interviews with practitioners are deemed especially important as discussions of apparent programme successes and failures can help develop hypotheses about what works for whom and in what circumstances.

To help explore and shape the research questions I embarked on the literature search and the informant interviews in parallel, with each phase informing the other in an iterative process. The literature search helped identify key areas to explore in scoping interviews and at the same time respondents directed me to literature and data relevant to my central research questions. This process is represented in figure 6.

Figure 6 **how scoping interviews and literature review fed into theory development**



4.2.1.1 Sources of Evidence

i) Key Informants

The scoping study included interviews with professionals who were integral to setting policy and establishing good practice in the field of EOLC; these included policy makers, commissioners, managers, politicians, clinicians and academics. Interview guides (appendix 4.1a-4.1d) were

developed based on the research questions outlined in Chapter one and covered the central challenges to providing consistent, good quality EOLC which began to emerge from the literature.

In-depth qualitative interviews were conducted between 01.06.2018 and 01.10.2018. Realist methods recognise that people in different roles bring different experience and insight, and respondents were selected purposefully by role and known area of interest. A list of key experts was initially populated from those involved in the consultation around the 'Ambitions for palliative and end of life care: a national framework for local action 2015-2020' (NPELCP 2015). A number of additional respondents were contacted on the recommendation of those being interviewed (snowball sampling (Ghaljaie, Naderifar and Goli 2017)).

During the interviews flexibility to determine which areas were to be probed in more detail was maintained, with the ability to explore different areas depending on context and experience of interviewee (Robson and McCartan 2016). The interview method drew on an approach influenced by RE (Pawson and Tilley 2004) demanding a level of active engagement between respondent and the interviewer, where the received narrative can be analysed against a variety of other interpretations. Relevant literature and recent policy pertaining to EOLC were used in the subsequent analysis to review interview data against the social contexts, constraints and resources within which the interviews were located.

Interviews were conducted either on the phone or face to face and lasted up to forty minutes. Data was then sorted into themes using the software programme NVivo which allows for full text reviewing of interview data. The software allows for easy labelling of codes and hence the development of themes, enabling different visualisations of relationships between the data. The ability to switch between different items of data (transcripts, codes, memos and annotations) allows for a truly iterative process. The broad themes emerging from the interviews were plotted into mind maps which were used to continuously develop and review the CMOs. Similar methods for analysis of the interview data were used across both phases of the study and are described in more detail in section 4.5.

ii) Searching the literature

Stage 4 and 5 of Arksey and O'Malley's (2005) framework for scoping studies (table 13 above) refers to extracting and analysing data either through 'narrative review' or a 'descriptive

analytical' method. My method of narrative review was influenced by Greenhalgh et al (2018) who suggest that whilst lacking the rigour of a systematic review, it serves to provide a broad critique and in this way helps broaden understanding of complex policy areas. The narrative review Greenhalgh et al (2018) emphasises, is not a 'poor cousin' of the systematic review, rather a 'complementary form of scholarship' which rejects the 'spurious hierarchy of secondary evidence' (p.6) and prioritises interpretative synthesis.

The narrative review... deals in plausible truth. Its goal is an authoritative argument, based on informed wisdom that is convincing to an audience of fellow experts (Greenhalgh et al 2018. p.3).

The literature search focussed on reports produced in England over the last two decades and defined the targeted population group as people identified by professionals as being at the end of life (likely to die in the next 12 months) and over the age of 75. Literature exploring all aspects of service planning, commissioning and delivery relevant to current practice in England was considered. All types of published and unpublished literature including guidance and policy reports were included. Whilst the focus was predominantly on England, comparative international literature focussing on health systems and delivery models of EOLC, was also considered – though the scope of international literature explicitly linking policy to outcomes was limited.

iii) [Search strategy](#)

Key sources of evidence consulted and the MeSH terms included in the data base search are shown in tables 14 and 15 below.

Table 14 Key sources of evidence consulted

Category	Specific source
Databases	<ul style="list-style-type: none"> • PubMed • Scopus • CINAHL • Cochrane Library
Grey literature	<ul style="list-style-type: none"> • National End of Life Care Intelligence Network • Cross checking references from primary studies and systematic reviews (snowballing). • Papers/websites recommended during interviews with key stakeholders (clinicians, commissioners and strategists).
Policy	<ul style="list-style-type: none"> • Department of Health • NHS England • Office for National Statistics
Organisations	<ul style="list-style-type: none"> • Age Info (Centre for Policy on Ageing UK) • King's Fund • The Health Foundation
Key Informants	<ul style="list-style-type: none"> • Experts involved in policy implementation

Table 15 MeSH terms included

<p>End of Life: exp Terminal Care, palliative care, terminally ill, and exp advanced care planning.</p> <p>Population: Aged, 75 and over, frail, elderly</p> <p>Resources: health care rationing, health care costs, healthcare economics, cost-benefit analysis, cost allocation, cost and cost analysis, cost control, cost of illness, health priorities, equity</p> <p>Care: patient-centred care, standard of care, advanced directives, comfort care, hospice care, holistic health, medical overuse</p> <p>Policy: policy or policies or law or legislation or strategy or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland or Department of Health</p>
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iv) [Selecting studies and charting data](#)

Following a series of electronic searches using MeSH terms outlined in table 15, a total of 176 papers were downloaded and collated in RefWorks bibliographic software – results are detailed in Appendix 4.3. Abstracts were screened against inclusion criteria and were reviewed and revised through the course of the study (table 16 below). Full manuscripts of

all relevant studies were obtained. Limits applied were English Language transcripts from 2008 onwards (marking the date of the first national EOL policy) and included all study designs. Searches were carried out in Autumn 2018 though updated continuously through the course of the doctorate. Data extracted was coded using NVivo until saturation was reached on key areas of interest. There was no formal appraisal of quality or allegiance to a hierarchy of methodology.

Table 16 Evolving criteria for selecting studies to include in scoping study

Evolving criteria for selecting studies to include in scoping study
EXCLUSION
Focussing on treatment of a specific disease
Not in English
Publications prior to 2008 (exceptions to this were policy/strategy documents of historical relevance)
EOLC in children or adults under the age of 75
Detailed evaluations of specific care models and tools
INCLUSION
Everything relevant to EOLC policy in England
Peer reviewed and grey literature
Relevant guidance and strategy docs from statutory and voluntary organisations
International literature relevant to a policy/systems analysis of EOLC – particularly comparative across a number of countries

4.2.1.2 Interviews

The intention of the realist interview is to help test the veracity of the proposed programme theory. It is this process that shapes the relationship between subjects and researchers. The job of the researcher is to communicate the theory under exploration in order that respondents can articulate their own points of view. A topic guide (appendix 4.2a) was drawn up to help develop these conversations, based on themes emerging from the literature. These techniques are referred to as the ‘teacher-learner relationship’ or ‘assisted sensemaking’ and refer to the idea that collecting data that is relevant to the evaluation includes an element of subtle teaching where the interviewee communicates the basic ideas on which the programme theory is based to the interviewee – allowing them to support or refute these ideas (Manzano 2016). The aim is that the respondent will be able to respond appropriately to inform the CMO configuration that is under examination (Pawson and Tilley 2004). The dynamics which arise from the application of these techniques mean

that, rather than adopting a neutral stance, the interview is actively engaged in the process and must remain aware of their influence and bias during the interview process (Manzano 2016)

4.2.1.3 Analysis of scoping study data

Mindful of criticisms around insufficient transparency in reporting (see section 4.5) I outline here each stage of the process I followed during data analysis – these methods are further elucidated in section 4.5.1:

- Interviews were audio-recorded and transcribed verbatim by me.
- Transcripts were initially read and coded manually. Once I had read through the transcript, I highlighted key themes and noted them separately at the end of each text – I also manually labelled codes as I read through each printed transcript. In tandem with this, and following the method outlined by Papoutsi et al (2018), notes were kept on CMO configurations and the relationship of these to the conjectured programme theory. An example of a chart used to document the building and refinement of CMO mechanisms is shown in appendix 4.11. At the end of the scoping study a number of conjectured CMOs (appendix 4.12) were developed which were used to inform the topic guides for the case studies and were then refined during the case study phase.
- Following this familiarisation stage, data was uploaded into NVivo. During the first stage of inputting into NVivo some of the early codes which had been manually given were assigned, whilst in other cases new codes were generated. The allocation of codes involved both induction (codes emerging from the data) and deduction (codes created in advance informed by the initial rough programme theory) (Miles and Huberman, 1994).
- The key stages of analysis were discussed at monthly supervision and a sample of interview coding was scrutinised across the team to ensure consistency in interpretation.

4.2.2 PHASE 2: Case Studies

4.2.2.1 Why use a case study approach?

A case study approach to gathering data was identified to interrogate how EOLC is rolled out at a local level. The method offers the means to closely scrutinise what matters to a range of stakeholders and is one of many approaches used in social science when ‘how’ and ‘why’ questions are being asked (Yin 2014). Case studies allow for an in-depth study of a complex intervention in the context in which the programme under review was implemented. The focus, in a case study is on relationships and processes with a view to better understanding the issue from the perspective of participants (Yin 2017).

Through the exploration of multiple perspectives and inquiry into the influence of key actors, greater insight can be generated into the research questions posed. Case study methodology has a practical versatility in its agnostic approach whereby "it is not assigned to a fixed ontological, epistemological or methodological position" (Harrison et al. 2017 p.7). The epistemological lens I adopted to inform the case studies was informed by Yin et al (2017). Accepting the multiple complexities of the real world Yin's approach (Yin et al 2017) fits with the philosophical paradigm of Realist Evaluation and was used here to guide the method followed. The approach allows for an in-depth study of a complex intervention or situation in the setting in which the programme under review was implemented. Through the exploration of multiple perspectives and inquiry into the influence of key actors, greater insight is generated into the research questions posed. As the data emerges, the programme theory is reviewed and tested in an iterative process of induction and deduction – in other words both 'facts' and 'premises' are drawn together in a process known as 'retroduction' involving multiple layers of data (Yin, R. 2014) to help uncover underlying mechanisms.

The intention of the case study was to interrogate and explicate the hypothesis developed in the scoping study. Pawson and Tilley (2004) posit that the aim of continued, focussed data collection is to look for

... nuanced outcome pattern of successes and failures within and across interventions. The primary tactic is thus to interrogate these hypotheses by making sub-group comparisons. (Pawson and Tilley 2004 p.11).

The theory emerging from the analysis of data collected in the case study is tested and adapted in an effort to explain variations in impact and outcome. An assumption is made that 'truth' exists on a number of different levels and proposed models and theories are in a constant state of flux and re-testing; the process is cyclical and emergent and 'truth' is illusory. The method of developing theory through interrogation of data collected is described more in section 4.3 and the method of data analysis in 4.5

Table 17 **What characterises a case study?**

There is a focus on a small number of particular cases
It takes a holistic approach to the study of social phenomenon in a natural setting – appreciation of context is required, unlike an experiment which aims to isolate phenomena in a closed laboratory setting
Cases must have bounded parameters
Each case is unique and enquiry into it involves multiple methods of data collection or evidence
The research questions focus on 'how' and 'why' of a <u>particular event/phenomenon</u>
Case studies are empirical in the sense that they rely on the collection of evidence - however given the complex nature of social interactions this will almost always go beyond countable aspects and trends and will involve interpretation and reflexivity
Case study focuses on a phenomenon in context where typically differentiation between boundary and phenomenon is unclear
It is a strategy or approach rather than a method

Based on Yin (2014), Stake (1995) and Merriam (1998)

The intention of the case study is not to provide an account that can be generalised, but to provide depth and detail of real-life understanding. The focus is on relationships and processes with a view to better understanding the issue from the perspective of participants (Merriam 1998). In this case studies were used to explicate the hypothesis developed in the scoping study. The emerging theory was tested and adapted, using a realist interpretive framework in an effort to explain variations in impact and outcome. The assumption is that 'truth' exists on a number of different levels and proposed models and theories are in a constant state of flux; the process of re-testing therefore should be cyclical, theory development is emergent, and 'truth' is illusory.

Health services are under constant change and adaptation, strongly influenced by the prevailing socio-economic and political climate. Case studies represent a research approach that can embrace and interrogate the multi-disciplinary complex nature of interventions, whilst allowing the various stakeholders (including patients) to have a voice.

4.2.2.2 Case study boundaries

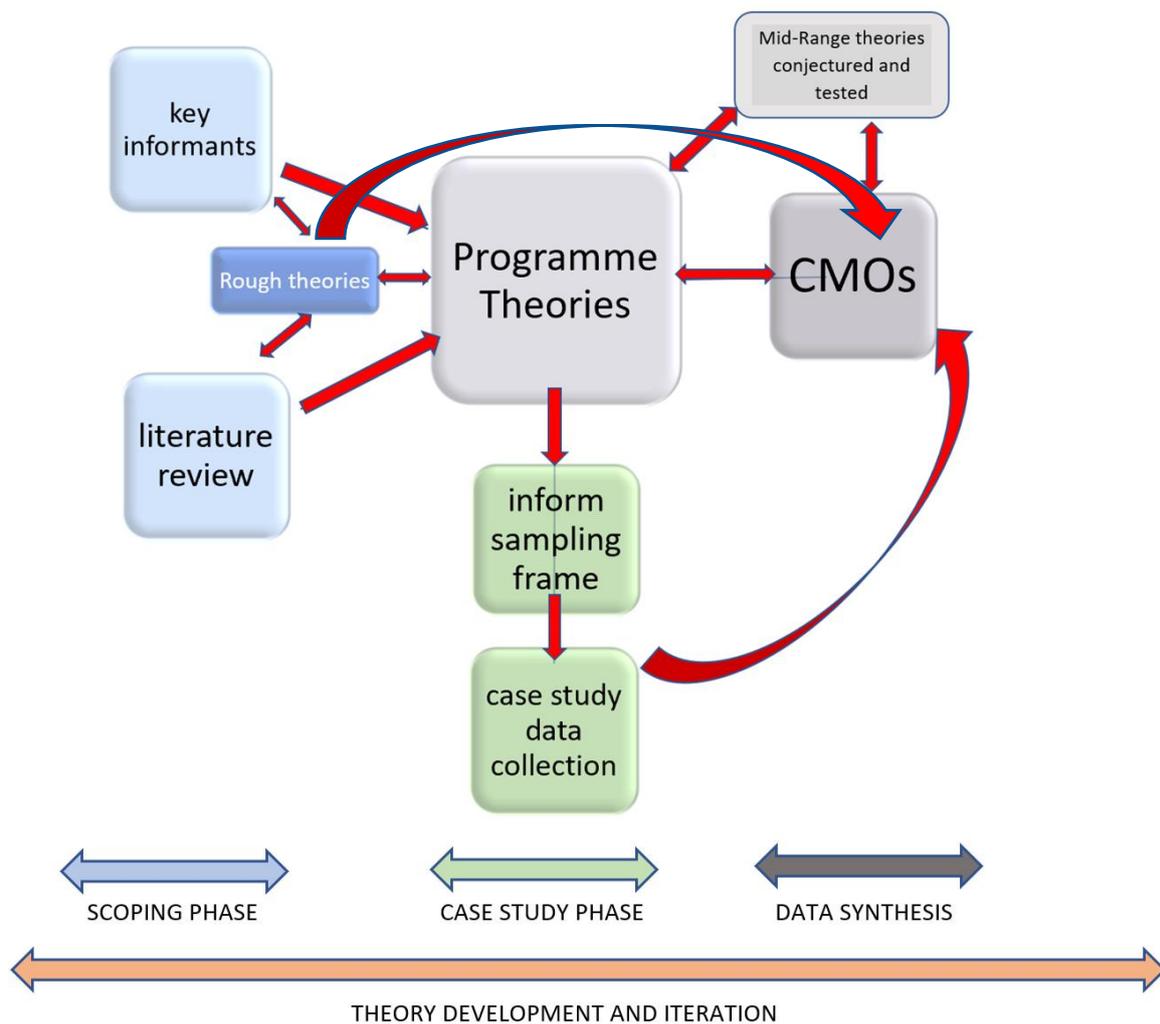
Although it is advised that the case under study needs to be bounded and its parameters defined and differentiated from the context (Mills, Durepos and Wiebe 2010), Robson (2011) warns that these distinctions can be hard to draw. In this study three CCGs are used as the case study sites, constituting organisations whose boundaries are particularly hard to define, crossing different sectors and professional groups and made up of increasing numbers of both permanent and transitory partnerships. Methods used to selected case study sites are discussed in section 4.4.1.

In summary, to gather information to inform the testing of CMO mechanisms postulated using an RE approach, I used case studies to test a series of how and why questions. The aim was to elucidate the context, mechanisms and agency that bring about outcomes (Porter 2015) and thus shed light on, and bring clarity to, the various theoretical mechanisms that underpin EOLC policy. The supposition was that close scrutiny of local EOL service provision and the response of the various stakeholders to the services provided, would support the development of explanatory theories. Given the complexity of EOL services, the overlap between different sectors and settings including mainstream health services, social care and charitable and voluntary provision, as well as the largely 'unboundaried' organisational set up of a CCG - a degree of flexibility was necessary in the research process.

4.3 Developing theory

RE is theory driven – articulation of theory is evident at all stages and data collection serves to test and refine the emerging theory. Figure 7 depicts how information from the scoping study was used to generate a 'rough programme theory' which fed into the development of CMOs and research methods used in phase 2.

Figure 7 How the scoping study fed into the case studies and theory development

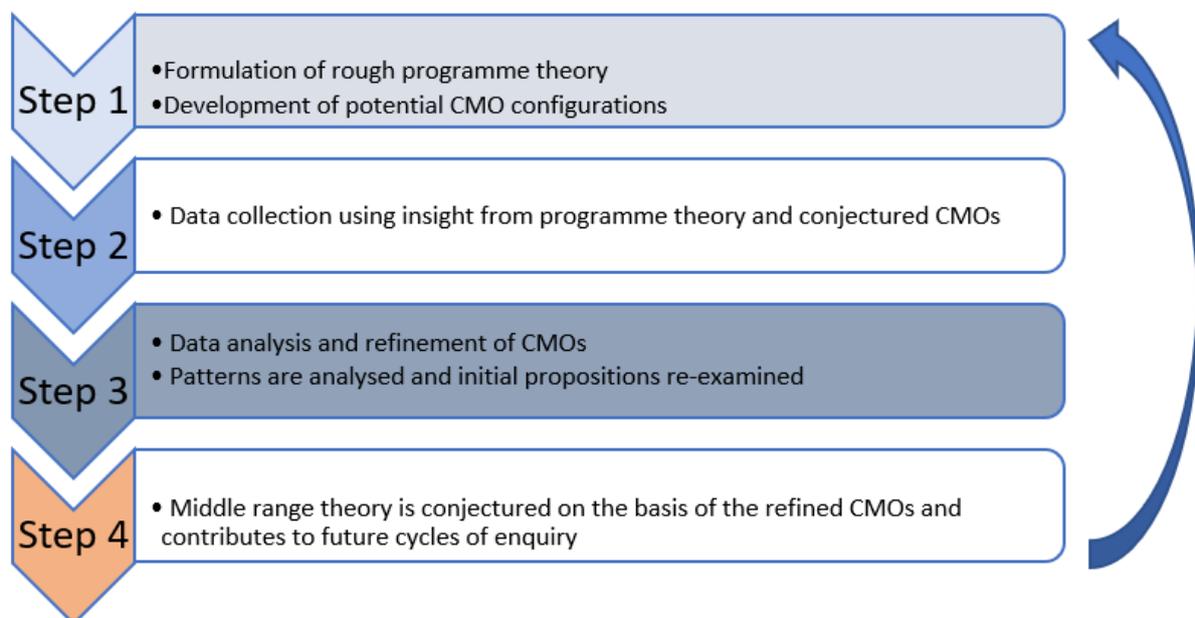


Developing a theory helps guide the evaluation and determines the value and utility of the results (Scriven 1994). RE starts with a proposed programme theory which is tested and refined through the evaluation process. The initial programme theory is based on previous research, knowledge and experience and the assumptions on which the programme intervention was built. The articulation of the theory behind EOLC policy is more implicit than explicit and the processes by which the policies (and theories behind them) are developed often remain opaque. The methods used in this thesis draw on the work of Shearn et al (2017) where ‘rough’ programme theories (RPTs) were built as frames against which to test the veracity of projected theory in ‘large, complex and messy interventions’. Programme theories do not refer to high level abstractions, rather they focus on linking method to outcome. A rough programme theory (RPT) elucidating how national policy operates is presented at the end of chapter five (phase 1 findings).

In order to build on theory and check its veracity the programme components need to be tested (Pawson 2003) and this is done through the creation of CMO configurations which are tested and refined throughout the research process. The RPT helped develop the framework to inform the criteria used for the selection of research participants through a process of purposeful sampling (Palinkas et al. 2015). This sampling method can be effective for identifying informants who are likely to elicit particular areas of knowledge or experience when limited resources are available (Creswell and Creswell 2017).

Collection of further data then leads to an iterative process of testing and refining the components of CMOs and the identification of ‘semi-predictable patterns’ or ‘demi-regularities’ – in this way a theory development process emerges (Merton 1968). The suggestion made by RE is that whilst social reality is not amenable to the kind of nomothetic, law-seeking approaches of positivist natural science, it need not be limited to discovering scientific facts but can aim for Merton’s (1968) goal of ‘middle range theory’ (MRT) (Pawson 2006). MRT is identified to help represent how the programme being studied intends to bring about change. The steps outlined here, detailing the stages of theory development, are laid out in figure 8 below.

Figure 8 Stages of theory development



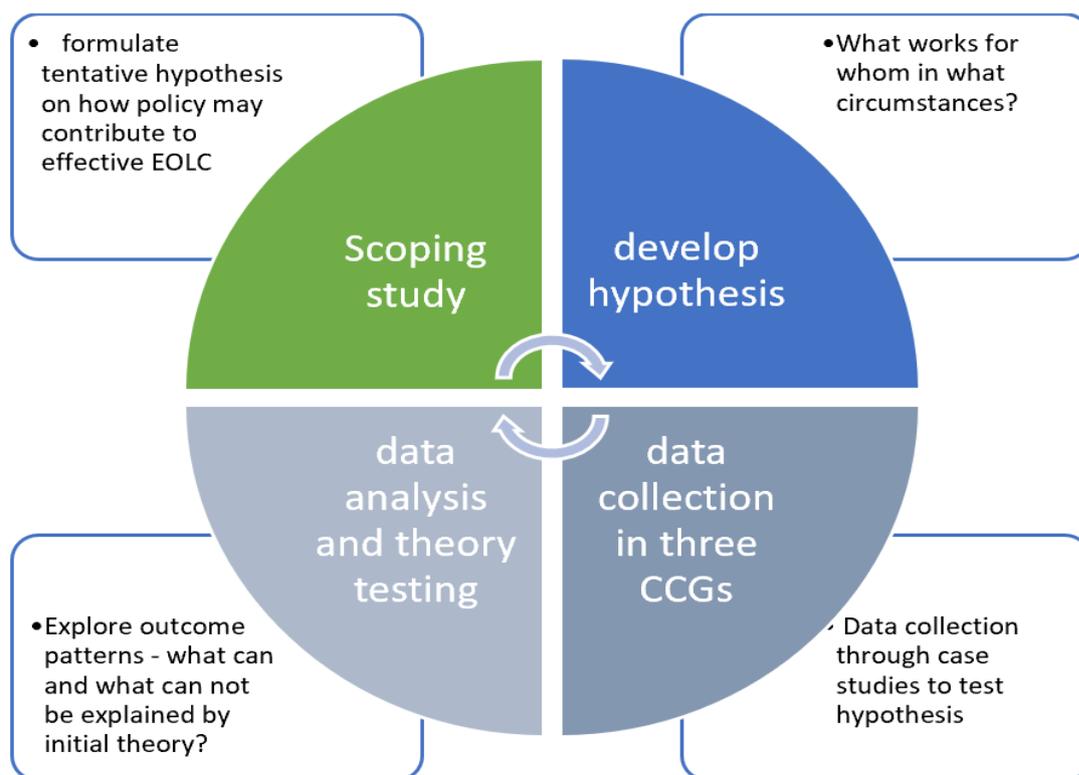
Adapted from Salter and Kothari (2014)

4.3.1 Middle Range Theory (MRT)

Jagosh (2011) suggests that an MRT is not 'abstract to the point of being disconnected from the actual workings of programme implementation, yet, not specific to the point of being relevant to only one case' (p.7). In other words, it can be used to develop and test ideas around a set of complex interactions. The notion of an MRT fits well with Pawson and Tilley's (1997) idea that RE shouldn't work towards an irrevocable truth – rather a set of ideas that generate a common understanding and can be built on and iteratively developed.

MRTs strive to provide a limited set of assumptions from which specific hypotheses may be logically derived and confirmed by empirical investigation. In other words, whilst some degree of abstraction is necessary MRTs 'remain close enough to observed data to be incorporated in propositions that permit empirical testing' (Merton 1967 p.39). Examples of MRTs include Normalisation Process Theory (NPT) (Murray et al 2010) which expounds how complex health interventions may be implemented and integrated into routine working patterns or the theory of 'social norms' which posits that behaviour is influenced by perceptions or misperceptions of how those around us think and act. Figure 9 shows how the stages of theory development have been applied to the current study.

Figure 9 Stages of theory testing in realist evaluation applied to current study



Adapted from Pawson and Tilley (2004)

4.4 Gathering data: Procedural details

4.4.1 Selecting case study sites

Using CCGs or STPs as a base for case studies?

At the time of planning field work during the Summer of 2018, local commissioning within the NHS in England was the primary responsibility of Clinical Commission Groups (CCGs). CCGs constituted following the 2012 Health and Social Care Act (Department of Health 2012b) were clinically led, statutory bodies that sought to commission health care across both community and acute sectors on the basis of local need. In response to criticism that care could be more efficiently commissioned from a larger population base and the argument that, in the case of commissioning health services nationally, small is not always beautiful (Edwards 2018), further re-structuring was envisaged. From April 2020 CCGs will cease to exist in their current form and will be amalgamated into 42 geographical footprints, referred to as Sustainability and Transformation Partnerships (STPs). Although STPs are now established across England, they currently (May 2020) have no legal status

and derive their decision-making powers from the statutory bodies responsible for their constitution. There remains uncertainty about the state and form that these 42 geographical footprints will ultimately take.

In summary given the ongoing organisational uncertainty at the time of planning field work (July 2018), CCGs were chosen to represent the most tangible governance structure, through which to organise case studies looking at local implementation of EOLC.

Criteria used for case study selection

Selection of case study sites was guided by the proposed programme theory and factors emerging from the scoping study which appeared to influence outcomes relating to EOLC care – shown in the table 18 below.

Table 18 Local factors considered to impact on EOLC

<ul style="list-style-type: none">• Financial situation of local health economy• Current performance of local services in relation to EOLC metrics (as determined by CQC and national data held by NEOLCIN)• Demographic makeup of local population. Including: percentage of the population over the age of 75; ethnic breakdown; Socio-economic profile• Geographical location within England• Urban or rural population• Current governance arrangements for local health economy particularly in relation to the degree of service integration• Presence of new models for EOLC/ways of working• Level of development of STP/ACO/vanguards• Strength and stability of local leaders• Motivation of local specialised commissioners and clinicians.

In line with the RE methodology the intention was to select three CCGs which would reflect, in different ways, how EOLC policy impacted on outcomes. Given that there were 211 CCGs nationally, attempting to achieve a sample which was truly representative of EOLC practice was considered untenable, yet some sort of stratification was necessary to determine the factors which may impact

on local performance. The final decision in site selection was guided both by a desire to choose sites that would provide contrasting characteristics as well as pragmatism and logistics. During the scoping study one of the professionals interviewed was part of a network of CCG leads for EOLC and she offered to support recruitment of sites by sending out an information sheet to CCG leads across London. A number of interested London sites (n=6) enquired about the study and following discussions, three London based CCGs were selected. Whilst this inevitably introduced a bias in the sample (all in London and all largely urban) in relation to the impact of national policy of EOLC on local practice, many of the key themes arising are of relevance nationally, and whilst inevitably incomplete, will provide local insights which will help piece together a complex and dynamic, broader picture.

Table 19 **Characteristics considered in final case study selection of London CCGs**

Characteristics considered when recruiting case study sites
<ul style="list-style-type: none"> • That each case study was based within a different STP footprint to reflect the developing influence and policy of the broader geographical area
<ul style="list-style-type: none"> • That they represented a range of service models and EOL pathways
<ul style="list-style-type: none"> • That a range of performance outcomes and indicators were represented
<ul style="list-style-type: none"> • That the demographics within each area offered contrasting sets of local priorities
<ul style="list-style-type: none"> • That key local staff were interested and motivated to participate in the research

Motivation to participate and a sense of reciprocal benefit and value both to CCG and researcher was also a major consideration.

4.4.2 Overview of case study sites

Table 20 provides an overview of key population data and demographics alongside comparisons to the national average. Table 21 shows local availability of care home beds within the case study sites and table 22 provides an indication of the financial positions of each of the CCGs within the wider health economy. Finally, table 23 shows CQC ratings for trusts based within CCG sites.

Table 20 Key statistics from case study sites compared to national average

Measure	Case Study A	Case Study B	Case Study C	National comparator
% who die at home (75-84 years)	26%	23.2%	21.6%	23.8%
% dying at home 85+	25.1%	17.6%	17.5%	16.4%
% who die in hospital (75-84 years)	54.5%	64.3%	57.2%	46.9%
% who die in hospital 85 years +	48.1%	66.3%	53.4%	43.8%
Death in Usual Place of Residence	40.5%	27.3%	39.9%	45.8%
Older people deprivation ¹	4	3	26	
Percentage born abroad	36.6%	54.1%	34.2%	14.6%
Average age	34.8	32.1	36.4	38.8
Proportion of population 65 years +	8.8%	7%	13.1%	17.7%
Percentage of BME	32%	73.1%	45.7%	14%
Gross annual pay	£37K	£28K	£34K	£29K
Life expectancy (years)	77.7 (men) 82.9 (women)	77.9 (men) 82.2 (women)	79.9 (men) 83.6(women)	79.5 (men) 83.2 (women)
Main migrant populations	1.Italy 2.France 3.Spain	1.Romanian 2.Indian 3.Bulgarian	1.India 2.Pakistan 3.Ireland	1.India 2.Poland 3.Pakistan

Data taken from:

Department of Communities and Local Government (2015)
 GLA Intelligence (2015)
 NEOLCIN (2020)

Legend:

Compared with benchmark



Higher



similar

¹ IDAOPI - The Income Deprivation Affecting Older People Index (IDAOPI) measures the proportion of all those aged 60 or over who experience income deprivation. Ranking by London Borough.

Table 21 Availability of care home and nursing home beds in case study sites

	London average	Case Study A	Case Study B	Case Study C	England average
Availability of care home beds per 100 people aged 75 years +	10.1	6.4	6.3	7.6	10.3
Availability of nursing home beds per 100 people aged 75 years +	4.9	5.2	4.8	4.3	4.9

PHE (2017)

Table 22 Financial situation of primary acute trusts within case study CCGs

Financial Position of NHS providers local to case study sites	
Acute hospital site A	2017/18 declared a small surplus following significant deficit in 2016/17
CCG – Case Study A	2017/2018 met allocated resource limit
Mental Health Trust serving Case Study	Trust reported a significant surplus in 2017/18 due, in part, to sales of property assets
Acute hospital site B	Significant deficit for 2017/18 with sizable variance in projected deficit - second highest deficit in the UK
CCG – Case Study B	Meeting allocated resource limit
Mental Health Trust serving Case Study B	Latest figures from 2016/17 – a small surplus reported on operating income
Acute hospital site C	2017/18 significant deficit with anticipated increase in deficit for 2018/19
CCG – Case Study C	Meeting allocated resource limit
Mental Health Trust serving Case Study C	2017/18 closed with higher deficit than predicted

References withheld for identification purposes

Table 23 CQC rating for EOLC in main hospitals servicing CCG

	Date of inspection	Rating for EOLC
Site A	October 2017	Outstanding
Site B	Jan 2019	Requires Improvement
Site C	July 2018	Good

Data from CQC website <https://www.cqc.org.uk/>

4.4.3 Interviews

Interviews have come to be viewed as a potentially sensitive and powerful method for exploring subjects' private and public lives, often being regarded as a 'democratic emancipating form of social research' (Kvale 2006). Kvale (2006) suggests that the interview holds the promise of a technique that provides an alternative to the 'objectifying, positivist, quantification of questionnaires and the harsh manipulation of behaviourist experiments' (p.481). People are generally responsive to telling a story and in doing so are prone to reflect on things in a more detailed and nuanced way than they would if giving answers to a survey – this may be particularly pertinent with sensitive issues such as EOLC. The process allows for subtleties to be drawn, probing for examples and deeper explanations (Robson and McCartan 2016). Through investigating the subject's view of the world, in their own words, there is a sense that the interview is a robust technique for giving voice to 'the common person'. However, whilst there is plenty of support for the benefits that can be gleaned from a sensitive and empathetic interview, Kvale warns of the potential impact of the power imbalance between interviewer and subject and the possible emotional manipulation of those in vulnerable positions. The interview, Kale (2006) contends, is neither a conflict nor power free zone and the tendency to lead, guide and suggest is something that I was particularly aware of when interviewing patients and carers, often at highly emotional and vulnerable times of their life. Whilst a dialogue may be seen as an equal discussion between two partners, an interview is a 'conversation with a purpose' – the purpose being for the interviewer to collect targeted information.

A research interview is not an open and dominance-free dialogue between egalitarian partners, but a specific hierarchical and instrumental form of conversation, where the interviewer sets the stage and scripts in accord with his or her research interests (Kvale 2006 p.485).

In today's consumer society the qualitative interview is an important tool used to elucidate consumers experiences and desires which may ultimately facilitate the shaping of subsequent choices, particularly by commercial or statutory bodies (Kvale 2006). Whilst eliciting information about EOLC may not have much in common with the investigation of commercial products, the potential for information collected to be used in a way which may potentially manipulate the consumer to the advantage of political or other agendas, should be acknowledged. Kvale (2006) suggests various routes for conducting interviews in a way which will help avoid the dangers of unbalanced consensus seeking. One such method, that chimes with the realist approach is that of 'active confrontation' – where the interviewer does not aim for agreement but attempts to uncover what may otherwise remain implicit by deeper probing, the aim is to 'propose' rather than 'impose' ways of seeing (Bourdieu 1999).

Specific challenges arose in using the realist interviewing technique (described in 3.2.1.2) with frail patients (and relatives) at EOL and their relatives/carers which are explored in Chapter eight.

In-depth qualitative Interviews

As in phase 1, in-depth interviews were conducted with each of the key stakeholder groups, lasting a maximum of 45 minutes. No payment was made for interviews though if expenses were incurred through travel/parking these were reimbursed.

4.4.4 Interview guides

Semi-structured interview guides were used with a list of topics to be covered and a series of verbal prompts to elicit further information. The intention was to cover key topics and themes which emerged during the scoping study as being key to unravelling the questions central to the research – thus conveying to the interviewee the theory under exploration (see section 4.2.1.2). Three different topic guides were produced:

- For use with service managers in CCGs (appendix 4.2b)
- For use with clinicians working with patients at the EOLC (appendix 4.2c)
- For use with patients and their relatives or carers (appendix 4.2d)

It was important during interviews that the wording could be modified to suit the context (Robson 2016) and that there was flexibility around order. However, I was also mindful that a well-constructed guide can reduce bias (Yin 2014) and therefore as much as possible the form and coherence of the interview was maintained.

4.4.5 Interview composition and sampling strategy

The aim of case study research is not to draw a representative sample from the population but more to gather a detailed picture from those who have characteristics relevant to the phenomenon being investigated (Mays and Pope 1995). Non-probability, purposive sampling was used to select respondents, with professionals being stratified by job title, experience and area of interest, and patients being stratified by setting and clinical prognosis. Purposive sampling is useful in particular case study situations (Neuman 2013):

- To select cases that are particularly informative
- To select people in difficult to reach, specialised populations
- To identify cases for in-depth investigation

For the professional sample, efforts were made to select a diversity of different professional groups (both clinical and non-clinical). For patients, given the challenges of achieving the targeted quota, recruitment was largely opportunistic, a range of methods (see section 4.4.7) were used with the intention to recruit across different settings and to include patients suffering a range of medical conditions. Targeted interview samples are shown in table 24.

Table 24 Targeted interview sample across each CCG

<p>Non-clinical staff</p> <p>Programme and project staff working either directly for the CCG or in associated community and voluntary groups running EOLC services within the locality (n=8-10). This list included:</p> <ul style="list-style-type: none"> • Local end of life commissioning lead (CCG or STP) • Leads of relevant new care models • Staff responsible for accounts and allocation of budgets • Project leads/managers • Staff responsible for training and support • Hospice or care-home managers • Academics
<p>Clinicians</p> <p>Clinicians working with patients at the end of life (n=8-10):</p> <ul style="list-style-type: none"> • GPs working in local practices • Palliative care consultants • Consultants in A&E • Nurses in acute and community settings • Health Care Assistants • Allied Health Professionals • Locality clinical lead for EOLC
<p>Patients</p> <p>Patients (aged 75+) identified by clinicians as being likely to die in the next 12 months (n=8-10).</p>
<p>Relatives/carers</p> <p>Family/carers (target n=8-10). Criteria for selection:</p> <ul style="list-style-type: none"> • Either linked to patients or • Had relatives who they cared for who were 75 years plus who had died within the last 12 months.

4.4.6 Sample size and saturation

Non-probability sampling is a process where data is allowed to accumulate until saturation is reached. This point is said to be achieved when additional participants no longer contribute any new themes to the data. Urquhart (2012) defines saturation as ‘the point in coding when you find that no new codes occur in the data’ (Given 2015). Corbin and Strauss (2008) surmise that saturation should

be more concerned with arriving at a point where further data collection becomes 'counter-productive', and where the 'new' does not conceptually add to the overall story or theory. Saunders et al (2018) highlight some of the inconsistencies in the practical application of the term. In this study sample size was influenced initially by guidelines set down in research literature (Charmaz 2011; Creswell and Creswell 2017) as well as pragmatic and resource constraints. The range of stakeholders involved and the coverage across three CCGs meant that I was aiming for broad coverage of key themes from the perspectives of different stakeholders, rather than in-depth accounts from any one group. In each case study I was mindful of the concept of saturation and if there was an indication in any category that multiple new themes were emerging as the work progressed, this would be noted in analysis and efforts made to add additional interviewees to that particular category.

4.4.7 Recruitment method

Recruitment of Professionals

Professionals were sampled purposefully on the basis of known interests, experience and role. Snowball sampling methods (Morgan 2008) were used to identify key players in local EOL services. Initial contact with professionals via an email invitation to participate in the study and an information sheet following this up after one week with a phone call. Signed consent forms (appendix 4.3a and 4.3b) were completed prior to the interview. This method of direct contact from the researcher was considered less likely to put pressure on CCG resources and is ethically justified provided that the professionals contact details are in the public domain. Inevitably there was a degree of overlap between professional groups with a number of clinicians carrying out service manager roles.

Recruitment of patients and relatives/carers

The sample of patients and carers were selected purposefully through two different routes:

- The 'participating' GP practice in each CCG accessed their EOL/Palliative Care Register and screened it to ensure that the list complied with the study inclusion and exclusion criteria. The researcher provided a letter of invitation (appendix 4.5) to be sent out from the practice together with a consent form (appendix 4.4b), project information sheet (appendix 4.7a), a participant response form and a stamped addressed envelope. Following an initial poor response rate an amendment was made (appendix 4.9b) to the protocol whereby one follow-up phone call was made to patients a week after sending

the letter to check it had been received and answer queries. The phone call followed a standard text which was agreed by Ethics (appendix 4.6).

- I attended relevant CCG based EOL network meetings to present a summary of the research and made contact with a range of health professionals including: GPs; palliative care consultants; geriatricians; OTs; district and community nurses; other health professionals linked to acute hospitals, and allied health professionals. If professionals had patients who they suggested may be appropriate they were given a 'research pack' containing information sheets (appendix 4.7a), response forms (appendix 4.8) and stamped addressed envelopes. Professionals handed this pack to patients, with a brief account of the research, and patients were asked to 'self-enrol' by returning the response form. Alternatively, in some cases where permission had been given, the protocol allowed for professionals to forward patient details directly to the researcher. In this way patients were recruited across a range care settings.

It was made clear in all written and verbal information that participation was voluntary and there would be no change to the treatment or care received if patients chose not to participate. Interviews followed strict protocols being mindful of confidentiality and sensitivity of the topic. Inclusion and exclusion criteria for the patient sample are listed in table 25 below. Biases introduced as a result of these inclusion and exclusion criteria are discussed in chapter seven.

Table 25 Inclusion and Exclusion criteria for patients

Criteria for selecting patient sample	
Inclusion	Aged 75 and over Identified by clinician as being likely to die within the next 12 months Able to make informed decision about participation and enter into discussion Representing a mix of one or more different conditions (e.g. cancer, CHD, frailty) Representing experience of a range of community and acute services
Exclusion	Recognised cognitive impairment which means they cannot engage in lucid conversation Non-English speaking – unless an interpreter in the form of a family or friend can be identified Those very close to EOL, i.e. expected to die within the next few days Patient who have not had a formal conversation with their clinician about EOL.

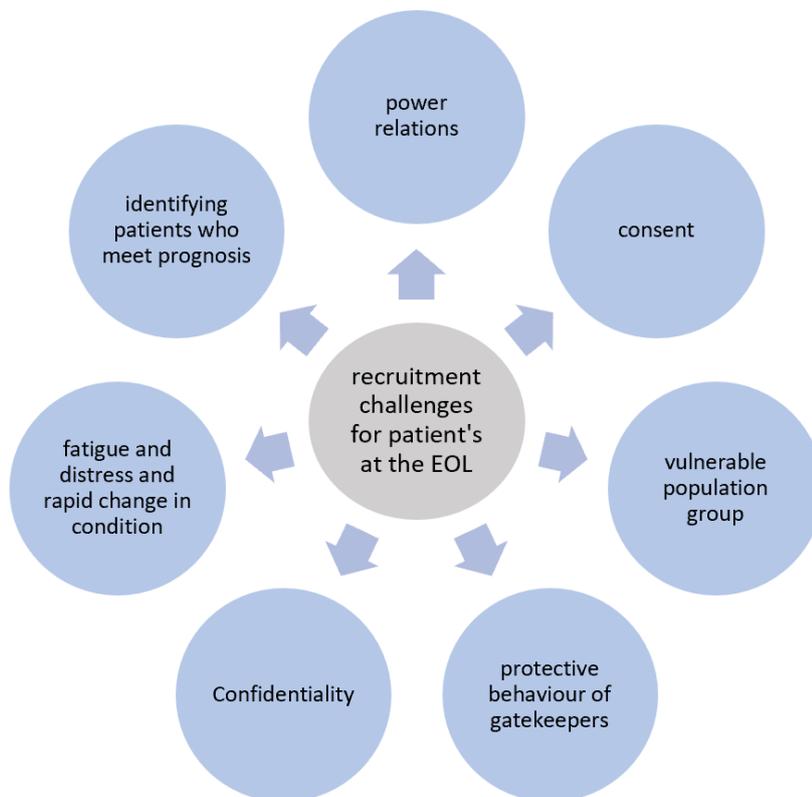
Making contact with and interviewing patients

Once the patient response form with contact details was received the patient or relative was contacted to organise a visit. Contact was made either directly with the patient (telephone or email) or through a relative/carer acting as proxy. The patient advised on the preferred method. Patients were asked directly if there was an appropriate carer/relative who could be interviewed about their own perspectives on the patient's care. If the patient suggested someone who was happy to participate, I offered to interview carers/relatives (either separately or together) on the same visit. Interviews were conducted at the patients preferred location or usual place of residence (home, hospice, care-home, nursing-home or hospital).

[4.4.8 Challenges in recruitment of patients at EOLC](#)

Recruiting patients at EOL presents a particular set of challenges represented in figure 10 (below).

Figure 10 Recruitment challenges with older patients at the EOL



Gibbins et al (2013) note that it is common for less than 50% of hospital-based EOL patients identified, agreeing to take part. Factors listed as barriers to participation include a range of ethical, logistical, clinical, procedural and relational issues. However, despite the challenges, the importance of striving to recruit patients at EOL has been highlighted. A 2004 conference statement from the National Institute of Health Research (NIHR 2004) emphasised the importance of conducting research with EOL populations in order to gather a robust evidence base. A number of studies have demonstrated that if proper and sympathetic recruitment procedures are followed patients appreciate the value of participation in research and are often prepared to take part (Kendall et al. 2007; Gibbins et al. 2013).

Table 26 Strategies recommended for interviewing patients at EOLC

Strategies recommended for interviewing patients at the End of Life
<ul style="list-style-type: none">- Flexibility in timing, site and pacing of research- Importance of appropriate messaging (both in relation to supporting written information and face to face body language)- Face to face communication is preferred to telephone- Broad clear eligibility criteria- The value of involving effective clinical champions- Anticipating both the concerns of patients and gatekeepers- Study protocols <u>have to</u> be written with some latitude in recruitment procedures- Finding the right time to approach patients – it should not be done when patients are feeling overwhelmed by recent prognosis.

The scoping study suggested that it was often the frail elderly, with a range of complex co-morbidities, who were particularly hard to identify and support. For this reason I was committed to identifying patients living at home, as well as those within hospitals, care homes and hospices. I was unable to locate any literature where this methodology had been previously used with this particular group of patients. Recruitment of home-based patients proved particularly challenging and will be discussed in more detail in chapter eight.

4.4.9 Characteristics of completed interviews achieved in each case study sites

Table 27 Interviews completed with service managers

	Site A	Site B	Site C
1	Nurse lead for care homes, Local Authority A.SM.1	Researcher/academic B.SM.1	London Ambulance Service manager. C.SM.1
2	Care home manager. A.SM.2	Senior transformation Manager. CCG B.SM.2	Hospice – lead nurse. governance C.SM.2
3	CCG commissioner A.SM.3	Care homes LA manager B.SM.3	Hospice manager C.SM.3
4	Public education and support charity A.SM.4	Senior commissioner LA – integration B.SM.4	Manager for out of hours palliative care service C.SM.4
5	Trusted assessor for care Homes A.SM.5	Hospital chaplain B.SM.5	Director (STP) C.SM.5
6.	Charity service manager A.SM.6	Care home manager B.SM.6	CCG Director C.SM.6
7.		OT professional lead. Adult social care B.SM.7	LAS Programme lead. C.SM.7
8.		Hospice clinical manager B.SM.8	Programme evaluation lead C.SM.8
9.		Hospital trust multi-faith manager B.SM.9	Manager 'Coordinate My Care' C.SM.9
10.		Volunteer lead B.SM.10	CCG Director C.SM.10
11.		Hospice nurse coordinator B.SM.11	
12.		Carer support manager B.SM.12	

N= 28

Table 28 Interviews completed with clinicians/front line staff

	Site 1	Site 2	Site 3
1	Service manager and PC consultant A.Clinician.1	Medical director. B.Clinician.1	Team leader and nurse for community PC team and manager for out of hours service C.Clinician.1
2	Community matron for district nursing services. A.Clinician.2	Hospital based palliative care consultant B.Clinician.2	Hospice lead nurse C.Clinician.2
3	Clinical lead EOL A.Clinician.3	CCG GP lead B.Clinician.3	Hospital based PC consultant C.Clinician.3
4	GP lead for EOL A.Clinician.4	Medical director of community services (STP) B.Clinician.4	Hospital based clinical nurse specialist. C.Clinician.4
5	Community Engagement matron - hospice A.Clinician.5	Geriatrician B.Clinician.5	PC consultant C.Clinician.5
6.	Care home - health care assistant A.Clinician.6	Hospital based consultant geriatrician B.Clinician.6	Palliative care ward Deputy Clinical Nurse Manager. C.Clinician.6
7.	GP and chair of CCG A.Clinician.7	Hospice Consultant B.Clinician.7	GP lead for EOL C.Clinician.7
8.	PC consultant – community based A.Clinician.8	Care home nurse B.Clinician.8	Psychologist C.Clinician.8
9.	LAS paramedic A.Clinician.9	LAS paramedic B.Clinician.9	Psychotherapist C.Clinician.9
10.	Junior doctor A.Clinician.10		
11.	Geriatrician A.Clinician.11		

N= 28

Table 29 Interviews completed with patients

	Site 1	Site 2	Site 3
1	<p>94 year old woman White English Confined to bed. Frail elderly – complex multi-morbidity Care home resident Interviewed in care home on her own. Recruited through care home manager A.Patient.1</p>	<p>93 year old woman White English Mobile Frail elderly on GP EOL list Interviewed at home where she lives alone Recruited through GP B.Patient.1</p>	<p>83 year old woman with dementia Mobile White English Dementia Interviewed at home with husband present Recruited through GP C.Patient.1</p>
2	<p>79 year old woman White English Wheelchair bound Abdominal aortic aneurism, COPD, severe osteo arthritis Lives at home with son Interviewed at home with son present Recruited through GP A.Patient.2</p>	<p>76 year old male Black Caribbean Cancer Mobile Living at home with wife Interviewed at home on his own Recruited through GP B.Patient.2</p>	<p>84 year old woman Mobile. White English Frail elderly Recruited through GP Interviewed at home with 86 year old husband/carer C.Patient.2</p>
3	<p>97 year old man Confined to bed White English Frail elderly Care home resident Interviewed in care home on his own Recruited through care home manager A.Patient.3</p>	<p>76 year old woman White English COPD – oxygen assisted breathing Arthritis Interviewed at home on her own Recruited through GP B.Patient.3</p>	<p>82 year old woman White English Confined to bed/chair COPD – oxygen assisted breathing Arthritis Interviewed on her own in PC ward. Later interviewed son by phone Recruited through community PC Consultant C.Patient.3</p>
4	<p>83 year old woman Wheelchair bound Welsh Care Home resident Interviewed in care home with son present COPD. Frail elderly Recruited through care home manager A.Patient.4</p>	<p>77 year old man White English Bed bound COPD – irregular breathing Frail Care Home resident Interviewed on his own in care home Recruited through care home manager B.Patient.4</p>	<p>87 year old woman Stroke White English Lives alone Frail Elderly Interviewed at home on her own Recruited through GP C.Patient.4</p>

5	<p>84 year old woman Confined to bed Hospice in-patient Cancer Recruited through hospice clinician A.Patient.5</p>	<p>75 year old woman Confined to wheelchair White English COPD, rheumatism, stroke Care home resident Interviewed on his own in care home Recruited through care home manager B.Patient.5</p>	<p>84 year old woman White English Mobile Cancer Increasingly frail Interviewed at home with her daughter. She lives alone Recruited through GP C.Patient.5</p>
6		<p>83 year old woman Confined to bed Cancer, palliative treatment Interviewed in hospice White English B. Patient.6</p>	<p>75 year male White, Southern Irish Cancer Interviewed at home with his wife. Recruited through the GP C.Patient.6</p>
7		<p>84 year old woman in hospice. Frail and confined to bed White English COPD, repeated hospital admissions, recent operation on bowel and broken hip Interviewed in hospice Recruited through hospice B.Patient.7</p>	<p>79 year woman White Belgium Haemophilia Bed bound Interviewed at home with her husband (aged 82) Recruited through palliative care consultant C.Patient.7</p>
8		<p>3 other care home residents – interviews aborted due to lack of capacity on the day</p>	<p>84 year woman White Welsh Wheel chair bound Cancer Interviewed at home where she lives alone Recruited through nurse at hospice C.Patient.8</p>
9			<p>80 year old man White English. Cancer Interviewed at home where he lives alone Recruited through nurse at hospice C.Patient.9</p>

N= 21

Table 30 Interviews completed with relatives/carers

	Site 1	Site 2	Site 3
1.	Female carer (57 years). Cares for 93 year old mother Spanish but English speaker Mother is blind, hard of hearing, arthritis, immobile. Recruited through carers forum Interviewed by telephone A.Carers.1	Female carer (76 years) Afro-Caribbean First language: English Carer for husband who died last year of advanced dementia Recruited through web site advertising carers group Interviewed by telephone B.Carers.1	Male Carer (83 years) Cares for his wife with dementia White English Recruited through GP Interviewed at home with wife present C.Carers.1 linked to C.Patient.1
2.	Female carer (60 years) Cares for 96 year old mother White English Mother has diabetes, heart problems, asthma, immobile Recruited through GP A.Carers.2	Female carer for 86 year old sister (92 years) Both from India. First language Gujarati. Sister suffering from advanced dementia B.Carers.2	Male carer for C.Patient.2 (86 years) White English Mobile Frail elderly Interviewed at home with wife present Recruited through GP C.Carers.2
3.	Male carer (50 years) Looks after 79 year old mother White English Suffers from: abdominal aortic aneurism, COPD, bipolar and severe osteo arthritis – unable to walk Recruited through carers forum Interviewed by telephone A.Carers.3	Daughter of 84 year old woman Heart disease Mauritian. Mother speaks Creole, French. - poor English. Recruited through carers forum Interviewed by telephone B.Carers.3	Male (55years), son of P.Patient.3, who died one month after the interview conducted for this research White English Interviewed by telephone Recruited through his mother C.Carers.3
4.	Male carer (55 years) Linked to A.Patient.4 Recruited through GP White English Interviewed in care home. A.Carers.4	Compassionate neighbour Matched with frail elderly woman with COPD Recruited through hospice Interviewed at patient's home B.Carers.4	92 year woman White, French Interviewed at home about her husband who died last year at the age of 92 Recruited directly from EOL forum meeting C.Carers.4
5.	Female carer (47 years) for 83 year old mother. White English Mother suffers: osteoporosis, frailty, immobile, depression Interviewed by telephone Recruited through carers forum A.Carers.5		51 year old woman White English Mother (C.Patient.5) invited her to join interview C.Carers.5

6.	Female carer (77 years) Italian – English second language Carer for husband who died 10 months ago from Parkinson. Recruited through carers forum Interviewed by telephone A.Carers.6		Female carer (70 years) White, Southern Ireland Interviewed at home alongside husband (C.Patient.6) who she cares for. Recruited through GP C.Carers.6
7.	Male carer (59 years) White English Carer for mother who died 6 months ago Mother suffered arthritis, frailty, poor circulation, obesity, COPD Recruited through GP Interview by telephone A.Carers.7		Male carer (82 years) White English Carer for C.Patient.7 Frail elderly Cancer Recruited through palliative care consultant Interviewed at home with wife who he cares for present. C.Carers.7
8.	Female carer for 90 year old mother Nationality: Italian – mother speaks no English Frail, immobile, mild dementia Recruited through GP Interview by telephone C.Carers.8		
9.	Female carer (49) for mother of 82 years Mother suffers from dementia and psychosis Mother from Jamaica. First language Creole. Recruited through GP Interview by telephone C.Carers.9		
10.	Male carer for 89 year old mother. Greek – speaks English Mother suffers cortico-basal degeneration, immobile, unable to speak Recruited through palliative care consultant Interviewed by telephone A.Carers.10		

N= 21.

Total Number of interviews = 98

4.4.10 Patient and public Involvement

The interview guide for patients was informed by the Opening Doors to Research Group (ODRG) at the Centre for Health Service Studies (CHSS), which is made up of 23 members of the public who are interested in health research. The group plays a key role in advising CHSS researchers and students on aspects of their research to ensure it is useful and relevant to end-users. Significant revisions were made following comments to an early version of the patient interview guide, helping to ensure that the wording used was appropriate, sensitive and the language clear and easy to understand. As part of the iterative process of enquiry and 'sense testing' of findings, early conjectured CMOs were presented back to the ODRG following completion of case studies. Comments were used to contribute to theory refinement.

4.4.11 Ability to revisit respondents, test theories

Proponents of RE advocate an iterative model with theories in a constant state of flux, demanding ongoing refinement and testing, enabled through revisiting research respondents to test the veracity of emerging theories. Such methods, however, present challenge with EOL populations who cannot easily be re-visited and some pragmatic 'work-arounds' were employed. A degree of iteration was introduced – for example through the 'sense check' referred to above. I also had a few calls and meetings with pivotal commissioners and policy representatives to clarify thoughts as they developed.

4.4.12 Observation of meetings

Observation of participants in research has its roots in ethnography and aims to elucidate diverse perspectives of the study population (Denzin and Lincoln 2008), often complementing and adding veracity to a range of other research techniques. Observation presents the opportunity to verify accounts and to see if the narrative collected from other sources of information fits with what is observed. Observation is 'pre-eminently the appropriate technique for getting at 'real life' in the real world' (Robson and McCartan 2016). According to Mulhall (2003) both accounts (i.e. what people perceive they do versus what they are observed doing) are valid, representing a different perspective of reality. Typically, the level of involvement of the researcher varies from high (where the observer is an ordinary participant in the research setting) to passive where they are more like a 'bystander' (Spradley 2016). The extreme of the scale is nonparticipation where there is no involvement at all. In my case I would describe my role as passive; I introduced myself at meetings and would respond to queries asked but had no active involvement in the regular course of the

meeting. The meetings I observed tended to follow a standard agenda and form and I was interested more in the range of participants, the aims of the meetings and the content of discussion rather than any more reflective analysis or the interpretation of deeper levels of meaning. My observation technique was largely unstructured, being led by meeting content rather than any form of specific observation schedule. I found Spradley’s (1986) guidance on the different aspects of the environment to observe useful to help structure my thinking (table 31) and improve the standardisation of process

Table 31 Spradley’s nine dimensions of descriptive observation

Dimensions of descriptive observation	
1. Space	layout of the physical setting; rooms, outdoor spaces etc
2. Actors	names and relevant details of the people involved
3. Activities	the various activities of the actors
4. Objects	physical elements: furniture etc
5. Acts	specific individual actions
6. Events	particular occasions, e.g. meetings
7. Time	the sequence of events
8. Goals	what actors are attempting to accomplish
9. Feelings	emotions in particular contexts

Adapted from Robson (1993) p. 320

I used a notebook to capture observations which were supplemented by fieldnotes written straight after the event, this is particularly important to capture detail and maintain accuracy. Data collected in this way was analysed in the same way as interview transcripts (section 4.5.1). The meetings I observed generally followed a tight timetable, with a lot of information to get through in a short space of time. Attending professionals tended to be under time pressures to return to the ‘day job’, the meetings did not therefore present an opportunity for me to follow my own lines of enquiry; simply to observe the everyday process of how end of life care strategy and operations were shaped within local health settings.

Where possible appropriate meetings relating to the EOLC agenda which existed within the CCGs were observed in each of the three case study sites.

Table 32 Meetings observed in case study sites 2018/2019

Site A	Care home quality improvement programme
Site B	EOLC steering group meeting STP health and care partnership meeting MDT care home meeting GP education meeting
Site C	EOLC CCG masterclass EOL Forum (x2)

4.4.13 Collecting data through documentation; secondary analysis

Professionals interviewed in the CCG were all asked if they could identify relevant reports or documents pertaining to local EOL strategy and service provision. Reports considered as part of data triangulation are listed in appendix 4.10, most are internal, unpublished working documents and presentations. The intention of referring to these documents was to ‘corroborate and augment evidence from other sources’ (Yin 2014, p107). Documents gathered were scrutinised for information that informed the line of enquiry, using a similar method employed in the narrative literature review. All relevant information was coded, in the same way as the interview data, using NVivo software.

4.4.14 Ethical issues

The design of the study involved the use of people as research subjects and a combination of both procedural and practical issues were considered in order to protect them from harm.

Practical ethics

As a researcher working with both professionals and patients in a sensitive area there were issues relating to consent, risks to participants, confidentiality and data storage, of which I needed to be mindful. Consent was sought from participants (professionals, patients and carers) prior to the collection of data. An information sheet was provided (appendix 4.7a and b) and subsequently a consent form was signed by both the researcher and the participant, with a copy held by both parties.

From the professional perspective the potential to disclose poor or negligent practice that might have been exposed during the research was considered – though given that interviews focused on the generalities of service provision, rather than specific clinical practice around individuals – the possibility of this happening was considered low. Patients were advised that should information be revealed which gave rise to concerns about malpractice or patient safety these may need to be reported through appropriate channels. This eventuality did not arise.

Ethical issues involved in undertaking in-depth interviews with patients at EOL have been explored from multiple perspective (Sivell et al. 2015; Addington-Hall 2002). A number of themes emerge, notably the challenge of acquiring consent without putting undue pressure on participants and issues around potential harms or benefit to the researched. Whilst some researchers highlight the potential upset from the emotive content of the material (Corbin and Morse 2003) others note the therapeutic value of being given space to share experiences and tell your story (Clarke 2006). Helgeland (2005) suggests that strong emotions are not necessarily destructive and that overprotecting participants can be patronising. Given the sensitivity of this type of interview the researcher must remain aware of the mental and physical state of the interviewee and re-establish consent at significant points in the interview. The importance of setting and context is also stressed, notably that the frail elderly are a vulnerable group and care must be taken to ensure there is no sense of coercion.

The presence of a companion/carer/family member at the interview may impact on the direction of the discussion and proper consent must be obtained even from those appearing unexpectedly. The interviewer should be aware that in a 'dyad' (with companion and patient both present at the interview) there is less control over the content of the interview which can more easily stray into unexpected areas with the potential to breach confidentiality (Allmark 2009).

Central to any consideration of ethics is the way 'power relations' play out in the interview (Kvale 2006). The power imbalance is evident at every stage; from themes selected, questions asked, the tone of the questions and in the analysis following the interview. It is largely the prerogative of the researcher to select the final quotes and represent one narrative over another. Whilst theoretically it is possible to allow participants the opportunity to feedback on findings, and to some extent mitigate this potential bias, in the case of frail patients at EOL, logistical and ethical issues mean that further follow up is particularly challenging.

Procedural ethics

Ethics for phase 1, the scoping study, was applied for through the School of Social Policy, Sociology and Social Research (SSPSSR) Ethics Committee at the University of Kent and approved in April 2018, allowing the expert interviews to progress. Ethical approval for phase 2 was applied for through the Integrated Research Application System (IRAS). Approval was received from NRES Committee Stanmore on the 15th October 2018 (IRAS project ID: 247340 REC reference: 18/LO/1443, appendix 4.9a). Following that research governance approval was sought from the three CCGs, with Site 3 acting as 'Host Site' and this was ratified on the 1st of December 2019 (appendix 4.9f). Additional ethics needed to be sought from a hospice (appendix 4.9e), a community trust (appendix 4.9g), an ambulance trust (appendix 4.9d) and three care homes as well as an application for a 'substantial amendment' (appendix 4.9c) following a change in patient recruitment method. Whilst the range of different settings used to recruit patients added to the bureaucracy of the permissions process, impacting considerably on workload, it was deemed worthwhile in relation to providing a broad diversity of patient experience. This will be explored further in chapter eight.

4.5 Data analysis, rigour and reliability

Analysis for the study was conducted in two phases with the first phase completed following the scoping study and the second during and after completion of the case studies.

4.5.1 Analysis: familiarisation and generation of initial codes

Similar methods of data analysis were used to analyse case study data, as is described in section 4.2.1.3 for the scoping studies. In addition:

- i) Observations noted following visits and handwritten fieldnotes were transcribed and uploaded into Nvivo.
- ii) After the first round of coding I consolidated and categorised codes into higher level themes and categories – separating themes out into those operating at different system levels (meso, macro and micro). At this point I also began to consider a number of demi-regularities; coding around themes of power, social norms, social capital and medicalisation.
- iii) Data from meeting observations and relevant documents shared with me during the case studies were coded in the same way as interview data allowing me to employ a number of different strategies to compare and triangulate data from different sources. Pawson (2006) describes the value of 'juxtaposing, adjudicating, reconciling, consolidating and situating

further evidence.’ The assumption being that in comparing data from different sources the explanatory power and rigour of the analysis is enhanced.

4.5.2 Refining data reliability, validity and rigour

Drawing on Papoutsis (2019) I did not immediately categorise data into CMOs, but approached each new bit of data with an open mind to understand the real issues emerging from the data before interrogating these against my CMOs which had been conjectured following scoping. Following the first round of conceptual coding I considered how each of the categories, and sub-categories emerging from the data related to my provisional CMO configurations (appendix 4.12). If data within particular categories did not support existing CMO configurations this was recorded as a theory refinement and coded as a child node which was revisited and reviewed at the end of each coding cycle. Where themes arose which were of interest but did not appear in any of my conjectured CMOs these were recorded as ‘new codes/themes’ and reviewed after the first tranche of analysis. As refinements were made to CMO configurations the data was reconsulted and re-scrutinised to find data to support new interpretations. Memos, annotations and secondary data from meeting notes were used to add validity to the findings from interview data.

Following the first coding cycle a retroductive process was used to attempt to interrogate the CMOs conjectured after the scoping study and identify the contextual conditions that are required for a particular mechanism to ‘fire’ to bring about the observed outcomes (Fletcher 2017). Appendix 4.11 illustrates this process – demonstrating the refinement of the CMO relating to ‘patient choice’. This process of retroduction is advocated by realists to help decide whether to accept, reject or refine existing theories and in so doing to move closer to a more accurate representation of the way things work (Fletcher 2017).

4.5.3 Synthesising data and drawing conclusions

Synthesising data and drawing conclusions was an iterative process, moving between inductive, deductive and retroductive modes of enquiry. The steps laid out in table 33 were used to help inform decisions regarding the relevance and rigour of collected data.

Table 33 Steps taken when analysing and interpreting data

Relevance: Does the data relate to programme theory?
Judgements about trustworthiness and rigour: Does the data warrant changes to programme theory?
Interpretation of meaning: Does the data fit with conjectured CMO configurations?
Interpretations and judgements about CMOs: <ul style="list-style-type: none"> - To which CMO does the data relate? - Does the data relate to the complete CMO or just a part of it? - Are there any refinements to the existing CMO which may need to be made?
Interpretations and judgements about programme theory: <ul style="list-style-type: none"> - How does this (full or partial) CMO relate to the programme theory? - Within this data source is there information which informs how the CMO configuration relates to the programme theory? If not are there data elsewhere? - In the light of this CMO and supporting data, does the programme theory need to be changed?

Adapted from Papoutsis (2018)

4.5.4 Validity

Validity of the research in RE, that is the assurance that the research is robust, meaningful and replicable, is determined at a number of levels: descriptive validity (the factual accuracy of the account); interpretive validity (the accuracy of the meaning derived from the data); and theoretical validity (does the data support the emerging theories?) (Maxwell 2012; Leung 2015; Dixon-Woods et al. 2004). There are a number of routes to improving validity including the provision of adequate details about the methods used, triangulation of data sources and collection methods, and rigorous testing and refinement of theories. I found the tool developed by Wong et al (2016) (see section 4.1.5.2) helpful in terms of providing clear guidance on a staged, reliable process to follow. Attention to transparency of, and clarity around method, will help ensure that the causal explanations that emerge from the research (the programme theory underpinned by CMOs) can be generalised across other settings and thus findings from small interventions can be used to test higher level theories. In this way knowledge accumulates and a broader theoretical base is constructed (Pawson and Tilley 2001).

Dixon-Woods et al (2004) argue that one major problem arising in appraising quality within qualitative research methods has been the tendency to treat the area as a unified field. The reality is that qualitative research covers a huge diversity of methodological approaches. Whilst to some extent, by following specific appraisal criteria (such as those laid out by Papoutsis in table 3.3 above), researchers may be more able to distinguish 'fatal flaws from minor errors', there remain significant challenges, particularly those relating to the quality of 'insight and perception' (Dixon-Woods et al 2004). RE draws on a methodological approach that calls on the skills of retroduction – where the researcher is encouraged to make subjective interpretations to help explain data – and may therefore be particularly vulnerable to such methodological flaws.

4.5.5 Researcher role

The researcher in RE is neither neutral nor impartial. As in other forms of qualitative research the impact of the researcher on the type and quality of data is considerable (Berger 2015). My background and experiences will have impacted both on the way research respondents engaged with me, as well as decisions and interpretations made throughout. The purpose of laying out clear processes for validity, reliability and rigour is to protect against undue influence of personality. Nonetheless the impact of individual researcher characteristics should not be underestimated and is considered further in chapter eight.

4.6 Chapter Summary

This chapter began with an explication of RE: the methodological framework in which the study is lodged, considering both its strengths and shortfalls. Possible ways in which some of the criticisms directed at RE may be overcome in the current study were considered. The second part of the chapter looked at the proposed method for both phases of the thesis; the scoping study made up of informant interviews and a literature review, followed by case studies in three London CCGs.

Chapter 5: Phase 1 Results- Analysis of scoping study Interviews

This chapter presents results on the first phase of the field work comprising of in-depth interviews with professionals involved in the development of EOL policy in England over the last decade.

5.1 Background

In-depth qualitative interviews, to inform the scoping study and highlight key challenges faced in commissioning and practice of EOLC in England, were conducted between 01.06.2018 and 01.10.2018. Respondents were selected purposefully by role and known area of interest. A list of key experts was initially populated from those involved in the national consultation around the ‘Ambitions for palliative and end of life care: a national framework for local action 2015-2020’ (NPELCP 2015), a document produced by a collaboration of 27 different organisations. Additional respondents were contacted on the recommendation of those being interviewed (snowball sampling). The final response rate is show in table 34.

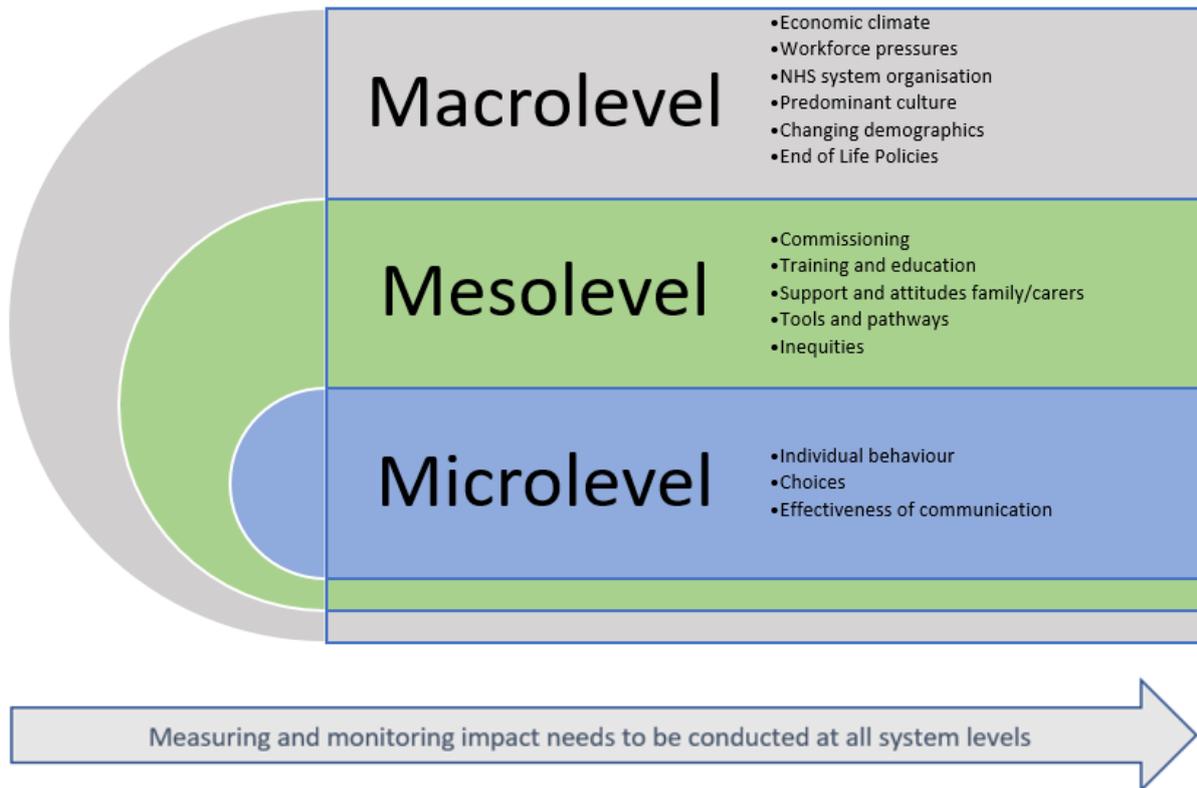
Table 34 Scoping study interview contact sheet

Total numbers contacted with request to interview	30
Non- response after 2 follow up emails	9
Responded to say they were not the most appropriate person or had moved to different roles	7
Final number of interviews conducted	14

The fourteen people interviewed, comprised a mix of professionals working for statutory organisations (NHSI, NHSE), charitable and voluntary organisations (Marie Curie, National Council for Palliative Care, Hospice UK, Royal College of GPs, Royal College of Nursing) and clinicians (Palliative Care Consultants). Respondents (SS1 – SS14) were assigned codes to assure anonymity. Many of the interviewees had a clinical background but were now working in a policy role for voluntary or statutory organisations. Although individual roles are hard to define exactly respondents are identified in the analysis using the generic role of either ‘policy/strategy role’, ‘clinician’ or ‘commissioner’.

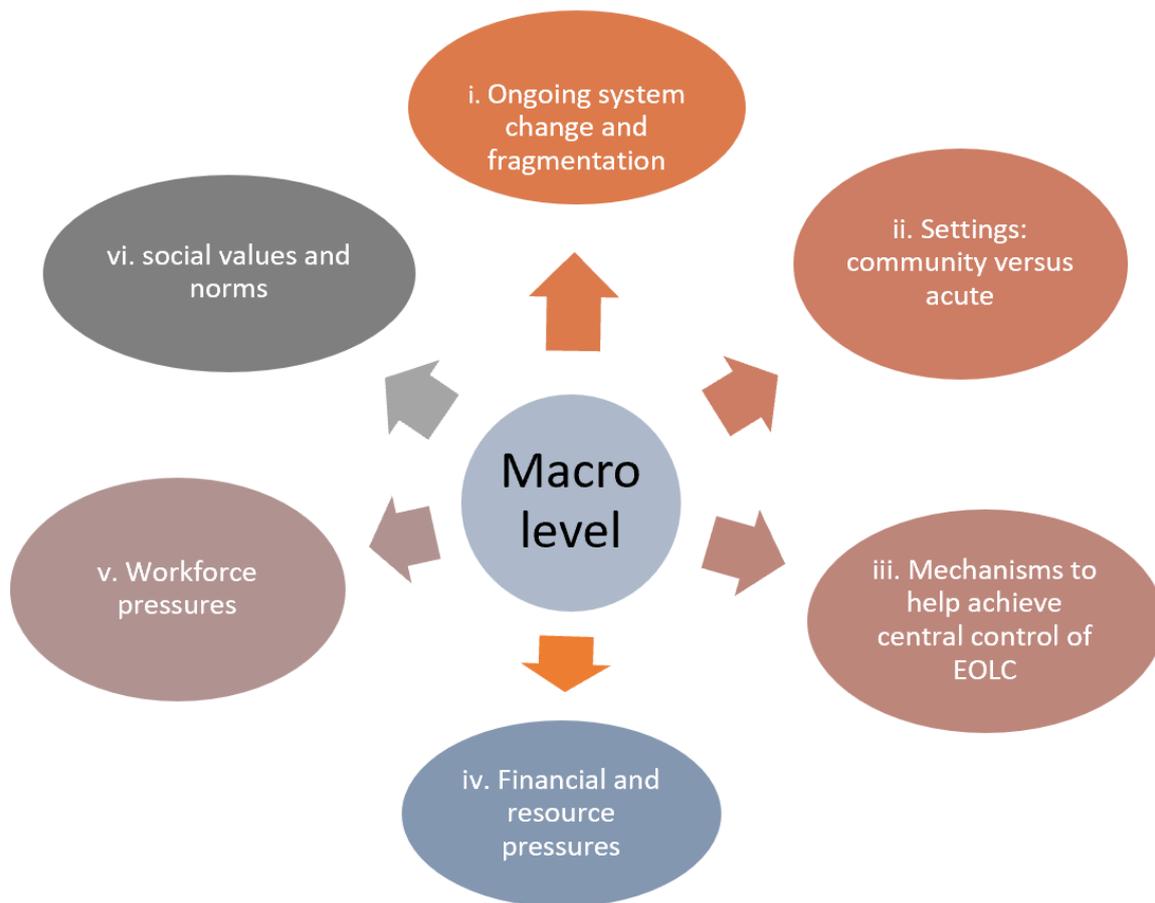
5.2 Key themes arising from professional interviews in scoping study

Figure 11 Key themes arising from professional interviews (scoping study)



5.2.1 Macro level

Figure 12 Mapping of key factors found to impact EOLC care at macro level: scoping study findings



5.2.1.1 Ongoing system change and fragmentation

The last decade has seen significant changes to the internal organisation and workings of the NHS (section 3.4.1) and this was mentioned in some capacity by most respondents. Many STPs are in the process of formulating strategy and building the networks, relationships and infrastructure necessary to embed good working practice across the locality:

... at the moment the work that the STPs are doing isn't tending to impact on local practice and is not really recognised within CCGs. The progress being made is significantly hampered by severe workforce pressures (SS10, Clinician/Policy/strategy role).

Whilst there was agreement that structural changes had delayed progress in certain areas and meant a loss in focus, it was accepted that long-term, STPs represented a more sustainable arrangement from the perspective of more effective commissioning.

I think ultimately from an EOLC perspective STPs will be a positive influence but at the moment whilst CCGs are still battling to get their palliative care services in order and to improve quality for CQC inspections – the extent of the workforce pressure means there is little time to look towards the forward STP vision (SS1, Policy/strategy role and clinician.)

Another challenge emerges from the way the system has evolved over the years in a piecemeal fashion without clear unitary vision. There is a sense of fragmentation faced by many patients as they embark on pathways of care, often crossing different sectors and settings. The obstacles faced in trying to get patients out of acute hospitals back into the community was noted as a particular frustration (SS11, policy/strategy role).

Lots of resource goes in but it's not very joined up and there are a lot of gaps. So, for example handing on from one stage of a pathway to next can be difficult. If a patient has an acute admission it can then be really difficult getting them out again into the community. This is a huge problem (SS11, policy/strategy role).

One consultant was adamant that if he could change one thing to improve EOLC he would focus on joining up the health and social care system and in so doing improve the social and personal care received at the end of life. His vision was that if all HCAs, district nurses, social workers and therapists worked for the same organisation there would be better communication and a common set of standards that were to be collectively achieved. Fragmentation in service provision and the fact that different aspects of provision are funded by different pots of money has led to poor sharing of information, replication of work and passing the buck with no organisation wanting to take ultimate responsibility. Crucially system players at all levels must try to ensure that 'intent doesn't get lost in arguments about governance and data sharing' (SS9, policy/strategy role). One respondent expressed surprise that there was no mapping piece looking at investment in different sectors to allow for comparison.

Nothing is joined up and nothing is properly compared. If enormous amounts of money are invested - what are the outcomes – and how does it impact on tariffs? We just keep on adding little bits here and there but there's not a significant strategic overview... (SS6, clinician and commissioner).

5.2.1.2 Settings: community versus acute

Discussion of different settings touched on both the economic arguments; that transfer of care from acute to community tended to produce cost savings, as well as around valuing patient experience and choice.

We've shifted too far towards acute. . Waiting times and people stuck on ambulance trolleys outside A&E are a nice sexy topic in the media....but nobody is really telling the story that those ambulances are there because there isn't enough nursing support in the community to be able to keep people from dialling 999 when things get bad... (SS10 policy/strategy role, clinician and commissioner).

Respondents were unanimous in their praise for the type of care provided in a hospice, yet pragmatic that hospice money could be more effectively spent, in some instances by providing similar services in the community (either patients homes or care homes). The Hospice at Home model was welcomed as an integral component of community EOLC bringing the skills, ethos and practical care associated with the Hospice Movement into the home environment. There was a call for more evidence to demonstrate the cost impact of keeping patients, identified as being at EOL, in hospitals for long periods of time, versus other more innovative models. Even hospices, universally recognised as providing gold standard care, were considered up for challenge:

We need to get more bang for our buck to reach more people. Hospices are independent entities – how much impact would it have on the system if they were reconfigured? We just don't know enough about the cost-effectiveness of money spent in both hospices and hospitals (SS8, policy/strategy role).

A piece of research from The Nuffield (Chitnis et al. 2012) was cited as providing strong support for bolstering community services; a cohort of nearly 30,000 patients receiving Marie Curie community care, were matched with a control receiving no community support and were found to have significantly better outcomes including drops in emergency admissions, increased death at home and reduced system costs.

With these findings in mind a number of masterclasses and training courses focussing on ways of reducing pressures on acute services are being planned (SS9). Joint work being undertaken by NHSI and NHSE, guided by some of the thinking espoused in the 'Last 1000 days campaign' (NHSI 2016), draws attention to the value of patient time and work to minimise time wasted, particularly when patients are left to languish in hospital or other settings. The campaign focusses on reducing admissions, allocating patients to appropriate pathways, reducing length of stay and facilitating

rapid, supported discharge into the community. Improved discharge into the community needs to be tackled at a number of levels; not only in relation to boosting community skills and resource but also in challenging some risk averse cultures which adhere to an over-reliance on medical practitioners (SS9).

Running alongside a call for innovative practice and a shift in emphasis from acute to community, there was nonetheless, recognition that in the near future, the largest percentage of deaths will continue to occur in hospital and it was therefore imperative to focus on improving patient experience and bringing learning from hospice palliative care into the hospital setting. Two of the big charities are undertaking work to improve experience relating specifically to: outpatients; shared decision making; pain and symptom management, joined up communication between primary and secondary care (SS9, policy/strategy role).

5.2.1.3 Mechanisms to help achieve central control of EOLC

Prior to the 2012 Health and Social Care Act (DH 2012), EOLC was overseen centrally by the DH with a budget assigned to the National End of Life Care Programme. The 2008 End of Life Care Strategy was launched in a different political environment where:

National EOLC policy had money behind it and money makes things happen. There was an open landscape for developing work (SS1, policy/strategy role and clinician).

Post 2012 powers and budget were devolved to CCGs with a small EOLC Team based at NHSE tasked to work with the government and partners to deliver the government's 'End of Life Care Commitment'. Within the current set-up there is limited central control to influence outcomes and the role of NHSE focusses on networking and disseminating. The ambition is that sharing good practice will result in more equity, reliability and consistency in provision. Individual pieces of work are commissioned in areas where there is evident national interest such as developing national metrics. The role of the current NEOLCIN was described as 'providing a national steer' rather than a 'national mandate'.

The Five Year Forward Plan (5YFP) (NHS England 2014) has not prioritised EOLC and there are no mandatory powers, to assure specific standards are met. Respondents reported the plus side of this is that it *'pushes those who are motivated and interested in this area of work, within CCGs, to be more creative and have more co-ownership over initiatives'* (SS1). However, devolving powers

locally was seen to inevitably build more variation in practice into the system; *'Inequality and inequity is inherent in the idea of localism'* (SS1).

Levers, incentives and targets

One short term ambition is that targets for EOLC will be set by STPs and CCGs and local areas will be financially penalised or rewarded depending on whether or not targets are met – clearer indications of how this will look will emerge as STP planning develops. A danger is that targets may be set that have unintended consequences, for example paying per intervention may have the impact of increasing numbers of interventions per se – rather than simply increasing the number of appropriate interventions. Another anxiety voiced about setting targets was the fact that one target, introduced at one point in the pathway, can have a deleterious impact on activity at another point in the pathway; some parts or people may benefit to the detriment of others. For example, large cuts to social care over the last decade have begun to impact on health settings and are said to be one of the reasons why it's harder to discharge old, frail patients from hospital back into the community (SS9). The Liverpool Care Pathway was cited as an EOL pathway which when incentivised, in some cases, resulted in poor patient care due, in part, to people trying to meet targets (in this case achieving the numbers signed up to the pathway) whilst lacking resources to properly train staff. More emphasis, it was suggested, should be paid to patient reported outcomes (PROMS), rather than simply the demonstration of 'numbers on a list' (SS5, policy/strategy role).

Currently GPs are incentivised to create EOLC registers though reportedly are not remunerated for this in the same way as for other registers (SS5). Financial incentives for EOL are provided per list with additional points for extra work – for example, an annual review for diabetes, or asthma or feet checks, or an ACP. Whilst EOLC registers were recognised as being important in terms of patient identification, there was a feeling that some registers may not be kept with such accuracy as other databases.

Another tool mentioned as having a role in promoting greater consistency in national performance was the CCG Improvement and Assessment Framework (IAF) published by NHSE (2017) which provides a set of measures allowing CCG outcomes to be compared. It is designed to provide a greater focus in assisting improvement, alongside NHSE statutory assessment function. This approach aims to reach beyond CCGs, enabling local health systems and communities to assess their own progress from ratings published online. The framework acts as a focal point for joint work and support between NHS England and CCGs. It helps align the NHS Constitution, performance and

finance metrics and transformational challenges and supports the delivery of the FYFV (NHS England 2014a).

CQC Inspections

The Care Quality Commission have a responsibility to inspect both health and social care providers, checking that people receive safe, effective, compassionate and high-quality care. These inspections were seen by respondents to have an important role in bringing failing organisations into line and thus helping to reduce national variations in practice. It was, however, acknowledged that CQC was not omnipresent and, whilst an effective regulator, could only ‘scratch the surface’ (SS3, SS4, SS8). One of the roles of NHSI is to support trusts who have been rated as ‘inadequate’ or ‘require improvement’ in relation to EOLC and it is reported that numbers in these two domains have gone down from 91 to 56 over the last two years. Improvements have been achieved through site visits, mapping exercises and improvement collaboratives. In 2018 a ‘Getting to Good’ programme is focussing on the sharing of good practice.

The role of policy

Ambitions for Palliative and End of Life Care (NPELCP 2015) was broadly welcomed as a successful attempt to bring a number of policy reports together and unite stakeholders in a common direction. Strategy documents were considered valuable in that they provide a best practice template and examples were given of how national strategy and guidelines helped shape local practice. Indeed, it was evident in the EOL Forum meetings observed in sites B and C (see table 32), that the priorities for care laid out in the ‘Ambitions Framework’ (NPELCP 2015) were used as a framework to help focus discussion in the meeting and set aspirational targets against which progress was monitored. Whilst respondents acknowledged the huge variability in the way commissioning was undertaken most were confident that national EOL policy was used as a reference tool to help guide what services were needed.

What I’ve seen commissioners do, on a number of occasions, is a mapping and gap analysis of current service provision against the recommendations in ambitions work to see where they may need to bolster services (SS11, policy/strategy role).

Several respondents had been directly involved in drawing up local plans which were inspired and guided by national policy, or in other cases, respondents recounted how strategy documents were used to help local planning:

I've seen 'Ambitions' used at CCG level - the whole local economy comes together to look at the framework and use self-assessment tools to identify gaps and then they challenge each other to see what can be done to become more 'compliant' with policy and ensure that they aren't just putting on a sticking plaster - but really building best practice (SS1, policy/strategy role and clinician).

National strategy was seen to be influential in the way that CQC set the standards against which inspections are carried out:

CQC look to national policy and guidance to inform the way they inspect and what they're inspecting (SS3, Clinician).

However, whilst examples of good practice were identified, so too was the fact that despite efforts to consolidate policy, the number of documents in circulation continue to confuse the picture and despite the continued rhetoric the often gaping chasm between policy and practice was evident:

The big issue is how to translate the policy into practice across CCGs where there is so much inequity ... we need to involve other professional and non-professional groups. EOLC must become everyone's business (SS11, policy/strategy role).

5.2.1.4 Financial and resource pressures

Austerity formed the backdrop of all the interviews with constant reference to financial pressures and acceptance that if EOLC was to become a priority area it needed to compete with a myriad of other pressing health and social care concerns. Financial deficit was also a strong and recurring theme noted in meeting observations (see table 32). The fact that funding for EOL not only cuts across health and social care, but within settings, the boundaries between one pot of money and another are blurred, means that the final pot of money allocated to EOLC remains hard to define. One challenge with non-specialised services is that there is often overlap; where does EOLC begin and end? District nurses were cited as a case in point – they often deal with EOLC but have lots of other roles as well – yet there is no specific proportion of the budget attributed to EOLC. Moreover, how district nurses decide to divide their tasks varies with the individual and the organisation. Whilst there is no separate budget for EOL in social care, it remains something that occupational therapists (OTs) and social workers deal with on a regular basis. The only formally allocated budget relating to EOLC in the NHS is specialist palliative care and the Continuing Health Care Budget yet controlling

the size of this pot is often something that is said to feel out of the control of CCG commissioners (SS5, SS1, SS10, SS6).

5.1.2.5 Work force pressures

Workforce pressures compounded by rising demand and tightening budgets were highlighted as a significant challenge, particularly in the community.

There is a massive crisis ahead which everyone is closing their eyes to. Recruiting in the South East for example, post Brexit, is a nightmare. It will become close to impossible to recruit nurses and HCAs - but people haven't yet woken up to the problem. I'd like to do a big piece of work looking at workforce needs (SS8, policy/strategy role).

The decimation in numbers of district nurses who traditionally would visit patients at home at EOL was signalled as a particular concern. Despite acknowledgement that attention was now being turned to issues of workforce capacity (particularly pronounced in the light of Brexit) - some commentators felt that whatever was currently being put in place would not be able to fill the growing gaps. The picture reported was of a workforce constantly chasing its tale:

The biggest challenge is being understaffed and not having time between caring to do essential team building and professional development... (SS3, Clinician).

The lack of integrated planning across different sections of the work force was seen as a further obstruction to good practice – particularly the fact that carers were employed by social care, rather than health, meaning that though health and social care professionals need to work together to provide integrated care for patients at the EOL, this was not reflected in workforce management and planning.

Finally, in relation to workforce planning the importance of good leadership was mentioned. CQC data suggests that trusts with good EOLC care have credible, consistent leaders (SS9).

5.2.1.5 Social values and norms

Amongst the respondents there was a clear narrative emerging that EOL must lose its predominant hold on the acute sector and that a re-adjustment of resources was necessary, with a much stronger focus on community support and recognition of the wider determinants which contribute to a good experience at EOL.

If people have to travel from Royal Marsden to Cornwall once a week for three months for a specialist cancer drug – is that good use of the last 3 months of their life? (SS5, policy/strategy role).

It was suggested that the accepted orthodoxy around medical hierarchies should be further challenged and respondents welcomed the growing acceptance of qualitative and mixed methods approaches. For professionals working in palliative medicine there was an occasional sense of perceived inferiority; the inevitable slide into death not measuring up in value to the heroics of saving lives.

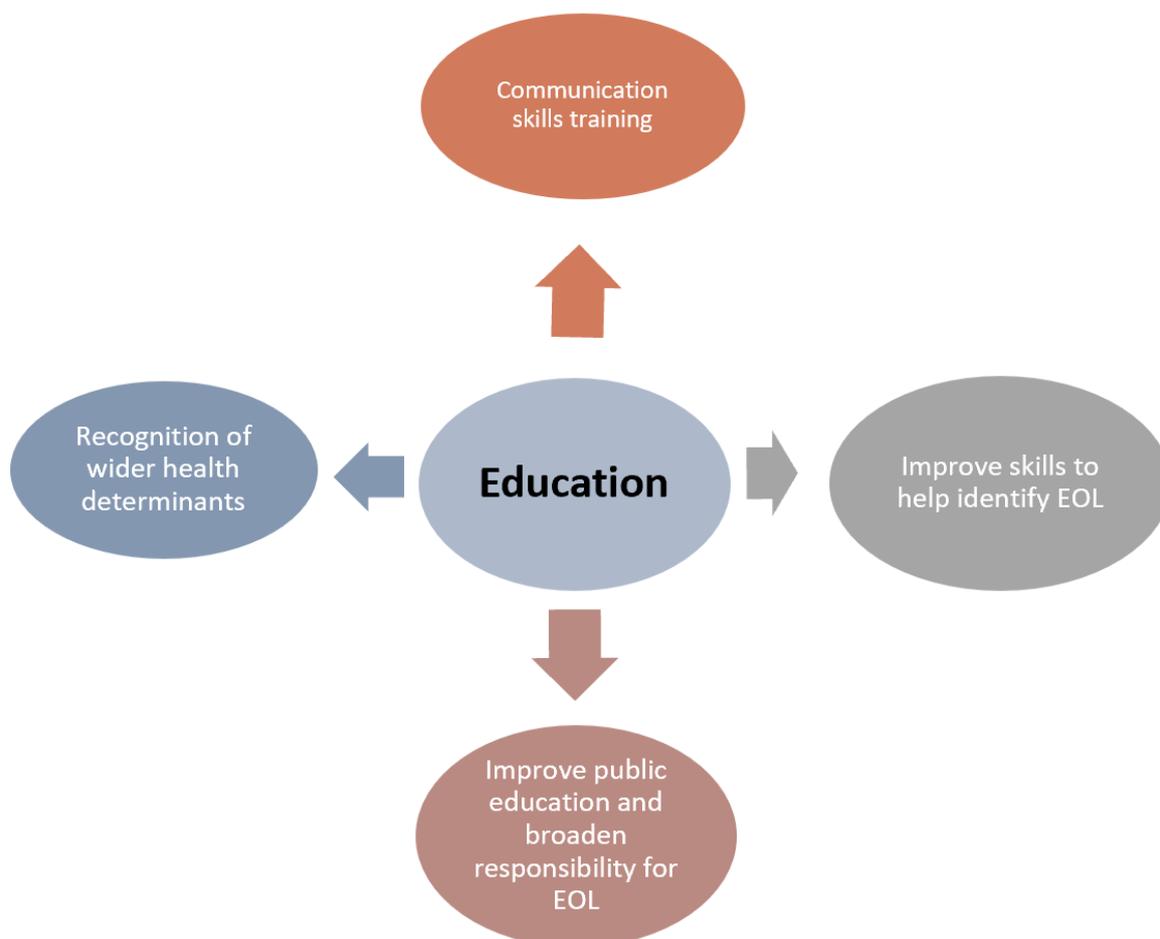
I see what I do in palliative medicine, to be as important as what an oncologist does in cancer or what a surgeon might do. It equates to positivist and naturalist arguments around the value of research. But we've got mixed methods now so at least we are getting somewhere with research (SS1, Policy/strategy role, clinician).

5.2.2 Meso level

Three key themes were drawn out at meso level; education, commissioning and care pathways – these are discussed below.

5.2.2.1 Education

Figure 13 Mapping of key educational issues raised by respondents



Education around EOLC was mentioned frequently with particular reference to communication and identification issues. The majority of those interviewed suggested that there should be broader responsibility for EOLC and that rather than resting with clinicians (GPs or palliative care specialists) it should reside with everyone (patients, relatives, social care professionals and a wider range of health workers). Education is needed to challenge traditional ways of thinking and equip the work force with the necessary skills to begin to change the status quo. Bringing about change requires routine training both in identifying people who may potentially be nearing EOL and in communicating with them to help them reach informed choices about treatment, care pathways and preferences for the last weeks/days of life. It was recognised that to begin to tackle the accepted

norm, whereby death is viewed as a medical problem, a broad-based education programme is required targeted at staff, patients and relatives/carers.

We know we need to get it right in the last few days but it's more than that; we need to get it right much earlier, much further upstream, encouraging people to plan and put their house in order. Everything needs to be better linked up (SS9, policy/strategy role and clinician).

Education of the workforce

It was suggested that it may be helpful to take a step back and to revisit policy and strategy around EOLC, asking how aligned it is with the curriculum of nurses, doctors and other health professionals (SS3).

I would argue that some of communication skills training isn't of sufficiently high quality to give people the confidence to embark on those really hard conversations about what matters to you (SS3, Clinician).

Primary care staff and specifically GPs were seen to be pivotal to embarking on early EOL conversations. It was reported that Marie Curie suggests the average time a patient received Marie Curie nursing support was 8 days. Although clearly of value it was felt that support was needed much earlier than this and earlier identification of need would play a part. Whilst it was understood that national curriculums contained varying degrees of standard information and training around EOL it was acknowledged that relevant ongoing support was needed for professional development. One respondent involved in the field of education told the story of a family who, she believed, had 'imploded' because over a 12 month period no responsible professional had found the time or the courage to have a conversation about advance care planning. The patient, suffering from advanced prostate cancer, had never been told that death was imminent.

Time constraints on staff were acknowledged and the concern that unless appropriate courses were mandatory or a standard part of the curriculum, the reality was that staff may be unable to attend. Such pressures were 'bad enough in acute but in private care or primary care it's even harder to get the time to do extra training' (SS3, Clinician).

Education of the public

Whilst education of health professionals was referred to more frequently than public education there was, nevertheless, recognition that changing public perceptions of death and dying was an important part of a broader approach.

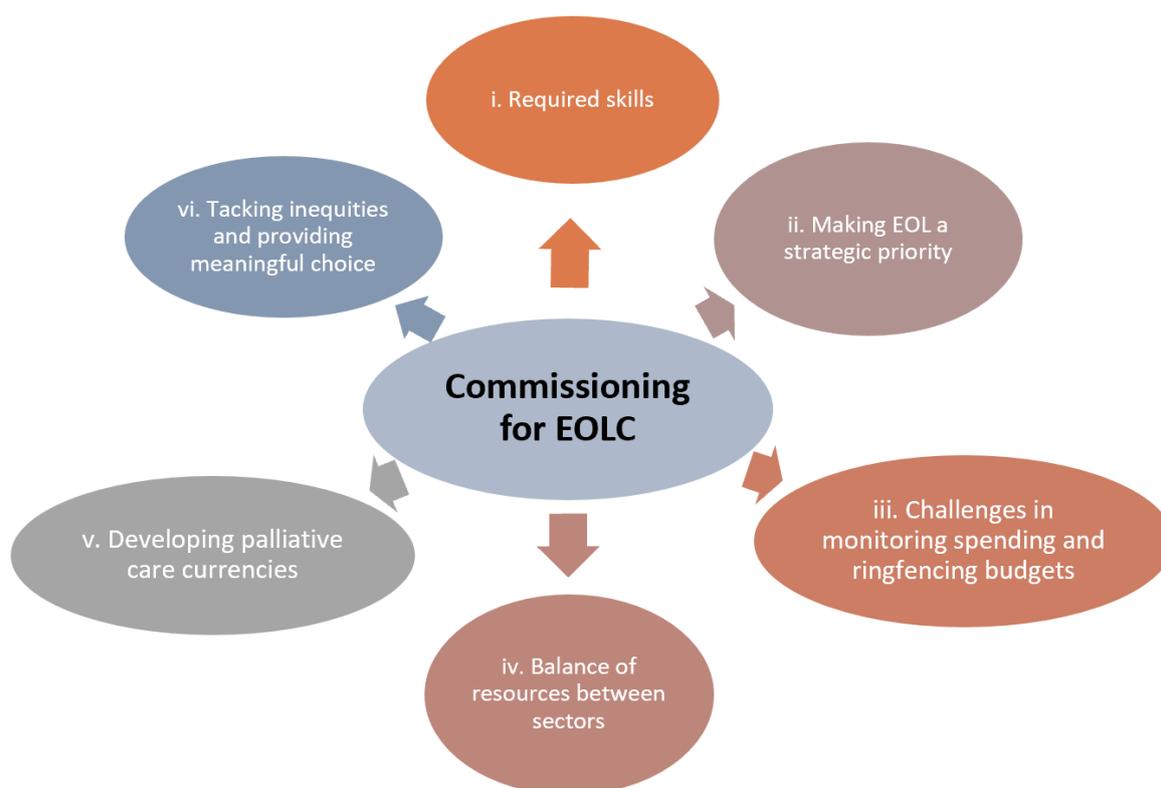
I would also love to see a proper national campaign. In the same way as we have seen the stroke campaign ‘Let’s talk about stroke..’. I’d like to see ‘Let’s talk about End of Life’ (SS5, policy/strategy role).

Broader determinants of health

The role of the broader determinants of health (housing, environment, social support) need to be considered as part of the package of education both for the public and professionals. An understanding of how connected health outcomes are to broader social issues will help ‘enfranchise responsibility’ for EOL (SS11, policy/strategy role).

5.2.2.2 Commissioning

Figure 14 Mapping of key factors relating to EOLC commissioning: scoping study findings



Local commissioning of EOLC was said to be wrought with difficulties, demanding levels of resource and expertise that were often in short supply. Whilst considerable knowledge has accumulated as to what good EOLC is, what it looks like, and how it can be delivered, it is evident that a key challenge

now lies in supporting commissioning and implementation; particularly in relation to ensuring equity, consistency and timely provision of services.

We know what good looks like – we need to focus now on delivery and consistency (SS10).

i) Skills required for commissioning

The degree of knowledge required to commission effectively should not be overestimated and was witnessed in the three End of Life Forum meetings observed in sites B and C (table 32), chaired in each case by the respective CCG commissioner. Whilst people reported commissioners to be ‘well-meaning’ a number of commentators worried that they (particularly those who were new to the job) were lacking required skills and knowledge.

I sat down yesterday with two newish EOLC commissioning leads – we were preparing a joint strategy – they were fantastically organised but they didn’t have a clue about EOLC ... they need much more support and direction! (SS6, clinician and commissioner).

One clinical lead interviewed believed that there was a ‘massive gap’ in the way commissioners were supported and was planning to develop a more formal programme to support their work.

ii) Making EOLC a strategic priority

Whilst EOLC may not currently be formally recognised as one of the top priorities in the 5YFV (NHS England 2014) commissioners and others recognise its increasing relevance and importance, not only in relation to patient experience but also in terms of how it links fundamentally to many connected areas of health and social care.

A freedom of information request asking CCGs whether they had a strategy for EOLC revealed a vast degree of variation across English CCGs, with some not considering palliative and EOLC a core service (Lancaster et al. 2018). This discrepancy in the importance attached to EOLC is reflected in commissioner time allocated to the work within CCGs. One respondent observed how, despite trying to raise the profile of EOLC, they had only one officer responsible (part-time) for EOLC compared to 12 people working on primary care and 10 on urgent care. The factors that lead to CCGs prioritising EOLC in different ways are complex and reasons cited include: historical spend; local need; knowledge and skills of commissioner and competing pressures faced by the CCG.

iii) Challenges in monitoring CCG EOLC spending and ringfencing budgets

Comparing services and levels of provision across CCGs is problematic, not only because of different demographic profiles, but also because some areas receive higher levels of charitable funding from hospices and community provision than others (SS10). Moreover, when considering commissioning for EOL provision it should be noted that effective care involves more than just the provision of palliative care and includes access to drugs, pain relief, district nursing, social care and equipment.

The person who has EOLC in portfolio just looks at hospice and community PC and isn't concerned with, or doesn't necessarily have oversight for, the other core elements that we think are so essential to good EOLC (SS10, policy/strategy role, clinician and commissioner).

Increasing pressure on resource and changing demographics mean that the profile of EOLC is changing and with it the growing challenges of demonstrating cost effectiveness, particularly in relation to economic modelling for different care pathways; how does high investment in the community impact across all system levels? Most business cases currently need to show how investment in 'out of hospital services' will bring about a reduction in hospital use, or shortening the length of stay.

A number of respondents mentioned the difficulties of comparing the size and appropriateness of the budget allocated to different sectors/settings or interrogating the pots of money going into both curative and palliative care at EOL. The conclusion drawn was that an exercise to map how the budget was spent across the different areas of care and treatment would be instructive, despite evident challenges.

iv) Balance of resources between sectors

Commissioning patterns and forecasts, it was suggested, are often based on what happened the year before. Traditionally this may mean high spends in the acute sector with less resource going to the community and primary care. The 'financial envelope' from the previous year is used as a marker for prospective spending rather than looking at outcome data or anticipated need.

I think the reason we are so under resourced is a hangover from the past, an historical narrative. Money often follows where you have very enthusiastic and organised people. It depends how well pitched and elevated and enthusiastic the previous work has been (SS6, clinician and commissioner).

Commissioning behaviours may also be influenced by a reported power imbalance between commissioners and service providers, exacerbated, it was suggested by the fast turnover of commissioning staff, meaning that providers 'are the only consistent item on the landscape' (SS11). It is anticipated that the move away from smaller commissioning models (CCG level), towards the more robust STP level, will help transfer more power and resources back into the hands of commissioners.

The commissioners come up with a budget and the providers dictate how it's spent.... Providers have a lot of power particularly where the commissioner is less knowledgeable and confident... (SS11, policy/strategy role).

v) Developing currencies for palliative care

Recent work done by NHSE on developing palliative care currencies was mentioned by a couple of respondents. The potential to identify unit costs for health care provides the opportunity to be more in control of spend and was considered to be of interest. A 'currency' in health economics is used to describe a consistent unit of health care which can have a price assigned to it and be used as the basis for payment. Currencies are used in planning and commissioning – they help categorise patients into different levels of complexity and thus determine treatment pathways and resource implications. In palliative care, services are currently commissioned through block contracts for services, local tariffs (e.g. for a palliative care bed on a ward) or spot purchasing. A currency model, it was suggested, may create a more transparent way of purchasing services around individual patients. Results from the 2015/16 testing of the currencies provided inconclusive results of the benefits and respondents in the scoping study who were involved with this work suggested that the system was a long way off being able to create national tariffs. However, although not conclusive, the preliminary work was seen to have been of considerable value.

It gave a really useful methodical understanding of how palliative care could be broken down into units of care for patients (SS8, policy/strategy role).

If successful the system would be similar to the Australian model where providers are paid for the number of patients they see, with a tariff determined by the level of need. Some hospices suspect that such a system may result in greater transparency in funding, with the potential to be rewarded in full for the complete package of work provided – rather than the current slightly arbitrary division in funds which means health funding comes from one pot and social care from another. However, the complexity of unravelling historical funding systems and finding ways to account for the various

forms of treatment and care provided, in a series of different settings, has meant that there has been reluctance on all sides to fully embrace the work on currencies.

Attempts along the way to produce tariffs for EOLC have fallen on stony ground on a number of occasions and I can't see how this won't happen again. The key is the complexity of the pathways and the multitude with interrelationships that people experience in EOLC. Medical and social and wider than that – defining what constitutes a package of care in last 3/6/12 months of life is problematic. Asking people how much they spend on EOLC is so variable because they include different things in the measure e.g. only palliative care consultants or specialist nurses – but so much more is involved (SS7, policy/strategy role).

NHSE are not currently mandating for uptake of currencies though the model is available for CCGs to take up at a local level.

vi) Tackling inequities and providing meaningful choice

Increasing geographical inequity, was seen to be a central challenge to current EOLC provision. One tried and tested method of tackling growing variations in practice was through highlighting local performance against benchmarks – challenging local providers to improve practice. Methods suggested to try and reduce the extent of inequalities were considered in 5.2.1.2. Below, a number of other factors linked specifically to commissioning, are considered, including the choice agenda, mechanisms intended to empower patients and the way inequities manifest themselves in relation to demographic and disease variables.

Inequities

Inequities that have come about in relation to condition, notably the fact that cancer continues to be better resourced than many other conditions is something that a number of respondents noted. The fact that the course of the illness in cancer, follows a more predictable trajectory; was put forward as one reason why more work and planning may go towards supporting cancer patients. Efforts to address this inequity were evident and two key drivers were identified which were said to have helped facilitate early identification and hence greater resource allocation to non-cancer diagnosis:

- Locally enhanced incentives for GPs have been used to encourage the development of End of Life Registers and Advance Care Plans.
- In areas where there is coordinated 24/7 palliative care and single point of access care on offer - clinicians may be readier to offer effective prognostication and put people on

the EOLC register. One reason posited as to why early identification has not been pursued in some areas is lack of resource to enable meaningful follow up. Professionals were less motivated to identify EOL patients and place them on a register if no obvious benefit was conferred.

Continuing Health Care Fast Track

Fast track Continuing Health Care (CHC) funding was mentioned as an example to highlight the huge regional variation in EOL services, with one respondent referencing a report to the House of Commons Committee of Public Accounts (2018) which suggests that too often patients aren't made aware of the funding or that there is no one to help them navigate through a complex system and, as a result, their care is compromised. The CHC fast track funding tool, introduced in 2008 and revised in 2012, is intended to ensure that individuals with rapidly deteriorating conditions, which may be entering a terminal phase, are supported in their preferred place of care as quickly as possible. The CCG is duty bound to take responsibility for commissioning and funding appropriate care. However, there is debate and confusion as to how people are identified for this pathway and it is interpreted in different ways by different clinicians.

The choice Agenda

The role of the choice agenda in potentially accentuating inequality was touched on by some respondents. There was a recognised danger that in extending choice of treatment the system is prone to privilege those with the loudest voice.

The choice agenda is very political. We need to get the underlying conditions right if there is to be genuine choice.... Often choice goes in favour of those who are best able to advocate for themselves i.e. the most advantaged (SS1, policy/strategy role and clinician).

Personal Health Budgets

There was some discussion of personalised health budgets (PHBs), currently being trialled for EOLC, and central to the agenda of extending choice. It was suggested that such a system could give those with long term conditions, who were knowledgeable about different types of treatment, more freedom of choice. In rural areas, where it is often hard to access paid

carers, PHBs can possibly be used to pay neighbours who provide less formal support. It enables more flexible/informal care and potentially gets rid of unnecessary bureaucracies.

However, there was scepticism that those whose condition has deteriorated more rapidly or who had perhaps been given a catastrophic terminal diagnosis, would be a position to plan or operationalise their own care.

I'm quite sceptical - when you are dying or someone you love is dying the last thing you want to be doing is managing a PHB (SS8, policy/strategy role).

5.2.2.3 EOLC tools and pathways

A number of respondents mentioned innovative EOLC pathways they were involved with. The Amber Care Bundle, for example, was mentioned as a good example of a service helping to encourage open communication between patients, families and staff, particularly in cases of uncertain prognosis. Others described work to transfer resources from acute to community through the creation of robust community staffing, involving the creation of more health care assistants (HCAs) and clinical nurse specialist posts to support patients both in care homes and their own home. Social Finance are currently supporting a range of integrated projects developing new partnership models for EOLC. The emphasis is on co-creating new models which build up community resource and support with the ambition to reduce pressure on acute services and improve patient experience. Money provided to invest in initial infrastructure is repaid if savings are evidenced in line with those forecast in the business model.

One example mentioned in Waltham Forest, hosted by North East London Foundation Trust was in the form of a partnership agreement, being created between social enterprise, the CCG, the community provider and the acute trust. A programme lead will be hosted by the Foundation Trust but answerable to the partnership. The investment challenge is to support the transition to improved 24/7 community support following a clearly defined model which can be rolled out in other areas at the end of the project. Money will be loaned by Social Enterprise and paid back if savings can be recovered due to less demand on acute services. Other Social Finance projects mentioned included supporting additional resources to provide more ACPs in care homes; support to rapid response community nursing teams providing phone advice or home visits and care home projects providing telemedicine support from specialist nurses. Results from this kind of integrated partnership project are awaited with anticipation.

Another example of integrated working was the Coordinated Safe Integrated (CoSI) team which constitutes a partnership between Woking and Sam Beare Hospices supported by Marie Curie and funded by Central Surrey Health. The team offers coordinated 24/7, skilled, personal and nursing care in patients' homes, as their illness progresses, allowing them to remain in their preferred residence. The service typically supports patients in the last 6-8 weeks of life. Much of the new thinking privileges the role of good communication – both between patients, families and professionals, but also between organisations. It is anticipated that improved communication would go some way towards removing misconceptions about what hospitals and community providers can and cannot do.

The broadening responsibility for EOLC was reflected in a number of models mentioned. Notable is a 'companions' service being piloted with support from Marie Curie in Musgrove Park Hospital – the project involves volunteers being recruited to sit with patients who have been identified as being in the palliative phase. The role of the volunteers is to try to improve the empathy and respect with which patients are treated in hospital at EOL. They have a dual role advocating for the patient and helping with nurse assessment of their condition. The service is seen to be a pragmatic solution to helping make hospitals a more acceptable place to die within current budgetary constraints. The model has been well received by both hospital staff and volunteers and there is an ambition to roll it out more widely, however procedures for selecting volunteers in some trusts are onerous and are reported as a current obstacle to wider take up.

Some respondents, whilst acknowledging the value of good practice felt that too much emphasis was put into continuing to create new models, the number of different EPaCCs currently being used across the country being a case in point; each area trying to provide their own assessment of effectiveness of the model being used, and a limited ability to transfer data across geographical boundaries. Discussion about the frustrations of EPaCCs and how they led to fragmented, disjointed patterns of care, took up a significant part of the discussion at the EOL Forum attended in case study B. It was suggested that continued replication of similar models was not the best use of scarce resources and instead more focus should be put into rolling out and transferring models which have already been shown to be effective. Given the time and resource pressure that individual CCGs were under it was suggested that national agencies and charities had an important role in doing more to highlight projects and tools that were working well and facilitate roll out:

My personal view is that over the years we've had pilots, pioneers, vanguards. You name it we've had them. And to be one of those sites you get significant financial and practical support along with advice on data collection and evaluation. The problem then is scaling up and sustainability. If you don't then get funding to roll out and scale up across the country they will always remain as pockets of good practice. There are plenty of vanguards where they just don't have the money to scale up what they have been doing (SS5, policy/strategy role).

5.2.3 Micro level

Exploring factors impacting on the individual at the micro level is complex, in part due to the sensitivity of collecting meaningful information from people who are dying, but also because preferences and values are so specific and unique to each individual and are liable to change as the patient gets closer to the point of dying (Gomes et al. 2013a; Munday et al. 2009). There is currently work being done by HEE to improve the collection of patient level data both using direct measures and reports from relatives and carers.

The extent to which patients are prepared to confront death and discuss this is influenced not only by the attitude of the individual themselves but also the attitude and approach of those around them. One clinician (SS6) suggested that the key question always to ask people is, 'what's important to you today?' Through such questioning it is possible to reveal the reasons for making certain decisions; it may be that people want to stay alive to see a favourite grandchild get married, or to sort out financial matters. At other times they may be so fearful of dying that they are prepared to go on at any cost, regardless of the quality of life— in such instances it may be possible to reassure them about what death looks like and assuage some anxiety. Clinicians interviewed also recognised how frequently patients were encouraged or pressured by relatives or clinicians to stay alive longer than they may have chosen themselves. One clinician told of a friend with cancer who confided that the hardest part of 'letting go' was telling her oncologist that she did not want any more treatment. 'She felt that she was letting down her doctor!' (SS9). Another consultant recounted how just that day he was sitting by the bed of a patient who was saying 'that's it – my time is up!' whilst the daughter by his side protested, 'No Dad! You've got to fight – you're not giving up!' (SS3)

There was acknowledgement from respondents that individual reaction to death and dying were influenced by a broad range of determinants:

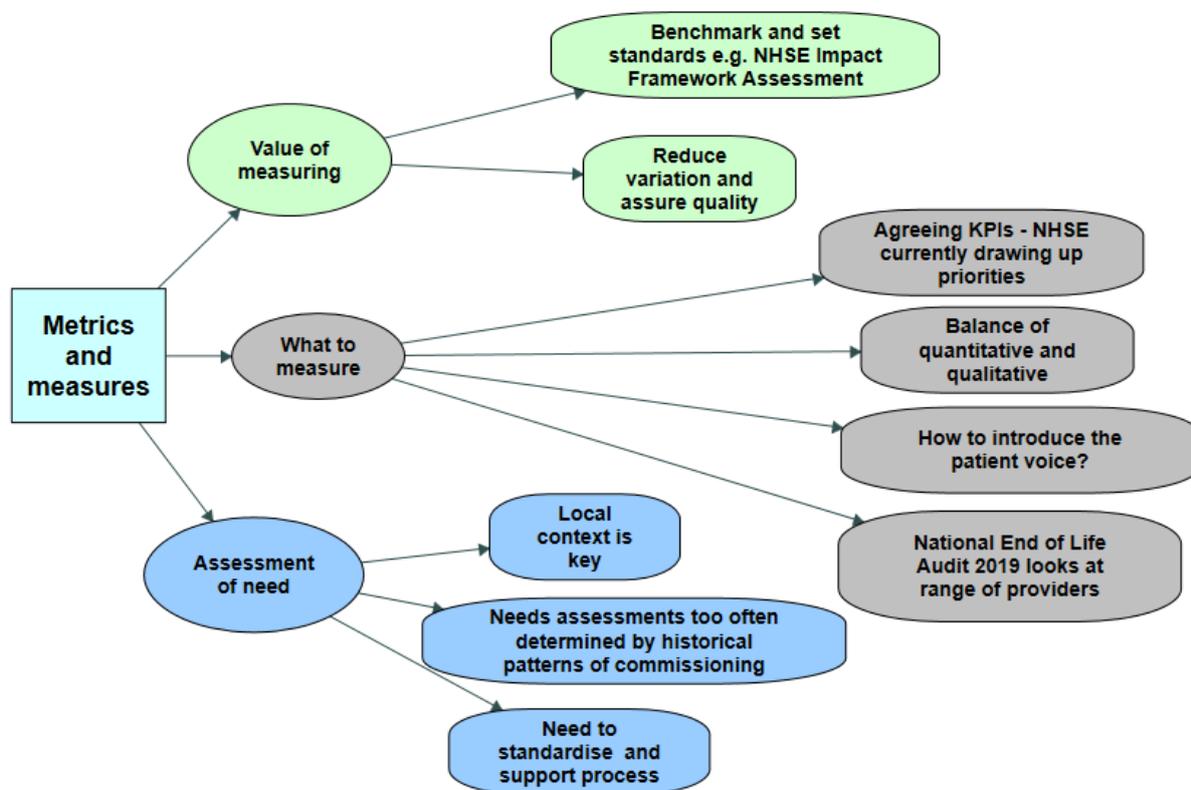
There is something about all of us, both as individuals and as a system, needing to be more realistic – we need to have more courageous conversations with people. Asking what people want and being

clear about benefits. We continue to be a 'death denying society'? (SS9, Policy/strategy role and clinician).

5.3 Metrics and measures

Metrics and measures are viewed as a theme which cut across all system levels (see figure 11). Figure 15 extrapolates a number of key factors that emerged during the scoping study in relation the measuring.

Figure 15 Mapping of key factors relating to metrics and measures for EOLC



5.3.1 The value of measuring at all system levels

Respondents agreed that data collection was imperative to the maintenance of strong effective services. Yet knowing what to collect, how to collect it and to ensure that collected data was used properly and acted upon, was generally viewed as problematic. Collecting data which can both be analysed locally and compared nationally was seen to be one of the most important ways to drive consistency. With the rise of localism, where outcomes and services become more divergent across the country, the way to control for this was seen to be through rigorously highlighting variations in data between areas. Ensuring that data was both meaningful and accurate was therefore key and

there was discussion as to the relative value of the various KPIs collected. It was acknowledged that it may be easier to collect quantitative data (indicators that could be measured and counted) rather than the more ephemeral patient centred indicators around experiences of care and perceived quality of life.

It's much easier to justify a spend on something that is quantifiably measurable. For example, if you can show that a drug is going to extend life by 6 or 9 months – how do you compare this with improving the quality of someone's death? (SS1, Policy/strategy role and clinician).

It was also noted that more value could be obtained from joining up and triangulating data and that views and feedback from NHS staff are currently undervalued.

We don't always measure the right things. I've notice through my QI experience that people tend to measure what they think they can get data on – rather than think about what might be useful or what they need or look at how we're making a difference (SS9).

Yet also acknowledged was the need to start somewhere and the fact that too much debate over what to measure could lead to paralysis. Whilst some felt that particular areas of data collection required more attention, the majority were pragmatic about the pressures, citing the view that data should only be collected if it was clear how it was going to be used.

National benchmarking

The EOLC team at NHSE have compiled a list of nationally available indicators from a range of sources including national audits, VOICES and other mandatorily collected forms of data. They are currently consulting with their board to help agree a common set of EOLC KPIs. The intention is to standardise practice and facilitate a common language and understanding around EOLC. Once agreed such a list will help local commissioners identify the metrics that need to be stipulated in contracts. The focus of the work is to help assess what 'success looks like'. The end result may be a metric around the level of variation that is accepted or it may be a target to try and achieve.

The National End of Life Care Intelligence Network (NEOLCIN) has been pivotal in developing comparative data sets to benchmark practice nationally. Whilst over the last couple of years one of the key indicators used to compare local practice has been 'Percentage of patients dying in preferred place of death' there was acknowledgement that this measure lacks sensitivity. Focus is now being transferred in the new 'CCG Improvement and Assessment Framework' to a measure recording the

'number of emergency admissions in last years of life'. Those respondents who commented on this were agreed that whilst crude, it was a more sensitive indicator which linked more accurately to the effectiveness of a number of different components of the system (SS2).

A number of respondents mentioned an ongoing three year project commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The project, referred to as NACEL (National Audit of Care at the End of Life) is an independent piece of work which focuses on the quality and outcomes of care experienced by those in their last admission in acute, community and mental health hospitals throughout England and Wales. The aim is to measure to what extent the priorities for care of the dying person, outlined in the document 'One Chance to Get it Right', are being achieved at a national level.

The NACEL will build on previous audits, with services being assessed against the Leadership Alliance for the Care of Dying People's Five Priorities of Care, CQC domains and NICE national guidance and quality standards. Both carer and staff views are included in the audit for the first time.

5.3.2 What to measure?

In order for data to make a difference it must be meaningful – which, crucially, means identifying sensitive and nuanced indicators.

We're currently looking at dash boards and metrics for performance. These are reasonably standard for acute but less clear in the community. We're searching for an appropriate EOLC community dashboard and doing some work to identify appropriate metrics (SS9).

Data collection, appraisal and evaluation of services was seen to vary across sectors and settings with hospices and palliative care being reported as having a particularly thin evidence base. Currently research looking at the impact of hospice interventions on the amount of time people subsequently spend in acute is revealing interesting findings demonstrating that more resources put into community and hospice interventions, may result in less pressure on acute services and overall system savings.

Historically measures collected at EOL have included outcome based quantitative data such as place of death, condition, age, time spent in hospital, whilst patient centred data has been considered harder to gather. The VOICES survey (views of informal carers for the evaluation of services) carried

out for the first time in 2011 by the Office for National Statistics (ONS) was broadly welcomed and seen as a positive step towards attempting to capture (via the proxy of relatives) the views of patients. The survey focusses on issues around dignity and respect, pain relief, ease of access to services and dying in the place of preference. One of the shortfalls of VOICES is that data 'comes through the filter of grief, loss and bereavement' (SS1) and whilst it has an important role, efforts to continue to collect first-hand patient data should not be abandoned. Indeed, NHSE reported plans to develop more sophisticated patient centred data, based around ongoing pilot work in 20 trusts, though at the time of the scoping study, progress was stalled due to issues around safeguarding and accountability. Whilst different forms of patient centred data are recorded locally unless the data is consistent across regions and can be nationally collated and benchmarked, a lot of the potential value is lost.

Other ways mentioned to build patient views and perspectives into EOLC work included techniques such as those practiced in QI at Hospice UK where they carry out 'Patient Walk Throughs' – walking through patient pathways, accompanied by those with 'user experience' to provide a narrative of the types of factors that a patient considers as they encounter different bits of the service. The value of 'real time' feedback was also stressed – where data from patients is fed back to staff as soon as it is collected to enable them to link immediate actions with direct patient response/outcomes. Locally there is no imperative to collect a common set of EOLC related KPIs and a range of different tools and techniques were mentioned. One local CCG EOLC lead said that she was focussing on triangulating a range of indicators including patient and staff experience as well as information about ACPs. Another spoke of an audit where records from all patients with unanticipated deaths had their clinical notes reviewed to assess factors which may have been missed.

Another form of deep dive, supported by hospice UK involved snapshots of 'case file reviews' where hospital files of those who had died within certain time periods following admission (0-3 or 3-20 days), were examined in detail. The data was reviewed with clinicians from palliative and urgent care with a particular focus on opportunities that may have been missed – outcomes were said to be insightful with a number of areas being noted where processes could be improved.

One respondent mentioned the drive for all trusts to employ a 'medical examiner' as recommended by the Shipman (The Home Secretary 2007), Mid-Staffordshire (Francis 2013) and Morecambe Bay public inquiries (Kirkup 2015). The responsibility of the 'medical examiner is to sign off death certificates, a role which entails examining a number of indicators including length of stay and speed

of discharge. One of their jobs is to phone the family and ask 'was everything ok?' – the focus is on the quality of care from a patient perspective. It is hoped that this new process will promote awareness of the importance of patient experience at EOL.

5.3.4 Assessment of need

A couple of respondents suggested that it was not unusual for needs assessments to lack rigour or standardisation, citing a study by Sleeman et al (2018) which looked at 78 Health and Well Being Strategies and showed that only 21 demonstrated evidence of need in relation to EOL . A key problem, it appeared, was the tendency for assessment of need to be determined by historic patterns of commissioning rather than real-time local data. Whilst it was acknowledged that local systems needed to come up with solutions to local problems, there was a feeling voiced that mandatory minimum standards would help improve consistency in provision.

5.4 Rough Programme Theory

As discussed in section 4.3 RE is theory driven and data is collected to constantly refine and interrogate conjectured theories. Following the scoping study an RPT was drawn up as a basis for further theory development during phase 2. This RPT is represented in table 35 below.

Table 35 **Rough programme theory for EOLC policy**

That national end of life policy provides a framework and standards that can be applied locally to EOL care with a view to maximising equity of provision and quality from both a patient and systems perspective.

In relation to individual patients and drawing on Ambitions for Palliative and End of Life Care (NPELCP 2015) this translates to:

- being treated as an individual
- being involved in decisions
- having fair access to different services
- that care is coordinated
- that comfort is achieved

Whilst at the level of the system, although not explicitly spelt out in policy, for the purposes of the current thesis, the assumption is that:

- resources are managed to maximise value for money across both health and social care
- that the EOLC services are delivered to acceptable standards nationally within agreed parameters
- that a range of real choices are offered to patient around preferred location for care and treatment and that staff are trained in effective communication techniques
- that policy is politically acceptable (both locally and nationally, and to a range of key stakeholders)
- that delivering of policy is feasible and that staff are enabled to carry through policy directives.

5.4 Chapter summary

The scoping interviews highlight many of the key themes emerging from the literature and reiterate the huge complexity involved in exploring the value of national policy and its influence in helping develop local systems which may lead to the more consistent and effective provision of local EOLC services. In particular the interviews provide insight into the rapidly changing policy environment and the impact that ongoing NHS organisational change has on both commissioning and service provision. The sense of fragmentation and the way services have built up, piecemeal, over the years has meant that comparing the value of different services in different sectors, has tended not to happen, instead there has been a propensity to accept and replicate historical patterns of commissioning. The move now is towards a re-education of both the public and professionals, placing more emphasis on a broader responsibility for EOLC with a shift from acute hospital into community settings with greater

24/7 support for pain relief and expert advice. The rise of localism was noted, and it was suggested there may be value in providing more support and standardisation to the commissioning process. Data collected in phase 1 contributed to the development of programme theory. A number of conjectured CMOs were drawn up which used to inform phase 2 of the thesis; the case studies.

Chapter 6: Phase 2 Results

This chapter presents findings from phase 2, primarily consisting of case study interviews, supported by meeting observations and perusal of relevant documentation (see Method's chapter four). Given the complexity of material, comparative analysis was not carried out between case study sites, rather themes were reviewed globally and by stakeholder group.

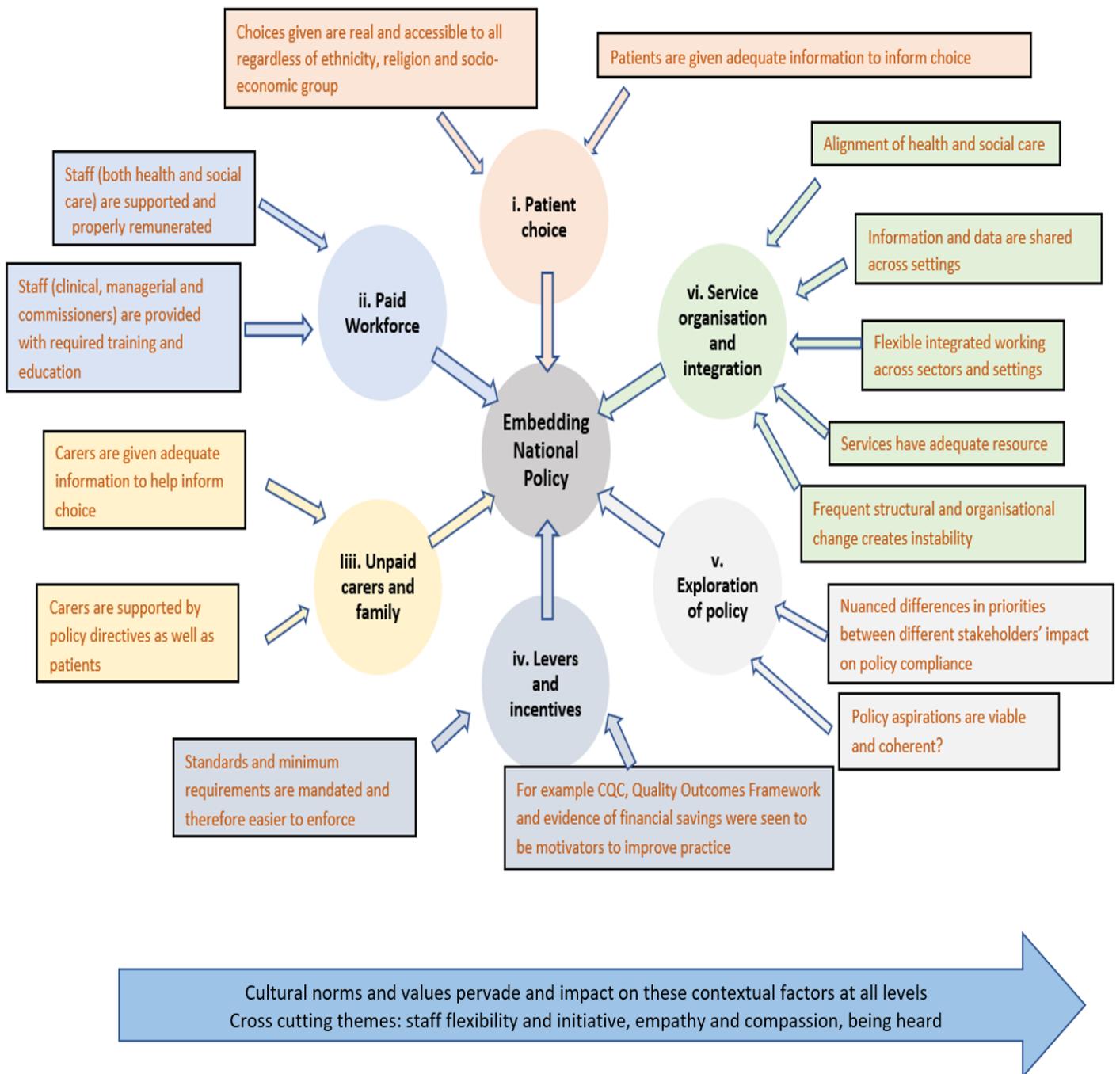
The chapter is divided into two sections. The first section begins with an exploration of the multiple, interconnected contextual layers that impact on the ability to fully enact the aspirations of EOL Policy (see chapter three). The second section moves on to explore the seven CMOs deemed to have the greatest explicatory power in helping to elucidate what needs to be in place in order for the programme theory to work.

Respondent quotes are anonymised and are distinguished by stakeholder group (patients, relatives/carers, clinicians and service managers) and case study site (A, B and C).

6.1 Contextual factors:

In RE terminology, contextual factors operate together to trigger or 'fire' an underlying mechanism; they can be viewed as 'operating in bundles of factors' (Maben 2012). Following the collection of data, contextual factors which appeared to influence outcomes were assigned codes and then mapped into themes (see section 6.5). These themes, summarising phase 2 findings, are represented in figure 16 which shows the key contextual factors enabling the successful implementation of EOLC policy. They are presented as aspirational factors which need to be in place if mechanisms are to be successfully triggered:

Figure 16 Contextual factors that contribute to embedding EOLC national policy



6.1.1 Patient choice

Providing patients with the opportunity to make meaningful choices for EOLC is based on a number of premises:

- that professionals initiate appropriate EOL conversations at the right time
- that professionals identify when patients are approaching the EOL so that chosen care can be put in place
- that patients are willing to engage in conversations
- that the choices provided are meaningful and the options presented are based in the reality of what is available
- that choices align with patient priorities
- that access is equitable regardless of ethnicity, religion and socio-economic group.

6.1.1.1 Professional communication skills

Clinicians and service managers repeatedly spoke of the importance of being able to proactively raise questions with patients about preferred choice at EOL – yet many acknowledged that raising such a sensitive issue was challenging and required training. A few suggested that conversations about dying tended to be left until too close to the end at which point they became over-invested with emotion. The majority of professionals in the research agreed that the existence of an ACP, created during EOL discussions, was important both to guarantee improved patient experience and reduce inappropriate admissions to intensive care:

Many patients, relatives and staff – only understand that someone is dying too late. They end up in ICU because no one had the time or the courage or the inclination to set a ‘ceiling of care’ with the family because it felt too difficult to do this (B.Clinician.1).

Communication with relatives (as well as patients) is central to any holistic care package. One nurse working on the PC ward of a local nursing home described how relatives can be reluctant to accept a palliative prognosis, at times challenging the course of action prescribed by clinicians. She recalled one particularly agitated woman whose husband had been admitted, frantically fighting to have him returned to hospital. The nurse sat down with the woman – trying to convey what it meant to be palliative and explaining how his condition would progress. Eventually the woman understood and accepted that this was the best option:

...no one had really taken the time to explain what it all meant. It was a shock to her that this was probably to be his last stop and we were talking about EOL and ACPs (C.Clinician.6).

There was reported to be little consistency in the way conversations were initiated, who was responsible for them, or the stage of the patient pathway at which they were most appropriate:

What we most suffer from is that many of our staff – particularly those in the community, don't feel able to offer these frank conversations. Specialist palliative care nurses and consultants will – but most people don't have these specialist skills (B.Clinician.4).

A number of commissioners and clinicians reflected on the importance of broader public awareness and the value of educating the general public to become more confident discussing death and EOL choices – in so doing establishing a more receptive starting point from which conversations can be initiated. In case study 1 the CCG funded a voluntary 'socially minded partnership' who work with communities to lift the taboo around death, dying and bereavement and to raise awareness of the importance of EOLC planning. The project in CS1 trains volunteers from Age UK to become peer educators, in so doing raising awareness in the community and contributing towards putting ACPs in place. A part time coordinator trains and supports volunteers and finds opportunities for conversations. Part of this public education involves the promotion of 'death cafes' which encourage the public to come together in informal forums to begin to think about and discuss death:

What I see in death cafes ... is a release and an opening which means a lot more conversations can start which leads to all sorts of better outcomes...many families don't know what their dying relative wants....(A.Non-Clinical.4).

6.1.1.2 Identification of EOL

Even though dying comes to us all, the trajectory that leads to death is often hard to foresee. Some frail patients hold out for months longer than anticipated whilst others die without any EOL prognosis. Identification of patients at EOL (be that in their last year, or their last days) was seen to be problematic.

This local authority commissioner believed that the problem could be assisted by encouraging broader ownership of EOL issues both from a health and a social care perspective.

GP identification of EOL is a major problem. One of my aims in social care planning is to change the culture of ownership. EOLC is everyone's problem and a myriad of professionals should be involved in EOL conversations (particularly social workers and OTs). My plan is to commission training of social care professionals in initiating EOL conversations (B.Non-Clinical.4).

Another anticipated outcome of better public education was that being more familiar with the process of dying and knowing what to expect imparts more confidence, meaning that carers would be less likely to call out emergency services when patients could be managed better at home.

Although for some patients, such as those with cancer, the prognosis followed a predictable trajectory, for other conditions levels and speed of deterioration could be hard to predict. A number of different tools and indicators were mentioned by clinicians such as the GSF Prognostic Indicator Guidance (Royal College of Practitioners 2011), SPICT (The University of Edinburgh 2019) and the Electronic Frailty Index (Moody, Lyndon and Stevens 2017), though despite these it was agreed that many still die with no EOL status having been flagged. In part this was attributed to lack of staff capacity, but also, in other instances resulted from the fact that professionals saw no advantage of flagging people as EOL.

In the borough there are thousands of frail elderly. Not all will have palliative needs and only a few would be specialist palliative care... the bulk of those would be under care of generic teams. It's a simply enormous population so you have to know what the benefits of identification would be...(C.Clinician.5).

6.1.1.3 Patient engagement in EOL conversations

Patients exhibited different levels of tolerance/enthusiasm for wanting to be involved in decisions around their own care. Some approached their disease in an active, engaged way. The more knowledge they had about their treatment the more in control they felt. Some wanted to have things properly explained so they could make informed decisions whilst others, perhaps the majority, were more passive; happy to hand control over to the doctors.

No, we rely on them to tell us what to do – we go along when we feel we need to. They're the ones who tell us what we have to do. We go round and get an appointment and go from there. I had a blood test yesterday. They give us the appointments and we go. I don't know what it was for – or if I did know I've forgotten - but I'm waiting for the results! (C.Patient.2)

In a number of cases the carer takes on the role of gatekeeper between professional and patient. Here James, a cancer patient, explains how his wife is the one who wants to find out as much as she can about his condition:

Caroline my wife wants to know everything. She gets in their face (the medics). Sometimes I wonder if I really need to know what she wants to know. She's on all the websites and all the different forums. So she knows everything – I can't be bothered with all that. Knowledge is power. She wants to take control (B.Patient.2).

In terms of preparing for EOL, where patients did have discussions and made plans, it seemed to provide comfort and assurance. Barbara talks about a much loved husband who died earlier that year:

His CMC said that he didn't want to be resuscitated and the guidance around it was that you don't call 999. The two of us had always been in agreement. It's about quality of life not quantity. It didn't matter if it was him or me. We didn't want to become a vegetable or to be dependent – that is no quality of life. He wanted to die in his chair ... watching his television, with a glass of whisky in his hand. And I would have said to him 'you've had a good life' We discussed all these things a long time ago (C.Carer.4).

6.1.1.4 Are choices meaningful?

Historically one of the measures used to determine the effectiveness of local EOLC services has been an indication of the number of people dying in their preferred place however, what emerged over the course of the fieldwork, was that decisions over preferred place of death are rarely binary. Choices are impacted by multiple, rapidly changing contextual circumstances. In this account, Elizabeth, a 94 year old woman, confined to bed in her care home, talks about the importance of having things that are familiar around her at EOL. Having the nurses and the carers talk to her, and communicate on a human level were, for Elizabeth, the most important aspects of good care:

If my health gets worse I want to stay here and they know that.... I don't want to go to hospital. You see - you get to know people here. I can talk to people about how things are going. If you go to hospital its unfamiliar – you're surrounded by all sorts of new people. The care here is so good...in a hospital I think you would be told to get on with it. I wouldn't get my Horlicks (A.Patient.1).

Care home managers reported that supported by better training and education for staff there is a growing confidence that the sector will be more able to cater for residents at EOL, enabling them to remain until their end, in the home. Whilst there was support for the aspiration to help enable patients remain in a familiar environment as their health declined, a number of respondents queried the value of 'preferred place of death' as a valid KPI. One palliative care consultant was particularly scathing; her analysis was that for other NHS interventions such as operations or childbirth - 'you are presented with a list as long as your arm of what might happen to you'. However, if such detailed information was to be made available for choices in dying, she suggested the decisions arrived at would not be economically viable.

I suspect if people were presented with all the information a lot of people wouldn't choose home. Patient choice might be a good thing depending on where you live. If I was living in a nice middleclass area, I may want choice ...but imagine I live in poverty – like many people do in this area. Imagine my whole life has been in poverty – I've never really been encouraged to have a voice about very much – ok so this is a generalisation. Or I'm elderly – and it's always been 'doctor knows best dear' because that's how they've grown up. Paternalistic medicine is the norm. Let's be honest, 20 years ago we didn't give people a choice. We just did it because we knew best. I think there's a myth about giving people choice – the choice we give isn't realistic (B.Non-Clinical.8).

The same clinician went on to describe some of her teaching. Exploring EOL choices with students she asks them to raise their hands if they want to die at home; lots of hands go up. And she says 'Who wants to die in hospital?' Very few hands go up – and then 'who wants to die in a care home?' – even less hands go up. And who fancies a hospice? And again quite a few hands. Then she builds the scenario further and gets people to imagine themselves having deteriorated and being unable to eat, or dress or go to the loo – being dependent on husbands or wives or daughters to carry out the most intimate of tasks. Imagine, she then says, 'the carers haven't come and you've soiled yourself – your 20 year old daughter is having to wash your bottom'. And when she repeats the question 'where do you want to be now?' many more are moving towards institutional care. Finally she says 'and now it's 2 in the morning - you're breathless and terrified, your 80 year old husband is terrified too and keeps on asking if he should call an ambulance'. It is at that point, she says, people begin to actually say they would be happy in a care home.

6.1.1.5 Choices align with patient priorities

Quality of life, being treated with compassion and the importance of maintaining dignity and independence were common themes within patient narratives – there were several accounts where

patients inferred that 'living a good life' was more important than the clinical drive to extend life. Patients often reported a 'tipping point' or 'bottom line' – drawn to define the point at which diminishing levels of independence and dignity would mean it was no longer worth the struggle to keep on living. Generally, there was agreement that for as long as they got pleasure out of life they wanted to go on – beyond this they were happy to say goodbye.

For a number of patients' life was bearable as long as they were connected to family and friends, with isolation particularly mentioned as being hard to manage:

Oh I just want more visitors – it's isolation and loneliness that get to me... I was just such a social person- that's what I miss (C.Patient.8).

And for others it was when independence began to ebb away and everyday tasks grew difficult that depression set in:

I can't do the things I want to do. It's frustrating. I can't even put the washing machine on!
(B.Patient.6)

A significant number of patients were adamant that they did not want aggressive treatments or operations to extend life further - simply to have their pain managed and be cared for:

I've told my wife Cynthia, that given this cancer is incurable – if they offered me chemo and it just gave me a few extra months I wouldn't take it. Why do I want to punish myself? I'd rather go with dignity
(B.Patient.2).

The desire for independence and dignity remained strong as people grew weak and frail. This woman, suffering from cancer, but living at home supported by carers, forcefully rebutted her daughter's encouragement for her to go into a home:

I don't want to go into a home. I want to stay here and have my independence. My daughters don't understand it! They think I'm silly. They seem to think that I'm not with it - that I don't know what I'm doing. And I don't seem to be able to convince them that I do. I'm well aware of what I'm doing
(B.Patient.3).

Tensions relating to choice and tolerance of risk

The notion of risk is interesting to consider alongside the tension between patient choice and clinical guidance. Risk was mentioned from time to time by respondents, increasingly concerned with being held responsible for neglect by an increasingly litigious medical system. As a result patients, sometimes against their wishes, can be passed along professional pathways with each new part of the system trying to relinquish responsibility – passing the patient on until the highest level of acute care and observation is reached:

People in different parts of the system can no longer tolerate the level of risk. We have a joke about moving the 'risk' – we say 'move that risk' – it's about how people will shift responsibility on as fast as they can (A.Clinician.2).

One nursing home manager referred to some staff as more 'risk averse' than others; being prone to call ambulances if they lacked confidence to deal with palliative patients themselves. In the same way, ambulance staff spoke of concerns around having to follow prescribed pathways. For example, if called to deal with someone who has a condition such as sepsis the prescribed pathway for this condition is hospital admission – yet if the patient already has an EOLC prognosis and a CMC in place a tension arises over which prescribed path to follow.

At times tolerance of risk appeared to be influenced by the values held by the respondent. For those who valued life extension over quality of life certain risks could not be tolerated. One son for example spoke about his ailing mother whose swallowing function was weakening and to prevent choking the consultant had suggested she drink thickened water. The trouble with this, the son explained, was that his mother hated the thickened water:

When specialists come in from a particular field it can be a bit myopic. They just see things from their one perspective. But for me everything has to be a balance of quality of life over quantity. My mum needs to enjoy the life she has left to lead and if that means not drinking thickened water – then so be it! Extending life whilst it impacts on quality isn't worth it as far as I'm concerned. What's the value? Obviously I don't want her to choke –that's not the outcome I'm looking for - but who wants to eat bland food and drink thickened water (A.Carer.4).

Impact of value systems on available choices

Value systems were also touched on by one hospice manager, who was involved in implementing volunteer led community support projects. She referred to the challenging cultural backdrop to her

work; namely the notion, strongly held by some of the clinical workforce, that clinicians and clinical environments provide the gold standard of safety and assurance to those at EOL. Developmental programmes on the other hand, attempting to integrate non-clinical volunteers to support those at EOL within their home environment, are viewed by some with suspicion. People spoke of tensions in locating community projects within more traditional hospice care.

When choice may not be supported by the system

For a small number of patients interviewed it appeared that their quality of life was considered so poor that their preferred choice would be to hasten death – an option in the current legal climate which is not available:

If I could find a way of doing it I would. I'm contemplating saving up a store of paracetamol (B.Patient.4).

6.1.1.6 Equity of access to services

Respondents were clear that choices should be available to all those in need regardless of where they live, their condition, ethnicity or socio-economic group. Factors implicated in equity are considered below:

Geographical area

Each local area had a range of different services available for those at EOL meaning that there was no one common set of 'choices' available. The 'post-code lottery' relating to care was widely referred to. Many examples were given, though one service that got particular mention was the Fast Track Continuing Health Care (CHC):

I have the data for London on allocation of CHC per 50,000 head of population and the variation in the way its allocated is absolutely shocking (A.Clinician.1).

Inequitable access to hospices was also reported, with one of the three case study sites not having a hospice based within the CCG. Whilst, in this case, the CCG commissioned hospice beds it meant that logistical arrangements for relatives were not so easy. Another area of considerable disparity was in overnight palliative visiting services – with one of the CCGs not providing this service. Those service providers who work across a number of different boroughs are particularly aware of the impact of inequitable services as is revealed in this comment from a manager of the ambulance service:

There are such significant levels of variation between local areas that it can make it difficult to follow the wishes laid out in the Coordinate my Care (CMC) Plan. In our latest London scoping there are about five different Single Point of Access (SPA) systems² – each slightly different from the other (C.Non-Clinical.7).

Socio-economic group

Whilst those needing clinical care are entitled to receive this from the NHS regardless of income or socio-economic status, social care is not supported in the same way, with access to state support based on income (Carers UK 2019). The case studies found evidence that social care provision from the local authority is often not deemed 'fit for purpose' (see section 6.1.2.1).

Those who could afford to employ carers directly – rather than through local authority authorised agencies – appeared to have better experiences of care. Only a small number of interviewees in the study had carers who were exclusively privately funded but these accounts conveyed the sense of a system that provided better experience for patients and carers – where there was more control to provide regular carers with whom relationships could be built up.

The joy is we know who we're getting – we get the same person every-time... (C.Carer.1).

Although there is limited state provision for respite services, having money available to organise flexible breaks for carers, was something not available to all participants. Here Bob talks about his wife Barbara, who suffers from dementia and has had the odd break in a privately funded nursing home.

What we've done through our life means that we can afford to arrive at this point. Lots of people can't ... It's difficult – we are all living longer – we're spending more money to keep people alive for longer – but many can't then afford the social care they need (C.Carer.1).

² A single point of access describes an access process where all services share a single set of contact information

Clinical Condition

Type of clinical condition is a key factor determining the care pathway along which patients are directed. Patients receiving specialist cancer or other services appear to benefit, not only from ongoing clinical supervision but once under a clinician for treatment of a specific condition this is often a route into services providing relational and social care. A couple of respondents for example mentioned that hospice day-care, offering social support once a week, was a service they particularly looked forward to and valued. Those, including the frail elderly, who suffered a number of co-morbidities but had no specific terminal condition, were potentially the group who missed out on organised social support. Whilst acute based clinicians mentioned that more was being done to improve identification of the frail elderly at EOL:

It is often the frail elderly who slip through the net so having a consistent way of reviewing need against a clear frailty protocol will help clinicians to ensure that necessary support is put in place (B.Clinician.6).

Ethnicity and religion

All three case study sites were ethnically diverse and challenges relating to ethnicity and choice were raised. Most fundamental was the ability to provide services in appropriate languages, having translation services available, and acknowledging differences in religious beliefs and cultural norms which may impact on service preference. For this elderly carer, born in India, whose first language was Gujarati, there was a sense that not having English as a first language led to a lack of entitlement and consequent disadvantage when trying to access statutory services:

The trouble for us is that the English we learn isn't equal to the English of you people. We just speak simple English – so we can't argue with you – if you ask them a question they won't reply they'll just ask you a question (B.Carer.2).

Cultural and religious beliefs and understanding may also impact profoundly on the way choices are made at EOL (see also section 6.1.5.5). Here a care home manager reflects on some of the challenges:

There are some cultures in Southern and Eastern Africa where they think that if something comes out of your mouth you are prophesising – in other words you are inviting it...we have a resident here now – she is EOL – she actually went to hospital when it wasn't strictly necessary for her to go – but the family insisted. They refused to sign a DNAR because it's against their belief...(B.Non-Clinical.6).

Such beliefs mean that discussing choices, around ceilings of care needs to be done with particular sensitivity – here a hospital-based geriatrician shares similar observations:

Plenty of patients and families have different expectations about ceilings of care – some patients and relatives want to try everything. A lot of our non-European patients are like this – I think it's a mix of factors: education, culture and religion (B.Clinician.5).

One particular concern for communities with Jewish and Muslim residents was the ability to secure the timely release of death certificates to allow for immediate burial. Death certificates need to be signed off by a doctor, a process which, particularly if the death falls on a weekend, can be slow and frustratingly bureaucratic. In case study B progress has been made through partnership work with hospital staff, religious leaders and the CCG to enable the process to be streamlined – hospital staff have been made more aware of the religious imperative to get the body released quickly. Doctors have been advised that if they have seen such a patient in the night before they die they should make every effort not to leave the next morning until the death certificate has been issued.

6.1.2 Paid workforce

6.1.2.1 Impact of staffing and workforce pressures

Effective working across relevant sectors and settings relies on having adequate numbers of staff who are appropriately remunerated and supported. The case studies revealed significant issues with both the current and future sustainability of the workforce. The challenges highlighted varied between sector and professional group with a distinction between the registered and unregistered workforce.

Care Sector – untrained workforce

There were very significant concerns voiced as to whether carers, employed to look after those at EOL needing high levels of care, were fit for purpose. The strong consensus, reiterated time and again by all categories of respondent, was that the carer workforce was poorly paid, poorly trained and poorly supported resulting in an unreliable workforce with low morale. Whilst some carers provided high quality, compassionate care the overriding experience highlighted by both patients and relatives was negative, with patients and relatives lamenting a lack of choice and control. Here Mark voices the anger felt by many at the poor status and level of resource assigned to elderly social care.

When my mum's care package went out to tender from continuing health care (CHC) – they just go for the lowest quote. If you did that for a sick child, and they were sending carers who were falling asleep because they are so exhausted – there would be an outcry. But that's fine for the elderly. Its fine if the carer signs something saying they've been there for an hour when they've only been there 10 minutes and they haven't even fed them properly. Nobody really seems to care much about any of this (A.Carer.3).

Despite the stress and anxiety of trying to find suitable support in what appeared to be a flawed system many relatives expressed sympathy with the underlying problems:

... the bottom line is that they're paying them peanuts and not looking after them – what do they expect to get? I think it's a combination of both not valuing them and caring for them – but probably also a personality thing as well – some just don't have the ability to be good carers (A.Carer.7).

In multi-cultural areas there were also challenges in finding carers who were appropriately matched in terms of language, beliefs and cultural preferences. One son describes how he stopped using one particular care agency after two months because the carers provided weren't equipped to provide the care he felt his mother needed:

...it just got too awful. They were bringing people over ... without any effort to help assimilate people to our way of life and culture...they wouldn't know how to make a bit of buttered toast...there was a Greek girl who had no English at all. She was a nice girl but she had to speak into her phone and do Google Translate. You can't do that with someone who is frail and elderly (A.Carer.3).

For relatives being forced to witness the perceived disrespect with which their loved ones were treated could be harrowing:

There was one who didn't even say hi to my mum – there was no engagement at all. I said to her one day it would be nice if you could at least speak to your client (A.Carer.10).

Problems presented by lack of initiative and understanding on the part of paid carers were echoed by other relatives, particularly when it came to looking after people suffering dementia or lacking cognitive capacity. Relatives complained that if someone lacking cognitive capacity said they did not want to eat or wash carers would often take this at face value – not considering that these were everyday necessities that should automatically be carried out.

For those living on their own, the erratic and unreliable timetables carers followed could be frustrating. Here Meriel, an elderly wheelchair user living on her own, having recently returned from a long stay in hospital, shares some of her frustrations:

In the beginning I had carers come in a few times a day. But there didn't seem to be any pattern to it. They'd give me my dinner at 2pm and put me to bed at 6 pm. They just came in at all hours. I couldn't cope with it – I just couldn't stand it anymore. I like my routine. ...there's nothing wrong with the carers – they're just not well trained – you don't know when they're coming and it's all so undignified – imagine having a young girl you don't know helping you in the shower (C.Patient.8).

Perhaps the biggest irritation voiced was the lack of control over who came and the frequent changes in, and turnover of, staff allocated by agencies. A small number of relatives got around this lack of control by managing a Personal Health Budget (PHB), effectively meaning they had more control over the selection and management of carers. The process however is reported to be far from transparent and very few carers were aware of the potential opportunities available. In the first place the carer has to request a PHB which they are subsequently in charge of managing; providing invoices and audits and taking responsibility for performance issues as well as the welfare of the carers. This 'solution' is therefore not for the faint hearted, demanding significant time, skills and motivation. Here a son currently trying to take control of a budget to employ carers talks through some of his anxieties:

I haven't got to that stage yet of knowing how it will turn out. My hope is I will be more in control of the quality and consistency of carers. All that mum has said to me is that she wants to stay at home. Her only real requirement is that 'KIND' people look after her. The problem with the PHB is that you actually have to employ the people... It's not straight forward. And the bit that makes me feel particularly uneasy is that you are responsible for disciplinary issues. At the moment I just have to call the care agency and say 'look that carer is just asleep all night – please deal with it! (A.Carers.3)

Clinical workforce

Problems with recruiting to clinical posts and awareness that gaps in numbers were creating additional pressures across the system, were frequently cited. Notably, CQC reports for case study sites A and B showed that numbers of palliative care consultants working at the hospital and

provision of seven-day services fell below the guidance given in 'Helping to deliver commissioning objectives' (NHS England April 2016).

In other areas, examples were given by managers finding it hard to recruit nurses to a range of new projects due both to the national shortage and particular local difficulties, in part exacerbated by regional differences in incentives. Scales for London Weighting for example vary between inner and outer London (with higher rates being paid in inner London)– though the cut off between the two was seen to be somewhat arbitrary. Here a hospice palliative care consultant explains his concerns about the gaps in the clinical workforce:

I think the biggest challenge faced at the moment is the workforce crisis. We've got unfilled nursing posts across the country. It's worst in North East London– we have 20-25% unfilled nursing posts. The money is there to pay them but there are no staff to fill gaps. Added to this is the fact that inflow of EU staff is decreasing and outflow of staff increasing. We always run a vacancy factor on our in-patient unit. We're making up the gaps with staff doing extra bank shifts and so on – so we've not had to close wards or beds – but it makes it hard to plan new services when you can't even recruit to existing posts (B.Clinician.7).

Significant problems were also experienced in relation to recruitment of community staff and the loss of many district nursing posts over the last decade was particularly felt. Whilst some areas were more successful than others at recruiting there was a realisation that given the national shortage, a gain in one area meant a loss somewhere else.

Commissioning workforce

Resource constraints observed to be a barrier to implementing EOLC policy goals in other parts of the system are unremarkably also experienced by commissioners. It is notable that each CCG within the three case study sites allocate different levels of resource to commissioning of EOL services. Whilst all three sites had a commissioner directly assigned responsibility for EOLC they were allocated different amounts of time to the job with some also being concurrently assigned responsibility for other clinical areas. At the time of fieldwork, CCGs were transitioning from working predominantly at the level of the CCG, to commissioning a range of services at a larger scale through the STPs (see section 3.1)³. Each case study site was based within a different STP footprint,

³ As from April 2020 it is forecast that CCGs will no longer exist as legal entities (ref NHSE).

made up of a slightly different configurations of CCGs, councils and NHS Trust. The varying pace of transformation within each site meant that commissioners were having to find their way around a unique and rapidly changing commissioning environment. Governance arrangements were complex and evolving with little consistency between individual roles. One of the leads (case study A) had at the time of interview in October 2019 just been made responsible for EOLC at the level of the STP as well as local commissioning within the case study CCG.

In case study B, the lead for EOLC was also responsible for winter resilience and capacity planning and whilst they acknowledged that the majority of challenges they face related to older people or those with complex needs, the full remit did not fit neatly under EOLC. Within this CCG there was one GP assigned three clinical sessions per week to EOLC issues.

Case study C had a Director of Quality, Transformation and Planning, responsible for EOLC services, who estimated that she spent just under half her time working on EOLC pathways. However, by the time the field work was drawing to an end this member of staff had left her post which was replaced by a new position; the Deputy Managing Director of the CCG. Due to constant change and flux across CCGs comparing the actual amount of staff resource being allocated to EOLC in the respective sites was challenging.

6.1.2.2 Staff support and remuneration

If the NHS is to robustly tackle the vacancy gaps in its workforce, there was awareness that improved staff care and support need to be an integral part of any workforce strategy. Several staff groups were highlighted as having pronounced support needs in relation to EOLC:

- Community staff, often working on their own, in people's homes.
- Ambulance staff who are known to suffer particularly high levels of stress (Unison 2015). One manager referred to the impact of the relentless and ongoing, frailty and isolation which they see in so many of the patients they are called to (C.Non-Clinical.7).
- Care Home and Nursing home staff may also be affected by the high numbers of deaths amongst patients with whom they have forged close relationships:

Two weeks ago we lost a woman who had significant health needs – she was ringing her bell all the time – she was very dependent and now she's not here and we feel the loss and emptiness (A.Clinician.6).

6.1.2.3 Appropriate levels of training and education to build the necessary skills

Clinical skills

These were believed to be critical to essential care at EOL but were not spontaneously called into question by respondents in the research. It was generally believed that clinical staff had appropriate skills to carry out necessary clinical analysis and treatment.

Communication skills

There was agreement that whilst some people, by nature were more empathetic than others, training in initiating empathetic EOLC conversations could nevertheless enhance skills. A number of examples were cited of communication training courses, often funded through the CCGs. Here a care home manager talks about recent training undertaken by nurses and senior health care assistants:

Our staff are getting better at initiating conversations. We had some training in 'difficult conversations' from the local hospice ...it gave staff confidence to talk about our 'EOL programme' – we try to do this at the point when patients and relatives come to look around – so it doesn't come as such a shock when they arrive (B.Non-Clinical.6).

Yet whilst progress was being made in improving access to education and training many still felt that more could be done to standardise practice.

Listening skills.

For some patients and carers a primary concern was not so much the act of talking – rather the act of being heard. Carers often referred to the fact that although they know the person they are caring for better than anyone, getting a professional to listen and to act on what they say, can be challenging.

Empathy/compassion

When patients were asked about what was important in the care they received, empathy, dignity and compassion came high on the list; yet commissioning to ensure that these traits are firmly embedded in practice remains challenging.

Commissioning skills

Commissioners, who were clearly signalled as being a pivotal group in ensuring that adequate EOLC services were in place, were identified as needing a specific and robust skill set. The ambition of some of those commissioners interviewed was to provide transformational services, rather than simply repeating historical patterns of commissioning. Achieving this requires significant competencies, yet it was suggested that these were not well-defined during recruitment and consequently people came to post with a wide range of skill levels.

Important commissioning skills identified during field work included:

- ***Knowledge of data systems***

Commissioners reported using a wide range of data systems to inform the knowledge gathering process (see appendix 6.1) including needs assessments of local population and outcome data from current services and interventions.

- **Identifying good practice: knowing how to navigate the evidence base**

Identifying good practice, encouraging dissemination and reducing replication were flagged as priorities by both commissioners and service managers. If models which were proven to be effective were not shared and disseminated this was likely to lead to resources being wasted in multiple local attempts to reinvent the wheel.

- **Awareness of factors which impact on quality**

EOL covers a vast array of services, organised in different ways across localities, often following slightly different business models. The task of maintaining clear oversight of the effectiveness of each service and recognising all the hurdles that impede effective provision is significant.

There are a number of national issues impacting on the quality of EOLC (as demonstrated in 6.1) which local commissioners tended to see as being beyond their remit – including for example problems with national recruitment of clinical and non-clinical staff and national training to raise skills levels. However, whilst commissioners did not feel they had the power to solve national workforce issues, or to come up with entirely new evidence based models, they did see it as their role to recognise and respond to issues particular to their locality relating to demographics; including

the age distribution, ethnicity, language, religion and cultural preferences of the local population. Here the EOL CCG lead explains her approach:

I understand our population by every stratification including factors such as ethnic diversity and poverty. I've got maps which show the distribution according to different stratification criteria and variance across boroughs and at local enumeration level. We then have to look at gaps within specific groups for the different religious communities – in this area Muslims are the predominant group ...we have developed a new EOLC champion who looks to assure we meet needs of our population whatever their cultural background (B.Non-Clinical.2).

6.1.2.4 Skills for care home staff

In all three sites measures were in place to bring training and resource for care home staff up to speed with other settings ensuring a more balanced offering across the system.

I've been working with the acute trust and have got a geriatrician who will work with care homes, GP, community rapid response team and community nursing services to begin to wrap an additional layer of care and expertise around our 549 residents who are spread across 7 care homes in CS2 (B.Non-Clinical.2).

6.1.3 Unpaid carers and role of family

The majority of patients, even those living on their own, or those in care homes, have some sort of network of family or friends who influence their choices– and should be pivotal to communication and planning at EOLC. Relatives impact on choices available to patients in a number of ways:

Relatives as enablers of patients remaining at home

For many patients, who may otherwise have had to go into institutional care, it was predominantly spouses or children who enabled them to remain at home. Whilst for most this was done within the confines of a loving relationship and therefore not without its rewards, the stress and burden of the caring role was nonetheless evident. Being a carer took time, energy and mental stamina.

It was evident in some interviews that carers were placed under enormous pressure. In one particularly harrowing interview, Nelema, a 91-year-old woman, originally from India, expresses her helplessness around knowing what to do for the best. Here she describes caring for her 88-year-old sister with advanced dementia:

At night if she tells me something is happening to her – she is anxious and I feel scared – I really feel scared. I just have to ‘salt and pepper her’. I ask her if she wants me to call the doctor – but she doesn’t want that – she says she will be alright and eventually calms down. But by then she’s in my bed – then she wants to get up and go to the toilet – it’s disturbing – I have to get up. If she’s still in her room she puts her light on and I know she will need help – she will be waiting for me to come and put her nappies on. Sometimes she forgets to put her nappies on and then there’s wee all over the bed. If I tell the doctors they can’t do anything. What can they do? What can I do? ... I don’t want to send her to a nursing home or something like that. They’ve got so many of them in a place like that – they can’t do everything for them...(B.Carer.5).

In a number of interviews, with elderly married couples, there was often a blurred line differentiating patient from carer. Joyce, for example, was a 79-year-old woman suffering from haemophilia – and largely bedbound – living with her husband Julian, who although more mobile, was himself suffering from lung cancer and COPD. Julian described how when his wife was last hospitalised he was horrified when staff announced she would shortly be on her way home.

Joyce was still poorly but the doctor said – ‘I’m sending her home’. I said, ‘you’re not’. I said, ‘look at the state of her’. ‘No, no’ I said – I’m not having that. The doctor said, ‘all the treatment that she’s having here she can have at home.’ She said ‘she’ll have district nurses and carers coming in.’ I thought I can do it all myself. But now I just do the basics (cooking, cleaning and my own stuff) and I leave the carers to it. It’s enough (C.Carer.7).

Family as advocates

There were numerous examples cited demonstrating how carers battled to help patients access services and find their way along often disjointed and fragmented system pathways. For those without family to advocate for them, particularly those living at home on their own, it seems likely that they are more likely to be overlooked by service providers. One manager who had worked to support carers for many years explained the importance of knowing what to ask for – accessing services often involves ‘knowing the ropes’ and having a strong advocate to navigate the system:

It’s all about their knowledge and understanding. You need awareness to know what sort of help to ask for...they need to understand that they really need to open up in order to get the services that they need (B.Non-Clinical.12).

Family as decision makers

Several stories were narrated where tensions or conflicts arose, either between relatives or between patients and their relatives, which impacted on subsequent treatment, sometimes going against the wishes of patients.

Here a PC nurse who now works as a network coordinator, charged with reducing avoidable hospital admissions, recounts the story of one of her patients; a lady suffering metastatic cancer. The lady, described as 'the matriarch of her family' wanted to continue to hold court, 'sipping wine' in her front room with family and friends, for as long as she was able.

And so the GP, myself and all members of the team – supported each other to make it happen — even though her health varied from day to day – there were days when she was more sleepy and poorly, or she would get an infection, but it was ticking along nicely and we were able to keep her out of hospital – until a family member living abroad came over. They hadn't seen her for years and were alarmed by how much she had changed. She was a very dominant relative and she called the ambulance and even though the ambulance crew could see there was a CMC in place they were somehow overruled by the relative (A.Clinician.2).

The professional involved explained how on discovering her client had been taken into hospital she had immediately gone to see her:

The memory will never leave me. Honestly. She was a tiny thin lady and she was sat up just begging me to take her home. She was cold, so I wrapped her up in that old-fashioned way with something round her head – then I laid her down and I promised her that I'd do everything to get her out of hospital. But she died there, and she really hated it! That's the kind of thing that happens a lot. Even when they have a plan there are things that can happen to subvert it at the last moment (A.Clinician.2).

It was not unusual for those at EOL to appear more accepting of their prognosis than their relatives who they claimed found it harder to discuss their dying. One patient, Enid spoke about her wish to die in hospice, rather than hospital but admitted that whilst she had tried to talk about it with her sons, she had found it hard.

I've got no fears talking about it – it's better out. If nobody knows what you want you're not going to get what you want. But my children – no – they don't want to contemplate it (B.Patient.3).

6.1.4 Levers and incentives: how are standards for quality of EOLC services enforced?

Respondents mentioned a number of mechanisms which proved useful levers in helping to achieve required standards:

6.1.4.1 CQC inspections

The fact that since 2016 CQC have inspected for EOLC was welcomed. Examples were cited where aspects of care had been highlighted in a CQC report as requiring improvement which in turn had supported a drive for enhanced funding:

There are national drivers - mainly it comes through CQC – it's very helpful that they now inspect for EOLC. So we are led by CQC reports as well as NICE guidance, the national audit of care at EOLC – these all lead to direct feedback and ongoing change. Our last CQC report showed that we were understaffed and so that supported the business case to build our staff base (B.Clinician.2).

6.1.4.2 NICE guidelines

Nice guidance was used as a marker; setting standards for good practice – though as this respondent suggests the extent to which national guidance was used was inconsistent:

I look at NICE guidelines for EOLC and various bits of legislation that dictate different things. I would expect all commissioners to be able to undertake this. However, commissioners come from very different backgrounds and how well they all achieve this is questionable (B.Non-Clinical.4).

6.1.4.3 Commissioning for Quality and Innovation, Quality Outcome Frameworks and Local Enhanced Services

Primary care and community providers were incentivised to provide interventions believed to result in enhanced EOLC. Examples given included:

1. extra payments to complete Coordinate My Care plans
2. extra training for social care staff
3. workshops for multi-disciplinary teams
4. enhanced monitoring of specific KPIs in care home residents, such as of residents on high numbers of medications or those without ACPs.

6.1.4.4 Targets and benchmarking

A couple of commissioners mentioned using data on the NEOLCIN website to review performance against local comparators. Using aspirational targets to set a goal was seen to be helpful, though one manager observed that in cases where there were punitive consequences of not achieving targets, this could lead localities into a downward spiral. In some cases the penalties which were incurred could exacerbate an already overstretched system, creating something of a catch 22:

The problem is sometimes that some of the reasons we don't achieve certain targets well, is that there are things that need more money to improve – and simply taking away money as a penalty just makes this worse. For example we know 24/7 medication is an issue in our borough, we know the community nursing offer is an issue – but we also know that we are strapped for cash and we can't provide enhanced services (B.Non-Clinical.4).

In some of the more diverse localities cultural, social or religious norms may not align with profiles and measures determined by national aggregates. KPIs for example, used as a measure of quality nationally, may not be culturally appropriate for particular communities. An example of this was the KPI encouraging reduction of deaths in hospital, when for particular ethnic groups hospital was the preferred place of death.

It's hard if CQC are looking at numbers of DNARs or CMC Plans as a quality marker – yet if it seems inappropriate to persist – because of religious or cultural preference – then this has to be taken into account (B.Non-Clinical.6).

Another issue highlighted related to the difficulty of identifying measures to reflect some of the 'softer' outcomes prioritised by patients (see 6.1.2.3). One hospice manager stressed the importance of improving the collection of patient experience perhaps using relatives as a proxy and suggested reviewing suitable KPIs.

6.1.4.5 Mandatory guidance on models for service provision

Mandating for greater consistency of both service provision and outcome was an area mentioned as needing attention. The example, discussed later in this chapter (6.2.1.6) of numerous EpaCs creating issues around data transferability, was a case in point:

The one piece of advice I would give people is that if you are creating policy which needs to extend over large areas, covering different systems, such as London the only way you can ensure that you have buy in is to mandate for it. The current problem is that it's not mandated – so people do their own thing (C.Non-Clinical.1).

6.1.4.6 Non-statutory monitoring of standards

In case study A a pooled budget (local authority and health) was used to fund the team overseeing care home governance and support. Jointly funded posts monitored the quality of care-home provision across the locality. The following insight from a member of this team demonstrates how information which contributes to raising standards is sought from both formal and informal channels:

Well CQC of course inspect. But everyone else who enters that care home, clinicians, managers, staff, relatives – they are all the eyes and ears. Regulation must be more than just ticking a row of boxes – it's really around a whole range of individuals feeding back (A.Non-Clinical.5).

6.1.5 Exploration of policy

Ambitions for Palliative and EOLC Care (NPELCP 2015) lays out six goals for achieving more consistent EOLC (individualised care, fair access, maximise comfort, coordinate care, staff are prepared to care and community involvement) and a range of building blocks, detailing a long list of contextual mechanisms, that need to be in place in order for these ambitions to be achieved. To interrogate how the priorities of stakeholders interviewed aligned with policy ambitions I carried out a thematic analysis by stakeholder group. Using NVivo, after coding all 96 interviews across the three case study sites, I looked at patterns across the most commonly repeated themes in each of the semi-structured interviews. Table 36 presents the dominant themes which emerged from this analysis.

Table 36 Dominant interview themes emerging in case study by stakeholder group

Patients	Carers	Commissioner/Manager	Clinicians
Patient centred compassionate care; being treated with humanity and dignity	Securing the best care for their relative particularly relating to management of paid carers	Ways of assessing needs	Coordination of care
Being listened to	Being listened to	Prioritising services and addressing gaps	Prevention of admission to acute
Maintaining independence for as long as possible	The burden of responsibility and tensions emerging when they have different priorities to patient	Communication and care planning	Responding to patient choice
Ease of access to services (both health and social care)		Resource constraints, prioritising and value for money	Flexibility and support across sectors and settings
Achieving consistent relationships	Negotiating care across a fragmented system	Flexibility and support across sectors and settings	Communication and care planning
Reducing isolation	Resource constraints	IT systems	Staff support and training – addressing gaps in the workforce
		Workforce planning	

Comparing the interview themes, presented in table 36, with the articulated policy goals (NPELCP 2015) reveals no significant areas of disagreement – giving some level of reassurance of policy acceptability. However, detailed analysis of stakeholder accounts highlights a number of tensions between policy and reported practice.

6.1.5.1 Does policy contain sufficient operational guidance?

The most significant overlap between policy and stakeholder accounts focusses on direct experiences of care i.e. the issues raised most commonly by patients. The way in which these desired EOLC experiences can be achieved (how aspirations can be turned into reality) was more the concern of those responsible for providing the care, and whilst policy documents provide guidance on what needs to be in place to achieve the policy goals, the extent to which information and support provided meets with the needs of those ultimately responsible for commissioning – was called into question. A number of suggestions were given by respondents regarding areas where greater support could be given including:

- guidance and support to commissioners in assessing local needs and accessing appropriate local/national data
- provision of suggested minimum standards or guidance relating to preferred type of service model with some level of mandatory enforcement e.g. specialist palliative overnight services.

6.1.5.2 Professional views on policy

The theoretical importance of policy was routinely taken as a given, with a couple of respondents invoking the Ottawa Charter's approach to public health which is built on five pillars:

- Personal education
- Supportive environment
- Community action
- Reorientation of health services
- Healthy public policy

The value of policy, one palliative care consultant explained, lay in helping people through changing the environment they are in, rather than changing people themselves.

A bit like some of the radical disability literature – people don't need to get up and walk – we just need to make doors that people can get through. So, there are a number of different narratives – but according to the Ottawa charter you need to start at the bottom with grass roots stuff – at the same time as working from the top with high level policy stuff. It absolutely works both ways (A.Clinician.8).

Another area of dissonance between prescribed policy and the lived experience of clinicians is the observation that patients are liable to change their mind as their circumstances and condition change. Yet the system can lack the flexibility to countenance that such a change in heart may be a positive choice, made in the patient's best interest. Dying in hospital, according to some, is seen as a failure, particularly for patients who may have indicated different intentions in their ACP.

In my head, the real pressure at the moment, from CCGs – is if you don't die at home – or wherever you say was your preferred place six months before you die, then you are seen as failing. But from my point of view if that individual calls an ambulance and gets admitted without saying 'I want to go home' – then what we should read from that is that they've changed their mind... (B.Non-Clinical.8).

The danger, it appeared was that once the policy had been articulated – it did not allow for the nuance of individual circumstances – a view supported by another senior clinician:

It feels sometimes like if we ask people where they want to die – and they don't give the system's preferred choice, which is home, we just go back time and again until they give us the right answer (A.Clinician.1).

6.1.5.3 Is policy coherent?

EOL policy was recognised to be just one policy in an already 'crowded environment' – meaning that it can be difficult to find the levers necessary to enact policy.

There are too many programmes screaming for prioritisation and managers move on. There is so much change both on the front line and from managers (B.Non-Clinical.1).

Given the broad landscape of EOLC and the fact that it is delivered across a mix of statutory (NHS services) voluntary and charitable organisations, it is hard for all levels of stakeholder to have a clear overview of how all the parts (both in terms of policy and practice) fit coherently together.

As was seen in chapter 3.4, English EOLC policy has evolved in a piecemeal fashion over the last two decades. Whilst 'Ambitions for EOLC and palliative care' (NPELCP 2015) was listed as the key working document used to guide and reference good practice – there was no real sense that either EOLC itself, or the policy guidance to support it, was easy to explicate. This lack of 'coherence' was evident in relation to how stakeholders found it hard to see their way through the system – often not knowing who to contact or how to achieve the 'seamless' service promised by the policy makers. This presented challenges both for service providers and service users:

EOLC cuts across traditional boundaries. It's not exclusively an acute or community problem – patients don't respect those commissioning or professional boundaries – that is a problem because it's hard to work with. Many patients end up in wards when they should be somewhere else. Many would be better off in a hospice, a care home or supported back at home – but it's hard – that's not to say it doesn't happen – sometimes it happens very effectively – but it could be easier (B.Clinician.1).

Coherence of the policy itself in terms of how easily it translates into a practical working document concerns only the small number of commissioners and clinicians who work to ostensibly enact policy. At this level the support offered by the pan London Clinical EOL Network was welcomed. The role of this group was to provide strategic leadership and expert clinical support to commissioners and providers across London. In each of the case study sites there was clear evidence, gleaned through interviews and observation of EOLC forums that there was an understanding of the key components of EOL policy and that 'The Ambitions Framework' NPELCP (2015) was used to plan services and review progress.

Understanding and application of policy by professionals was closely related to position and level of seniority with staff in management positions actively using and referring to policy. For staff on the front line the drive was to deliver high quality care rather than enact a policy of which they were generally unaware.

Clinical priorities and the articulated policy direction necessary to achieve such priorities need to be backed both with a firm financial base and governance and infrastructure arrangements enabling policy to be enacted. In the political climate of 2018/19, with the backdrop of a decade of austerity and three years of Brexit paralysis, the level of useful debate on political priorities around EOLC was seen to be losing some of the momentum it had at the turn of the 21st century. A couple of respondents who were involved in current EOLC policy referred to the Five Year Forward Plan and the fact that although there was mention of EOLC within it – it was given less mandatory leverage, in terms of targets, than other clinical areas.

In cases study C we have a good team who are well established. But local realities of delivering national policy relies on service provision and skills which are often not in place. They rely on budgets that are out of my control and contracts which I don't have direct leverage over (C.Non-Clinical.6).

The link between effective service delivery and joined up system level work was mentioned frequently – yet with stringent cuts to social care over the last decade it was clear that the ramifications of this were being felt across different pathways. System and infrastructure issues are explored in more detail (see section 6.1.6). Whilst it is the logistical and operational issues which impact on the way care is delivered – political will is needed to change the structural mechanisms determining the governance behind health and social care systems, something explored in more depth in chapter seven.

Some respondents suggested that certain aspects of policy and strategy may more easily garner financial backing than others. Education of the public around EOL and promotion of more open, timely conversations about EOL wishes were felt to be one of the areas not given the kind of priority that clinical practice was:

Even though raising public awareness is clearly written in strategies – CCGs just don't seem to be able to come up with the money. Improving choice, public awareness and communication are all seen to be essential in the latest policy guidance – but this doesn't produce funding. The funding is all earmarked according to historical spending into acute or community (A.ServiceManager.4).

Work force issues, particularly current difficulties of recruitment (see 6.1.2) are pertinent in relation to being able to fulfil national policy and although local actions can address these issues to an extent – gaps in workforce numbers are largely the remit of national policy.

6.1.5.4 Where patient choice does not fit with policy

National policies are developed based on the assumption that they will benefit the majority of the population. Within this broad-brush approach there will be a minority whose stated choices cannot be met by policy directives. At its most extreme this was illustrated by a small number of patients who suggested that they would like to be supported to find a way to end their life. Gary, for example was a 77 year old who I spoke to in the care home where he lived. He lay on a bed, frail and emaciated, his breathing was raspy and laboured and caused him anxiety. As we talked every now and then he repeated the refrain that he'd had enough:

What I really want now – is to end the lot – somewhere quiet – do you know how I could do it? I want to end the lot. I want peace and quiet. Do you know how to do it? (B.Patient.4)

And Brian, aged 97, who was too frail to spend much time out of bed but was considering whether he should get out his three wheeled stroller and do a bit more exercise along the corridor outside his room. He explained his dilemma was that he wanted to keep active - to enjoy the life he was living - but felt he'd lived long enough and did not want to exercise if it meant his life would be prolonged:

I don't want to exercise for the sake of it– as it were – becoming a hundred. I want to exercise only so that I can enjoy being alive (A.Patient.3).

Such comments shine a spotlight on the huge ethical dilemma involved in EOL choices and highlight some of the complexity relating to the agenda promoting improved patient choice.

6.1.5.5 Loss of faith in promises made by policy

It was evident, across all case study sites that whilst many practical and effective examples of the application of policy were cited, its value was lessened when those charged with implementing policy grew mistrustful of the offer being made or did not believe the policy would benefit the patient. Scarcity of resource was often a contributory factor, and if clinicians worried about an insufficiency of resource in the system, they became disengaged, worrying that policies appeared to promote false promises. One GP, for example, reflecting on challenges around early identification of the frail elderly, indicated that there may, in some cases, be a reluctance to use existing tools to identify vulnerable members of the population – particularly if there was a belief that there was not adequate support to provide appropriate follow up.

Anxieties were voiced about home deaths when considered alongside the reality of available community support. A number of clinicians cited instances when they had been reluctant to release patients home due to worry about the adequacy of home care packages. In a similar vein, a hospital geriatrician, lamented the fact that when discussing care plans with patients and asking about preferred place of death, she had become increasingly aware of what she saw as an 'exaggerated' view of PC services available in the community.

I think there is an issue around being realistic about what faces a patient who wants to die at home and what we envisage happening from our positions inside the hospital – i.e. the delivery of community PC to people's homes is extremely different to the reality that people experience and I think we need to be open and honest about what people get. I think we sell a vision of a 'great service' – which is quite different from what people actually receive and experience. And the result of that is

that you begin to lose confidence in that aspiration to help to get people 'out' to die at home (A.Clinician.11).

There was also cynicism voiced, that policies may be developed more with an eye on financial savings rather than concern to enhance patient experience. The debate around 'Dying in Preferred Place' - is a case in point. Some professionals felt under pressure to persuade patients to opt for dying at home - not necessarily because this would be their preferred choice - but because the level of required state resource is generally lower. Another area where there was a degree of dissonance was the drive towards ACPs. Although it is increasingly assumed that better communication around patient preferences at EOL will improve patient experience, there were a number of clinicians, and indeed patients, for whom this did not appear to be the case. In more ethnically diverse sites there was a suggestion that cultural and religious preference were often a key factor in choices made.

Some of the patients just don't want to do them. There is a bit of a myth. There are a lot of patients particularly in {CS2} who because of religious beliefs think that death is Allah's job and that he will choose when it comes. Thank you very much. And he will deal with the how and the why (B.Non-Clinical.8).

And whilst some patients suggested that sharing details of their dying preferences was reassuring, there were a significant number who found the notion of their own dying too brutal to contemplate.

6.1.6 Service organisation and integration

6.1.6.1 Low status of social care sector needs to be addressed

Numerous examples were cited to support the contention that clinical care was prioritised over relational care - reflected in the low pay and poor status of social care workers and by perceptions of staff in care homes and nursing homes, that they were seen as the 'poor cousin of acute and primary care'. Although care home residents often have complex social and medical needs, they do not fall under NHS governance systems and for this reason have, over the years, fallen behind in terms of benefitting from routine support and training. One care home manager articulated the challenges faced in fighting to raise the quality and standards of what she saw as a pivotal, but largely undervalued, service:

Too often people in social care are seen as second-class citizens to those who work in the NHS. It's our responsibility – as part of this world – to begin to change that. In hospitals – when they are very stretched it's understood that results in poor care – but people don't seem to be so understanding of

care homes...why are the staff in a care home different from the staff in hospital – or are they just given a lower value? (A.Non-Clinical.2)

Respondents cited instances where clinical outcomes appear to be prioritised over quality of life; demonstrated in the account given by this disabled son of the response to his mother falling in the ‘extra-care social housing’ residence where she lives. The policy in the home is that carers should not do any heavy lifting and the son, who is disabled, does not have enough mobility to do it on his own. On occasions when his mother falls therefore the ambulance service has to be called however if she not badly injured the call is not prioritised, meaning that she can be left for a number of hours on the floor.

It’s happened so many times and if it happens on a Friday or Saturday night she can be there a long time. Everything is about health and safety so people no longer work on their own intuition. It stops people wanting to do the right thing. I can’t express it strongly enough what a big issue it is. On other occasions she’s fallen and maybe the ‘right kind of carer’ is around - and together we have managed to get her back onto that chair and there’s not been a mark or scratch on her. And we’ve avoided calling the ambulance out (A.Carers.4).

6.1.6.2 Flexible integrated working with alignment of health and social care

There was strong rhetoric, particularly from commissioners and service managers, about joined up working and a clearly stated aspiration to continue to focus on ways of bringing about a seamless patient pathway. For a number of clinicians, familiar with the local system, establishing better partnership and joined up working, was cited as their key priority:

If my mother needed EOLC the one thing I would want is to ensure that the people looking after her were connected to and understand the different bits of the system (B.Carers.5).

The ACP (described in more detail in section 6.2.6) in case study C was an interesting example of how budgets and resources could be pooled to create broad system benefits:

For example, if our community trust doesn’t have enough staff on for 24/7 service provision they can call on one of the partners to see if they can help fill gaps. That’s when joined up work gets interesting it prevents things falling apart – makes everything more flexible and resilient (C.Non-Clinical.6).

In case study A where integrated working across the LA and CCG has been embedded over the last few years, a number of innovative examples of joined up practice have emerged. One example was a project focussed on care home management and quality, jointly funded by the CCG and the LA. They work with the specific aim to reduce avoidable hospital admissions and follow key aspects of the model espoused by the 'Bringing Enhanced Health into Care Homes' vanguard.

There were also a small number of examples of jointly commissioned projects, such as a user group in case study A, jointly funded by the LA. The group created an open forum and information exchange between service users and providers, where users are co-producers in setting the EOLC agenda. Also, in CS1 was a progressive pioneer project referred to as the 'Integrated Network Coordination Service'. The MDT, which is CCG funded, works across a number of trusts in this very diverse, deprived area. Services are wrapped around the GP who makes most of the referrals. The service picks up the most vulnerable elderly patients with a focus on patients where standard pathways have failed. It was emphasised that given the vulnerability of the particular patient group in this project sensitivity needed to be shown in measuring project success since standard KPIs may not be appropriate (A.Clinician.2). One example of what was deemed to be a success story resulting from good partnership working is narrated in table 37:

Table 37 **How partnership working can help bring about patient wishes**

Charlotte

I had dealings with Charlotte over a 2 year period. She was 94 when she died. She suffered dementia and severe short-term memory problems. She was on a very short loop. When you were talking to her – she would take out her fags – and say ‘I’ve only got two left. Then she’d take one out of the packet, put it back and repeat the conversation. ‘I’ve only got two left’...that was the sort of loop she was on. In the beginning, when I first met her, she chain-smoked.

One of the first things the doctor asked me to do when I started seeing her was to talk to her about what her preferences were, what she wanted when things got worse. And at that early point – even though she was ‘on a loop’ – she was able to give a good account of what she wanted. She lived alone in a ground floor flat and she could do what she wanted. She could go shopping, go to the doctor, feed her cat and the pigeons – that’s what she wanted to do. But also, in her lucid times we were able to understand, quite clearly, that if she got sick, she wanted to go to hospital.

A couple of months before she died, she was taken to hospital with vomiting. She had a bowel obstruction from a primary carcinoma of the bowel - so she was treated conservatively and then sent home – knowing that she would die. When she got back from hospital the doctor asked me to visit her and I had a conversation with her – she would say ‘darling, something is wrong’ – and she would touch her tummy. I’d ask, ‘if it starts to hurt – what do you want to do’ – and she would say ‘darling, must go to hospital’.

At the end – the last time I saw her she had a new kitten – there were four cats under the bed – and she was aware enough to know that was a problem. She said ‘don’t touch the kittens’ to me because she knew that I would anticipate this as being a problem! She was trying to encourage me not to look at them!

We had the conversation about going to hospital and I wrote to the social worker to remind them that if she started vomiting again the carers needed to get her into hospital. Sure enough, within another week this is what happened, and she died pretty quickly which is exactly what she wanted. I think everyone involved deserved to be congratulated for that – we got it right! There was a lot of courage needed by all the professionals involved to enable her to stay in her own home. It was brave of them. It could have ended up with us all at the coroner’s court with them questioning our decisions. But you have to do what you feel is right.

Source: A.Clnician.2

However, across the three case study sites, whilst examples of good practice were cited, no magic bullet was offered as to how best to achieve flexible, integrated working. Indeed, there was a high degree of realism as to the challenges involved. Respondents were mindful of the huge complexity involved in systems, organisations and individuals struggling to work in unison and communicate well. Here an academic talks of her experiences evaluating integrated care in case study B.

There is a gap between rhetoric and what actually happens...I attended lots of CCG meetings with a range of stakeholders from local trusts, social care etc. Irrespective of different levels of integration at management level, on the ground there was no difference – there was exactly the same dynamic –

which meant staff felt even more frustrated that there was the same level of dysfunction. Particularly when they felt like champions, being part of the vanguard – yet in my opinion, based on what I saw it made no difference (B.Non-Clinical.1).

The frustrations of organisations purporting to do one thing, yet front line staff experiencing something quite different were manifest:

Everyone on the ground wants to work together – they're desperate to know who to talk to on the other side but they can't – they don't know how or who to approach (B.Non-Clinical.1).

Another frustration raised was that in both large scale or small integrated projects the pace of change and progress was determined by the slowest part of the system – this was the case both at STP level where the financial position of member CCGs impacted on system wide decisions – as well as in much smaller schemes where various members of the partnership may have differing resource capabilities or opposing views on how to progress project direction.

EOLC has been very much embedded in the STP planning strategy.... Across the 5 boroughs the interesting thing is that our CCG and one other have put the money in to back it – but the other boroughs who are in financial dire straits are finding it hard to join us. So the work is stalling – particularly in terms of achieving something really innovative and systematic (A.Clinician.7).

Flexible staff showing initiative as key enabler

Service fragmentation and flexibility of working patterns were mentioned frequently, both as a facilitator of good quality service provision (in cases where flexibility was demonstrated) and as an obstruction (in instances where systems were seen to be siloed and intransigent). In terms of patient and carer experience, fragmentation and lack of signposting as to how to navigate themselves or their relatives along different pathways, impacts on their perceptions of care and the acceptability of current provision:

I think particularly when people get elderly there is a big overlap between physical health, mental health and social care needs. They need to be more joined up by a geriatric specialist (A.Carer.3.)

Ironically, as this manager notes, fragmentation of the system means that from a patient perspective it grows harder both to access services and to be released home once you are 'signed in':

We have fewer gates to direct people in but more gatekeepers; thresholds, criteria, ways of keeping people both in and out of services. It's hard for patients to get in and then hard to escape once they're in. The EOLC world is dominated by needs and risks and costs (B.Non-Clinical.10).

In an effort to help staff understand how one area of work may impact on and work with another the EOLC clinical lead in CS2 was in the process of trying to appoint EOLC champions across different settings. These champions would be located in community, acute trusts and social care and their function would be to highlight issues within their sphere which were likely to impact on EOLC services. The commissioner responsible for social care in this area explained how an EOLC champion may revisit social care plans:

When you are considering someone who is dying you should look at more than their clinical needs – you need to look at social needs too. ...I wanted to enable this and I felt there were a number of changes this would involve from a social care perspective including the training and breadth of understanding of our social workers. That would mean back office stuff being changed (B.Non-Clinical.4).

Pooled Budgets

Issues relating to organisational ownership and management of funds were touched on by a number of clinicians and commissioners. Whilst it was acknowledged that pooled budgets may facilitate more integrated care, perhaps more important than the location of the budget, was the governance system supporting joined up working.

I think perhaps we oversimplify things – by suggesting for example that the cure to everything is to pool budgets when in fact this blatantly isn't the case. You can't put everyone together into a big building that's 55 stories tall and expect it to resolve all your problems (C.Non-Clinical.10).

The Better Care Fund (BCF) (see section 6.1.4.4), a programme spanning both the NHS and local government was mentioned as a vehicle which seeks to join-up health and care services.

6.1.6.3 Information and data that can be shared across settings

One of the most common frustrations voiced, related to there being no one standard IT system in use across NHS providers. Systems used in one setting tend not to be transferable to another setting, meaning that if the patient is transferred or moves to another location along the pathway their data

often becomes inaccessible. The frustration was summed up succinctly by this hospital-based consultant:

Acute services use one system, GPs another, care homes another. At the moment we have all sorts of discussions in hospital – which a junior doctor then reduces to three words on discharge which is then buried in a GP record – and when the community nurse comes to visit them they don't have access to any of it. An IT system which could be used across different settings would make a big difference (B.Clinical.6).

And echoed by this hospice-based clinician:

None of systems talk to each other. The district nurses use 'System One' the community nurses use Coordinate My Care, someone else uses EMIS, we have everything on 'charity log' – nothing joins up or talks to one another. Nothing (C.Clinical.2).

Electronic Palliative Care Coordination Systems (EPaCCS)

Electronic Palliative Care Coordination Systems (EPaCCS) are used nationally to record patient's wishes in the last year of life (see section 2.2.2.1.4) and present one of the most cumbersome national challenges. Whilst there is agreement about the value of adopting a consistent approach to recording these wishes, the case studies reveal a system which was poorly aligned often leading to valuable data being lost or inaccessible as patients crossed between areas/settings/organisations. In London there is one coordinated EPaCCS in the form of Coordinate my Care (CMC). CMC was launched in August 2010 to deliver integrated, coordinated medical care, built around each patient's personal wishes. Effectively CMC involves an urgent care plan, created jointly by the patient and their health care professional, including wishes and care preferences as well as practical information. Yet, whilst the premise of CMC, that information gathered in this way should help to inform everyone working with the patient, appears indisputably sound, the reality, due to glitches in the transferability of the IT used to create the plan, is often fraught. A number of concerns specific to CMC were mentioned:

- Although some organisations were able to transfer CMC data this was not true across the board and there were worries relating to how data was kept updated and the degree to which the local system was incentivised to keep records active.

- For those living in areas that were on the boundaries of inner and outer London they may have an EPaCCS that could be read in the area where they were registered with a GP – but if the local hospital to which they were transported was in a different CCG or LA, it was likely that the data on the CMC plan would not be transferable.
- Until recently ambulance crews struggled to access information held on a patients CMC. The recent provision of iPads to ambulance crews and a system for flagging the existence of a CMC plan was positive, despite ongoing issues interfering with smooth implementation. In the absence of formal records ambulance crews described situations where they found themselves looking for contextual information such as the presence of hospital beds or anticipatory medications to indicate that patients may be EOL:

We don't always have access to their records and if there is no CMC record – then we have to work out whether or not the patient is EOLC and determine what the best steps are. A lot of patients have anticipatory drugs at home which we can give – but if the paperwork isn't there we can be nervous about giving these (B.Clinical.9).

- Those connected with the care homes experienced frustration around lack of interoperability of data between NHS and non-NHS settings. One care home manager related the frustration of creating care plans which are only of value if the patient remains in the care home:

At the moment if we have a DNAR here which has been signed by the GP – I don't know if that document is relevant once the patient gets transferred to hospital. Or what happens if that patient (with the DNAR) then falls and breaks their leg and gets transferred to hospital – then if their heart stops on the way to hospital – the LAS crew will probably have to resuscitate (B.Non-Clinical.6).

- To provide back up for instances where electronic CMC records cannot be accessed an initiative called 'ReSPECT' was used in some areas. The idea behind this is that it combines resuscitation decision making with treatment escalation plans – in what was intended to be an easily transferable paper-based format. ReSPECT was seen to be a 'backstop' until such a time when electronic data could be more relied upon. Yet tensions were evident in the EOLC forum meeting attended (*Case Study 3 21.11.2018*) with staff suggesting that challenges persisted; both in relation to some patients finding

themselves in an ambulance without the back up of either system and that maintaining two systems: one paper, one electronic, was unnecessarily cumbersome.

Despite ongoing concerns with CMC there was unanimous agreement that London benefitted from having one of the only consolidated EpaCCS used across the county. Other areas are not so fortunate and whilst robust data on EpaCCS is hard to come by one participant at an EOLC forum meeting in Case Study 3 suggested that there were something in the region of 86 different EpaCCS used across the UK. The result, according to this hospital consultant was: wasted resource; constant reinvention of the wheel; clunky, fragmented systems of information sharing and poorer patient outcomes.

EPaCs seem to me to be the most significant demonstration of lack of joined up thinking. Why does this all have to be so local? (C.Clinican.6)

Data requirements for commissioning; identifying an evidence base

The three case studies revealed manifest differences in service types, employing different numbers of staff, from varying levels of seniority in distinct compositions of professional groups. The evidence base that commissioners can access therefore often does not match the details of locally commissioned projects. The comments from this commissioner reveal some of these issues and how business models have to adapt to local constraints - meaning that replicating tried and tested models between localities is often problematic:

The finance director wants to make sure that everything is gold standard ...she wanted us to put as many nurses as we could in these posts – she advised against one nurse and one HCA since she felt this would make things more sustainable if one of the nurses calls in sick. Actually when we came to recruit this meant that it was less workable as a business model than we had hoped – firstly because of national shortage of nurses – but also because nature of work means that if you have two nurses in a home the structure of delegating isn't so clear... (C.Non-Clinical.4).

In instances where guidance was given as to safe staffing numbers or specific commissioning guidance from bodies such as the Pan-London End of Life Clinical Network, it was welcomed and some suggested that clearer guidance would be welcomed around achieving minimum standards and how to ensure that new contracts clearly reflect what needs to be in place in order for these standards to be met.

The gathering of appropriate data was recognised as being a key step to putting effective services in

place and whilst not an end in itself, it contributed to the building of business plans which were used to advocate for identified services. Commissioners from Case Study 3 had put significant resource into costing and justifying their newly appointed SPA PONS service; assessing potential savings the service would contribute in relation to reduction of inappropriate acute admissions.

As IT systems and interoperability improves it is hoped data collection will grow easier. Currently, whilst viewed as important, it was also recognised to be a significant drain on resource. Here a commissioner provides insight into the level of detail required when assessing local need:

When I started to look at EOLC – I needed to understand what was being spent where and how – and I found that out – I know exactly what’s spent in the community and in primary care...I know what’s spent in the acute trusts here and elsewhere. I know how long people spend in care and exactly how many people died over the age of 55 in 2017/18 in the acute sector and what they died of. I know what our death rates have been for the last 10 years and I know what they’re going to look like in 10 years’ time – and based on all that data I already know there’s a sizeable gap between service and need...I try to be evidence based in everything I do (B.Non-Clinical.2).

At the end of the day, working out how much is spent on each of the key services is not a precise art and ‘disaggregation of costs’ into specific clinical areas or population based groups can only ever provide ‘ball park’ figures – the challenge is to arrive at a figure that was ‘good enough’. Only once armed with this knowledge can commissioners and managers begin to determine how services need to be distributed across the different parts of the system (community, primary, acute) and where there are gaps that may need plugging.

Long term service transformation is frequently about building greater support and firmer foundations in the community – both through more robust primary and community care, as well as voluntary projects focussing on engaging civil society in community development and volunteering – based on the assumption that such practices save resources spent on acute care.

I put together a business case that proposed if we invested x amount downstream this should translate into larger savings in the acute sector. Commissioners need to be savvy to the relationship between community resource and the way it impacts on non-elective care in acute (B.Non-Clinical.2).

Some measures/data are easier to collect than others

Challenges around some types of data being easier to collect than others were touched on in section 6.1.4.4. and those working in community development reinforce this message. One project, referred to as ‘compassionate communities’, currently being evaluated by Nesta, has faced ongoing hurdles in its roll out as one palliative care consultant explains:

One of the big problems faced is that when we were trying to get funding to support this work – funders were proposing that unrealistic KPIs be met to demonstrate effectiveness in relation to a matched sample of ‘patients’. But we wanted to work with communities – so we couldn’t satisfy funders by calling them ‘patients’ – they weren’t patients! It takes a while to build up community knowledge. It’s not like a clear cut service where we can say x number of people will access this intervention each week over a course of time. It’s about building a resource (A.Clinician.8).

One clinician mentioned the importance of further research to develop tools which would help measure outcomes important to patients. The Outcome Assessment and Complexity Collaborative (OACC) (Witt et al. 2018) suite of measures were referred to as an example of an attempt to improve measuring of the key domains of palliative care: stages of illness; the patient’s functioning; symptoms and other important concerns and the impact palliative care services are having on the patient’s and family’s (unpaid caregivers) quality of life. However, valid measures which accurately reflect patient experience of care remain largely illusive (Fernstrom et al. 2016).

6.1.6.4 Services need adequate resources

Resource pressures were evident at all stages in the patient pathway with all three CCGs facing varying scales of deficit. The resulting landscape was fraught with tensions:

Everyone is begging for whatever crumbs of money they can access. I think it’s a really schizophrenic set of disincentives and incentives that are driving the system – the vision of what should be done doesn’t actually take account of the capacity on the ground (B.Non-Clinical.1, Academic).

Cuts in social care were often cited as were the knock-on effects that one system has on the other. The fact that age adjusted spending per capita on social care has fallen by 12% since 2010/11 (Charlesworth 2019) has not gone unnoticed though some boroughs have been more able to absorb funding cuts than others – with those in deprived areas perhaps feeling more of the impact than others.

There was acknowledgement that given the scale of the challenge to the NHS in dealing with the growing proportion of the population, living for longer with increased co-morbidities, ownership of the problem needed to extend further than a small number of specialised health professionals, and encompass instead a larger sweep of civic society. Schemes were mentioned involving volunteers to provide a range of support and nurturing for those at EOL. Hospices, which tend to get the majority of their funding from the charitable sector, are not bound in the same way as the NHS by statutory guidelines regarding service provision, but nonetheless are suffering from the growing clamour for their services and rising costs and this was mentioned by patients who were struggling to get the desired level of care.

The pragmatic approach, to delivering the best possible service within available budgetary constraint was both consciously and unconsciously evident within the professional narrative around service delivery. Whilst the impact of cuts on the quality of clinical treatment was generally not called into question, more likely to be mentioned as suffering from resource constraints was the relational side of care and the time that both health care professionals and carers were able to spend just being with and talking to patients. A lack of time to have important discussions with patients around what patients wanted at EOL was highlighted by this senior clinician:

There's not enough time in acute settings to spend the time needed to tell the patient and their families that they are dying – it often needs to be done over the course of more than one conversation – over more than one day (A.Clinician.1).

Ease of access to services and availability of resource is perhaps harder to identify in the community than it is in hospital. Those working in primary care often noted the difficulty in accessing services which enabled people to stay at home. Hospitals provide a boundaried environment where it is easier to ascertain whether available services are meeting the required standard – a question now asked routinely during mandatory CQC inspections. Patient's homes however, present a private space where scrutiny as to how resource is provided to meet needs, is not so easily put in place. Nonetheless, when asked about the challenges facing people at EOL, the most prevalent issues raised, alongside issues around communication and care planning, were concerns about adequate provision of social and relational care, as well as community PC support to those dying at home.

Another result of resource pressure is that services may become more insular and less flexible. Respondents referred to a tendency to 'pass the buck from one service to the other'. An OT, for example, working in adult social care, explained how when people are referred who need input from across health and social care, the professionals who make the first contact will try to be as flexible and integrated as possible in working to address the patient's needs. The problem, she acknowledged as resources tighten is that:

People are more likely to work to rule and this results in things being passed from pillar to post and the patient is not best served (B.Non-Clinical.7).

Although at times it is hard to distinguish between the psychological impact of being sick and dying and discontent with one's environment – there were a number of patients in their home or care home, who suggested that more resource – particularly social support to decrease their sense of isolation would be welcomed.

In 24 hours I might see three people. That's it. That's to do a nappy change, breakfast, lunch and dinner. That's it. There's no companionship in this place. I'm just stuck in a room...the only time I've been out of this room in 8 months was to go to hospital (B.Patient.4).

For others, although weakened and fatigued by their condition, there were frequent allusions to the feeling that pressure on resource meant corners were cut.

6.1.6.5 Frequent structural and organisational change creates instability.

For staff, who are charged with enacting policy, the frustrations created by numerous changes in organisational structure, alongside changing sets of priorities, were strongly felt. Specifically mentioned were changes within government (following elections and reshuffles of key ministers) impacting on NHS structures, often heralding new targets and priorities that can be hard both to keep up with and make sense of. Here an academic speaks of her experience evaluating an Integrated Care Programme:

In (CS2) there were a lot of changes in the CCG and amongst local government partners which caused ructions. When I came in to evaluate for the third year, the programme was already 'history' and had been subsumed under 'transforming services together'. Integrated Care (IC) was still going on but there were new priorities and IC had been subsumed under other programmes (B.Non-Clinical.1).

6.2 Conjectured context mechanism outcomes (CMO) for embedding policy

The first set of CMOs were put together following phase 1 (the scoping study) and were used to inform development of phase 2 (see appendix 4.12). Following the case study field work the original CMOs went through a number of iterations which were used to interrogate and reflect on the propositions behind the theory. During the process of analysis, interview data was assigned codes (both through open coding and coding against the initial hypothesis) (Miles, Huberman and Saldaña 2014), the codes were then mapped into groups or themes which were used to scrutinise each of the CMOs. The final set of seven conjectured CMOs are presented in the second half of this chapter. Much of the data to support the development of the proposed CMOs has been presented in section 6.1 (contextual data). In each case, as was stated in Chapter four, mechanisms are considered in two parts, with one part relating to the resource or intervention, and the other relating to individual agency. This thesis is looking primarily at the role of policy in influencing the quality of EOLC. Policy, or elements of it, are therefore, in each of the CMOs, considered to be the structural resource (intervention). The aspect of the mechanism that changes is the response of the key actors and this changes depending on the system level at which the particular CMO is operating.

Table 38 CMO1: Enabling and responding to patient wishes

At the level of the patient:	
Context	<ul style="list-style-type: none">• If there is adequate resource (human and financial) in the system• If patients are properly communicated with, in a timely fashion and provided with meaningful, informed choices – regardless of their ethnicity, religion and socio-economic group• If the system enables the patient’s wishes to be valued and heard and pays attention to both clinical skills and ‘softer’ relational skills• If EOL is recognised and recorded in a timely fashion• If the system is integrated both within and across departments/organisations/sectors• If the aspirations of policy align with patients wishes
Mechanism	<ul style="list-style-type: none">• Patients are provided with meaningful opportunities to make their wishes for the EOL known including indications on ceilings of treatment and preferred place of death.• Then patients will engage willingly with the process of care planning and clinicians, managers and commissioners will use policy levers to help fulfil patient’s wishes
Outcome	<ul style="list-style-type: none">• Better patient experience and person-centred care at the EOL

Supporting evidence from case studies

The patient story narrated in table 39 (below) is used to illustrate CMO1. The text recounts what a care home manager perceived to be a good death. The highlighted sections of the text show how actions taken by staff, pathways followed and staff flexibility and initiative helped achieve the resident’s wishes; that she should die at home surrounded by family. For patients who have been communicated with about their wishes for EOLC and an ACP drawn up, it was more likely that outcomes in terms of EOLC experience were improved.

Staff flexibility and being able to use initiative, rather than sticking to agreed or historical working relationships, was often cited as a mechanism used to achieve better patient outcomes. One hospice manager mentioned how they provide training rooms to the local acute trust free of charge in return for which they benefit from getting to know some of their community-based staff. In another example of flexible working a psychotherapist working for a hospice explained how he worked closely with the community based psychologist to ensure fair cover for all patients – rather than work strictly by organisational protocol which may have meant some deserving patients might not have accessed services.

The management get all flustered– they worry about where the money comes from. But we work it out between ourselves. We say ‘oh this one looks more like you than me’. Occasionally we’re aware that the final details of protocol aren’t all tied up – essentially we’re just working with the people of {CS3} trying to make their lives better. Does that sound very naïve? (C.Clinician.9)

Table 39 Patient story to illustrate the working of this mechanism

Story of a good death told by a care home manager

We had a family – a husband and wife – who moved into this care home together. They both had mental capacity – they had a double room on the second floor. They were doing well until the husband had a sudden illness and got taken into hospital whilst the lady stayed here – **we could see an immediate change in her condition, and we had conversations with the family about her. We told the family we thought she was approaching the EOL and asked if we could sit down with them and their mother to discuss her preferences.** She was a very quiet lady from Ireland – she would be more open when the daughter or son were around. **So, we booked an appointment when the son could be there.** We discussed what she wanted when the time comes. She was a Catholic and **she said she wanted to be visited by the Priest** – so we organised this for her. We'd **also coded her at our palliative meeting, so she had the DNACPR, an ACP and she had let us know that she wanted to die here.** When we reached the point of thinking that we wouldn't be surprised if she were to die within a few **weeks we contacted the PC team for anticipatory EOL medications. The Palliative Care (PC) team are very quick and responsive** – they are more reliable than the doctors who we find will delay – even if they know it's EOL. However, **if we send a request to the doctors through the PC team – they're more responsive – so we've found a better pathway. The PC team will send a fax to the GP asking for anticipatory medications** – and before we know it we'll get a call from the pharmacy to say they've received a prescription. **So, we picked up the medication and the doctor came to see her and discuss it.** We began to administer the medication **and she slowly began to deteriorate. The daughter who lived in India was contacted** by the other siblings to say 'mum only has days to live' – so she changed her ticket and came over early. **We provided accommodation for them and they stayed here for two nights. In the end the whole family were here when she passed away. Where families are more cooperative and where we have the support of the palliative team and the monthly MDT palliative meeting – all these things help improve planning for a 'good death'.** (B.Non-Clinical.6)

6.2.2 CMO2: Enabling and supporting staff and carers

Table 40 CMO2: Enabling and supporting staff and carers

<p>At the level of staff and carers:</p> <p>The importance of providing adequate support for staff and carers/relatives (paid and unpaid) enabling them to feel equipped to work effectively, in the best interest of the patient, was a recurring theme in the research. This CMO was not apparent from the data in phase 1. It was developed due the emphasis in many accounts collected during field work of the importance of bolstering support for those working in any capacity with those at the EOL.</p> <p>Context</p> <ul style="list-style-type: none">• If paid carers receive appropriate remuneration• If both paid and unpaid carers/relatives to are supported, valued, listened to and offered appropriate training• If professional staff (clinicians and service managers) are provided with adequate managerial support such as clarity around roles and boundaries <p>Mechanism:</p> <ul style="list-style-type: none">• Then carers (both paid and unpaid) and health professionals are recognised within policy and practice as being a key part of patient experience and in recognition of the centrality of their role are provided with appropriate levels of support• As a consequence of being looked after themselves carers (paid and unpaid) are better placed psychologically to provide patients at the EOL with appropriate care <p>Outcome:</p> <ul style="list-style-type: none">• Patients will be provided with holistic person-centred care in a familiar environment surrounded by appropriate levels of support and care.• Patient experience will improve• Carer burden will diminish
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Supporting evidence from case studies

Whilst this CMO draws together widely divergent groups (paid carers, relatives and other professional staff) and may therefore be in danger of conflating different issues there was a strong link between the support these groups received and the impact this has on patients. Both health professionals and carers (paid home-carers and relatives) suggested that when they were unsure about their roles and responsibilities, or they felt badly treated themselves, or indeed when stress and pressure of their role began to impact on mental health, this in turn, affected the way they were able to care for patients. The support referred to here relates to helping the carer to feel valued and respected (through remuneration and the provision of emotional and psychological support) rather than to knowledge based tools and training.

There were many stories told in the research by carers about the huge and often unsustainable burden and pressure put upon them through their caring role. Often 'support' offered by paid carers provided by care agencies exacerbated their problems leading, in some cases, to poor mental health of the relative in charge or, for others, it meant their relative was admitted to be cared for in hospital or care home. A couple of carers/relatives stated that because of impenetrable bureaucracy and a constant sense that they weren't getting what they felt entitled to, the best protective strategy to shield themselves from frustration and disappointment, was simply not to disengage:

They will not offer it {help} to you and they don't listen to you. There's a great deal of patronising that goes on – and not really supporting you to carry out the role. I found all the promised support comes to nothing. It's better just to do it yourself (A.Carer.3).

However, where finances allowed, and where unpaid carers were more in control of the support provided (particularly through employing private carers themselves (see section 6.1.2.1) or where their needs were, at least to an extent, supported through social and support groups, outcomes could be improved. A few carers attended, or ran, local support groups which reportedly reduced their isolation and loneliness. One carer in case study 2 ran a group for Asian carers initially supported by the LA – though when funding for the group ran dry she explained how members had begged her to continue. There was a strong sense that such groups reduced the sense of isolation:

You meet people who have gone through even worse – and I find that comforting – you feel supported (C.Carer.2).

I used to go to the carers forum– there are a lot of things they can do for you ...you didn't necessarily know what was out there for you – but they could help you with lots of things – like towards the cost of a holiday – you get to hear other people's stories (A.Carer.1).

Also important to carers were the perceptions of the levels of care and the three-way communication between themselves, professionals and their sick relative. Here a daughter commends the compassionate, patient centred, care her mother received:

I think we have been well treated– they have been caring. The doctors have sat with her – some doctors even recognise her now because she's been there so much. Recently there was a French lady doctor who sat with her and talked to her in French which my mum understands to make sure that she understood her wishes for the EOLC. That's better for me because it means I'm not stuck in the middle translating (A.Carer.9).

Professionals mentioned how they found it easier when there was clarity around their role. The stress of attempting to engage in complex multidisciplinary work environments – of having to surmount significant organisational barriers in order to get small tasks done – often had a negative impact on their experience of working life. Where staff felt supported and enabled to use their initiative, often working across organisational boundaries or following new pathways, this was seen to have beneficial outcomes.

6.2.3 CMO3: Alignment - clinicians are convinced of the value of policy

The concept of policy alignment was not envisaged in the earlier set of CMOs. It was introduced here as the importance attached by clinicians to believing in the credibility of policy aspirations, emerged from the data.

Table 41 CMO3: Alignment - clinicians are convinced of the value of policy

<p>At the level of health professionals (clinicians and service managers):</p> <p>Context</p> <ul style="list-style-type: none">• If health professionals believe that policy aspirations can be supported by available services and are in the best interests of the patient (both clinically, socially and psychologically)• If health professionals are aware of policy, see it as coherent, and know how to promote its implementation <p>Mechanism</p> <ul style="list-style-type: none">• Then clinicians will believe in the value of policy and so will actively promote policy goals and use the national policy guidelines to direct service provision• Clinicians will work flexibly, often on their own initiative, to bring about positive outcomes and promote the best interests of the patient <p>Outcome</p> <ul style="list-style-type: none">• Professionals act to support policy direction

Evidence from case studies:

Where clinicians saw the value of policy and believed in its coherence with the rest of the system they followed robust mechanisms to ensure that policy guidance informed all aspects of service delivery:

Yes, national policy is central to our work. Certainly the 'ambitions' work is something that courses through my veins. We often think about how our services fits with ambitions – for example, 'is everyone prepared to care?' (B.Non-Clinical.8)

Senior clinicians tended to be involved in policy at a number of levels:

We input into national policy and thinking – particularly through London wide meetings. We have both a hospital and borough wide strategy for EOLC and we try to structure our meetings around key strategy documents. For example, our EOLC forum is structured around the key planks of the ambition's framework. They are a very helpful guide – the challenge is to turn the aspirations into details and targets – having to deal with resource, staffing and funding constraints. So, implementation is the hard part – but we have to be influenced by the national agenda (C.Clinician.5).

Whilst the EOLC forum meetings were led by commissioners within the CCG, clinicians and service managers were actively involved in contributing ideas and implementing strategy. In case study C the EOLC forum had identified a gap in their overnight PC provision and had subsequently successfully applied for funding of an innovative overnight service, securing funding from Social Finance. At the time of field work the service was up and running with early data highlighting promising results which were said to be 'energising and motivating' the palliative care team. If successful the ambition is that through investing more in community services, the outcome will be reduced pressure on acute settings and significant financial savings which can be returned to the system.

6.2.4 CMO4: Measures - naming and Shaming

Table 42 CMO4: Measures - naming and shaming

Measures – Naming and Shaming	
At the level of commissioners, service managers and clinicians	
Context	<ul style="list-style-type: none">• If data are meaningfully recorded, collected and made publicly available so that stakeholders are aware of local variation• If data is collected at all system levels relating to demographics, condition suffered, pathways experienced as well as at micro level relating to experience of care• If data is collected from patients, clinicians and carers (paid and unpaid)• If data can be shared seamlessly across organisations and settings
Mechanism	<ul style="list-style-type: none">• Then policy will provide guidance, levers and incentives to begin to level unacceptable disparities in EOLC services across local areas• Then clinicians and managers will feel a moral and professional duty to improve standards to avoid reputational damage• Then the needs and preferences of patients and carers will be more robustly incorporated into service design
Outcome	<ul style="list-style-type: none">• Standards will be raised in relation to meeting local targets for KPIs such as reducing number of emergency admissions in the last three months of life and increasing numbers dying in their usual place of residence

Supporting evidence from case study:

Challenges around identifying appropriate KPIs and collecting valid data (both reflecting clinical outcomes and patient experience) have been discussed in chapters two and six. A strong theme running through the case studies related to issues around transferability of data both within and across different organisations and settings. In particular the need for inter-operability in IT systems was highlighted. Data now lodged on the NEOLCIN (Public Health England 2017) website is becoming

an important tool used routinely in the collection of local information. There was awareness that this data compared local performance to national comparators and a number of the EOLC initiatives encountered in the case studies were motivated by the knowledge that local performance in a particular outcome measure needed to be improved.

We recognise that numbers dying in {CS2} in hospital are comparatively high across London – we are working to address this (B.Clinician.3).

Data collection is also important in relation to service design and there was recognition that the voice and experiences of patients and carers should be a central part of all planning; there are strong links therefore between this CMO4 (measuring) and CMO5, relating to the importance of supporting commissioners and providing them with the necessary tools to identify local needs. On-going efforts were shared (both local and system level) to improve ways of collecting information about the experiences and priorities of both patients and carers.

6.2.5 CMO5: Supporting commissioners to implement good practice

The value of offering more routine support to commissioners emerged as the field work progressed, it became increasingly evident how variable the commissioning process is.

Table 43 CMO5: Supporting commissioners to implement good practice

Supporting commissioners to implement good practice
At the level of commissioners:
Context
<ul style="list-style-type: none">• If commissioners are supported in enacting policy and provided with necessary resource and training relating to: know-how in relation to needs assessment; guidance on minimum standards; access to good quality data; staff capacity and finance
Mechanism
<ul style="list-style-type: none">• Then policy can provide an effective framework to guide equitable local and national commissioning services• The commissioner believes that using policy benefits outcomes and as a result will be motivated to use policy to inform decisions around commissioning evidence based local services
Outcome
<ul style="list-style-type: none">• Higher quality, more consistent and standardised EOLC is made available to all regardless of geography, ethnicity, religion or clinical condition.

Supporting evidence from case studies:

For those commissioners interviewed in the case studies, who were: confident in finding their way round the system; familiar with the policy environment and had skills and experience both in assessing need and reviewing the evidence base, there was evidence of progress in setting clear policy driven agendas. Those responsible for commissioning EOLC within the CCG, across all three case study sites, were instrumental in organising and chairing multi-disciplinary EOLC forums. As part of the fieldwork I observed five EOLC forums and in each case saw how the framework was guided by the Ambitions Framework (NPELCP 2015). In case study C, following a mapping exercise looking at

current provision against the six ambition statements, the lead commissioner drew up a framework for action, against which progress was robustly monitored. Table 44 shows the ambitions listed alongside examples of the type of intervention/project the CCG was putting in place to help achieve the targets set by policy:

Table 44 Types of intervention measured by case study C to monitor targets set in Ambitions for Palliative and EOLC (NPELCP 2015)

<p>Individualised care</p> <ul style="list-style-type: none"> • training in difficult conversations and information governance for care home staff from members of palliative care team • Early identification of problems through health checks at 55 • GP masterclasses for primary care MDTs e.g. training users in Coordinate My Care (CMC) registers • Discussion of use of 'Respect' forms
<p>Fair access</p> <ul style="list-style-type: none"> • Reviewing numbers accessing continuing care beds • Working to re-establish palliative care beds at local hospital where ward has been closed
<p>Maximise comfort</p> <ul style="list-style-type: none"> • Review reports from CQC and patient feedback in care homes, hospitals, hospices
<p>Coordinate care</p> <ul style="list-style-type: none"> • Exploring options to avoid holding up discharge for example specific efforts are being made to talk to the prescribing team about discharge delays • Work to configure different IT systems (EMIS and CMC) including discussion around streamlining these with ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) DNAR • SPA PONS (Single Point of Access Palliative Overnight Service) to fill gaps in OOH services • Exploring ways to fast track access to local hospice • Improve CHC fast track process • Looking at ways to speed up discharge due to delays in accessing necessary medications • Working with local pharmacies to ensure that necessary anticipatory drugs are routinely stocked • Review bereavement support
<p>Staff are prepared to care</p> <ul style="list-style-type: none"> • For example, staff are embarking on 'carer assessments' - reviewing how caring impacts on physical, mental and emotional needs,
<p>Community involvement</p> <ul style="list-style-type: none"> • Planned partnerships with civic groups e.g. the Old People's Forum • Identify Age UK Resources • Interact with Care Connection Teams to coordinate initiation of EOL conversations

6.2.6 CMO6: System level structures and incentives support and enable the application of policy

Table 45 System level structures and incentives support policy application

<p>That system level structures and incentives support and enable the application of policy</p> <p>At the system level:</p> <p>Context:</p> <ul style="list-style-type: none">• If there is adequate resource (financial and human) in the system• If different parts of the system work together to enable sharing and consistency of data• If progress towards EOL targets can be measured, collected and recorded using appropriate measures• If local data is published and compared to national benchmarks and comparative local areas• If there are adequate incentives and levers in place to encourage those implementing EOL services to follow policy• If policy direction aligns with patient preferences as well as potential cost savings <p>Mechanism:</p> <ul style="list-style-type: none">• EOLC policy exists in a tangible form that can be identified, operationalised and understood by all key stakeholders (commissioners, professional health care staff, patients and carers)• Then staff at all levels are both motivated to implement policy and can access suitable tools (guidance on minimum standards, levers and incentives) to enable a more standardised application of policy <p>Outcomes:</p> <ul style="list-style-type: none">• Higher quality, more consistent and standardised EOL care available to all regardless of geography, ethnicity, religion or clinical condition.

As discussed in section 6.1.6.2, where the necessary contextual factors were in place, examples were observed of organisations and individuals coming together to use resources and know how, to effectively implement aspects of EOLC policy. The Accountable Care Partnership in CS3 was one such example, as were a number of integrated partnerships across health and social care in CS1. In CS2 the introduction of champions for EOLC (funded by the LA and CCG) into a number of different settings including local trusts, were an interesting example of inter-sectoral working; where the champion is tasked with networking and building relationships with stakeholders. One of their roles in this area of high ethnic diversity was to review how the needs of the ethnic community were being met.

6.2.7 CMO7: Redressing the imbalance between 'task orientated clinically focused care' versus 'relational empathetic care'

Table 46 Redressing the imbalance between 'task orientated clinically focused care' versus 'relational empathetic care'

<p>Redressing the imbalance between 'task orientated clinically focused care' versus 'relational empathetic care'.</p> <p>At the societal level:</p> <p>Context:</p> <ul style="list-style-type: none">• If the system recognises that both clinical care and relational care are intrinsic determining factors in overall patient experience <p>Mechanism:</p> <ul style="list-style-type: none">• Government policy in general and EOLC policy in particular includes specific strategies relating to more routine/robust integration of health and social care sectors and commensurate levels of support and remuneration for the social care sector• Then stakeholders at all levels embrace the narrative espousing social care and health care should be more equitable partners in public service provision <p>Outcome:</p> <ul style="list-style-type: none">• The reported chasm between the values assigned to clinical and transactional care on the one hand and relational/empathetic care on the other will be addressed. The status of social care will rise and workers in this field will be better supported and remunerated meaning that the aspirations of EOL policy are more likely to be met• The preference of some patients, privileging quality of life over length of life, will be better supported.
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Supporting evidence from case study:

The case studies found that where efforts were made to challenge some of the historical social norms which have tended to privilege the value of clinical care over that of relational care, this appeared to be welcomed by patients. Projects which recognised the importance of: open communication; integrated social networks and of being treated with compassion and kindness, were applauded. Examples of innovative projects that stood out in the case studies included:

- **A multi-disciplinary integrated network coordination service** in case study A, which worked flexibly with both mental health, physical health and social care to help ensure that the most vulnerable members of the population were provided with the best quality care at EOL. Despite working with patients, often with behavioural and learning issues, for whom normal pathways have failed, a number of stories, demonstrating success were cited (see table 39)
- **Death cafes:** public education initiatives to normalise conversations about death and dying have been well received.
- **A public education programme** in case study A provides unique training courses to communities and the workforce to help lift the taboo around death, dying and bereavement and to raise awareness of the importance of EOLC planning.
- **The New Public Health movement** (Awofeso 2004) was welcomed by a number of respondents, referring particularly to the emphasis placed on the relationship between health and socio-economic variables. Initiatives such as ‘compassionate neighbours’ are beginning to make a ripple and the outcome of the evaluation currently being conducted by Nesta (2019) is awaited with interest. The following account from one of the compassionate neighbours who is part of this scheme conveys how supportive a visit can be:

I visit her every Sunday. She does have family – but they’re not local –when the family aren’t there she’s mainly on her own ...I just try to provide social support. There’s a lot of joy in just being able to make a cup of tea for someone (B.Carer.4).

And here a palliative care consultant involved in the compassionate communities movement explains how ideally policy should work in tandem with other types of peer led initiatives.

Whilst policy is important to set a supportive environment – the influence on individual behaviour may not be as important as peer networks. You still need policies to support this

sort of programme – but both need to go hand in hand. Local action determines day to day decision making but higher policies set boundaries and frameworks (B.Clinician.8).

6.3 Chapter summary

In summary, this chapter has identified multiple, interconnected contextual layers that impact on the implementation of EOLC policy. Each of these contextual factors, in RE terminology, may work together or independently to ‘fire’ or turn up a ‘dimmer switch’ underlying the ‘mechanisms of action’. The second part of the chapter presented seven refined CMOs operating at the levels of: patient; carer; professionals; the system and society. The next chapter considers the rough programme theory conjectured at the start of the thesis and in the light of findings presented here develops a revised programme theory before moving on to using mid-range theories (MRTs) to assist with broader conceptualisation of findings.

Chapter 7: Discussion of findings

7.1 Overview

This chapter looks at the findings of the thesis in relation to new knowledge, considering how the study may contribute to a better understanding of the application of EOL policy. In keeping with realist methodology findings are discussed in the context of the 'rough' programme theory developed in chapter four and interrogated alongside a revised programme theory. The case studies, which introduced the views of a wide range of stakeholders, have provided insight into the extent of systems complexity and the emerging picture is more nuanced than originally anticipated. The revised programme theory provides a fuller picture of how policy is interpreted by the various stakeholders, how this impacts on their ability to implement policy and in what circumstances it is most likely to be effective. A broader search for theories to help elucidate understanding and illuminate the significance of the findings for policy and practice may now offer further insight. The process of drawing out 'demi-regularities' (see section 4.3.1) in research findings, which are represented in CMOs - leads to the conjecturing of 'mid-range' theory (MRT) and helps to consider how findings may be used to inform practice. This chapter introduces three emerging MRTs which may clarify thinking around the application of EOLC policy. Theories are used to provide a new conceptual map which will enhance our understanding of how the mechanisms developed in the CMOs are triggered.

It concludes with a set of recommendations detailing how policy may be used to address some of the key themes arising from the case studies, including the fragmentation of health and social care and rising inequities in local provision.

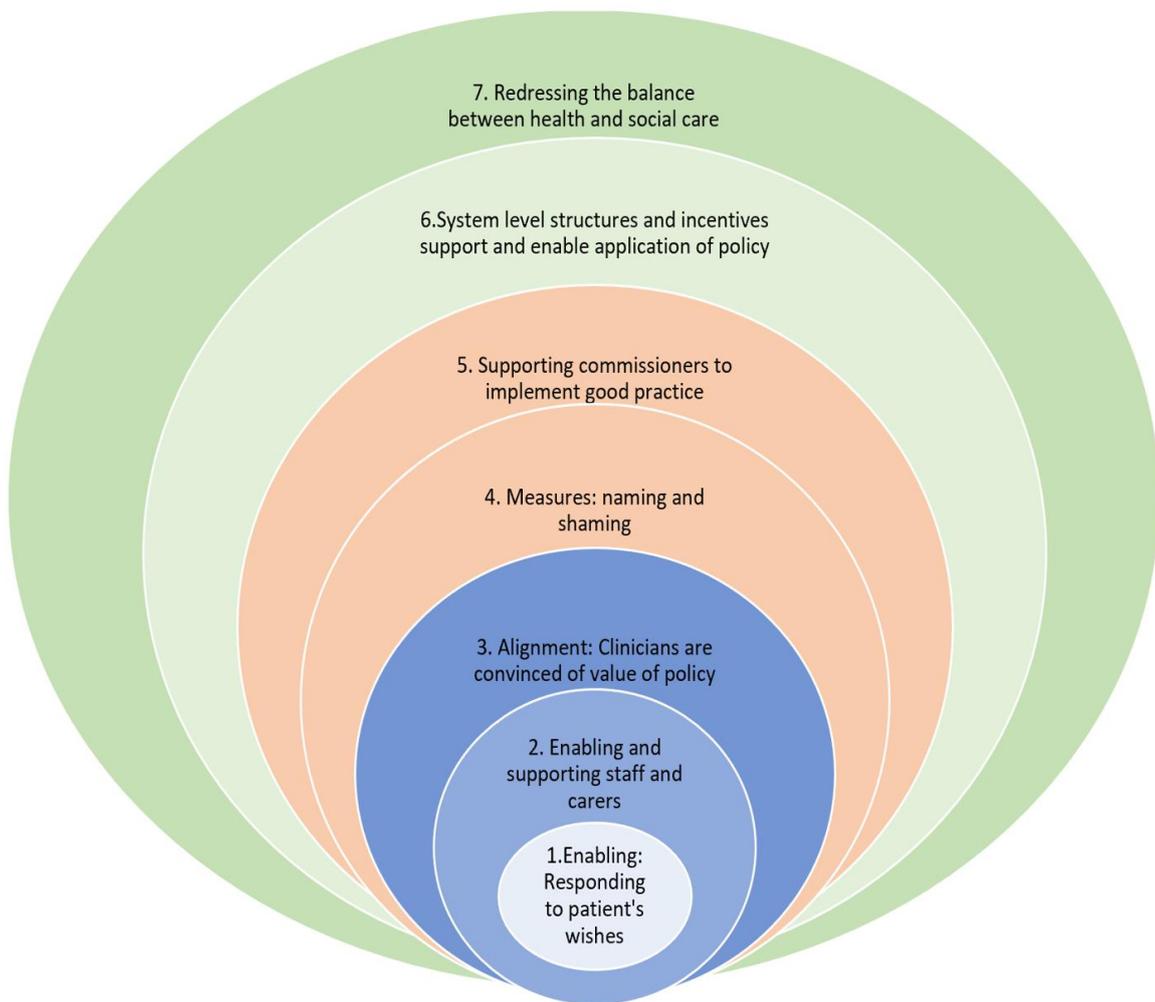
7.2 Developing programme theory

The initial rough programme theory (RPT) articulated in this study was necessarily unstructured – making the assumption that EOL national policy helped produce the intended outcomes (identified as consistent and good quality EOL care) without reference to the causal mechanisms behind the theory. The supposition being that the policy framework acts as a trigger to bring about a series of responses to put in place standardised services and monitor these against a set of aspirational statements. I suggest that programme theory for the National Policy relating to EOLC fits the typology that Greenhalgh et al (2009) describe as highly complex, large scale and/or messy.

National EOLC policy is not well-defined and commentators have pointed towards the myriad of guidance documents in circulation, some of unclear status and provenance (Centre for Health and Social Care Research 2016).

The scoping study and case studies have revealed a clearer view of the causal processes at play at different levels of the social structure; micro, meso and macro system levels. To help arrive at a revised programme theory the seven CMOs identified in chapter six are represented in figure 17, depicted in relation to their position at the broad system level.

Figure 17 The seven proposed CMO configurations associated with enacting EOLC policy



Key: Blue – Micro, Red – meso, Green - Macro

Whilst the differentiation between levels is not exact, and the different factors may be intertwined, recent evaluations of complex systems suggest that greater attention should be paid to the interactions between different contingent and contextual levels (Greenhalgh and Papoutsi 2018; Robert and Fulop 2014). Both institutional and environmental factors, together with human agency are seen to influence outcomes. Each level of the system influences and interacts with the other; micro-level encounters between patients, carers and health professionals, affect and interact with both meso and macro structures. Westhorp (2012, 2013) provides the analogy of climbing up and down ladders, where the rungs represent each level of the social structure within which a variety of mechanisms may be at play. Micro relates to individual factors, meso relate to interpersonal and macro to institutional, infrastructural and cultural.

EOLC policy per se does not work to bring about intended beneficial outcomes unless specific conditions are met – rather it acts in a way that Porter (2015) (see section 4.1.5.3) would refer to as a ‘resource mechanism’. Moreover, even when these conditions are met, the extent to which the enactment of policy achieves intended goals depends on the extent to which actors, at different levels, act to trigger the mechanisms involved. These dynamic contextual and mechanistic factors are considered in the revised programme theory elucidated below (table 47).

Table 47 **Revised programme theory for the enactment of EOLC policy**

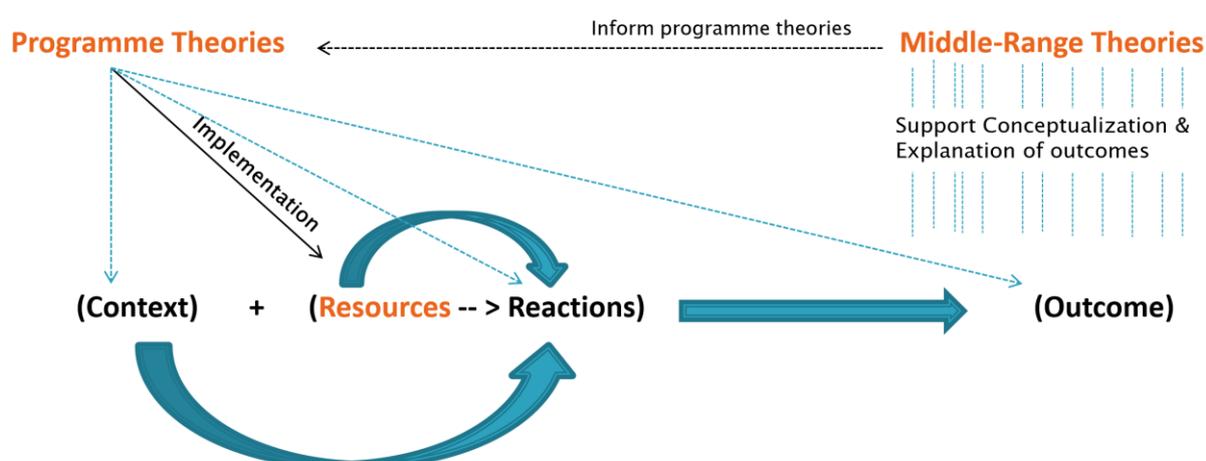
<p>Revised Programme Theory</p> <p>If the following contextual factors are in place:</p> <p>At the macro level:</p> <ul style="list-style-type: none">• If the system recognises that both clinical care and relational care are intrinsic determining factors in overall patient experience and provides joined up infrastructural support to enable effective commissioning and provision of effective services• If minimum standards can be set and levers identified to reduce current inequities in access to services <p>At the meso level:</p> <ul style="list-style-type: none">• If professionals (commissioners and clinicians) are provided with the necessary training and support and have access to the right forms of data on which to base decision making and if priorities held by the professionals align with those held by patients and carers <p>At micro level:</p> <ul style="list-style-type: none">• If the voices of patients are listened to and the system is able to provide choices which fit with patient preferences• If carers and staff are supported so that they feel valued• If EOL policy is coherent and health professionals' priorities and beliefs fit with the preferences of patients and their relatives <p>Then:</p> <ul style="list-style-type: none">• Professionals can engage with policy and witness the value conveyed to patients, through following prescribed policy• Stakeholders at different levels will act together, reflexively monitoring the impact of their work through observation and feedback from patients• Patients are more likely to have their wishes at the EOL recognised and fulfilled.

Realist theory encourages the researcher at this point to engage in the process of retrodution, where the identification of MRTs can provide greater insight into the programme under scrutiny. The aim of retrodution is to explore the:

Hidden causal forces that lie behind identified patterns or changes in those patterns (Wong et al. 2016).

The use of different theoretical lenses may further develop our understanding, enabling different ways of conceptualising the empirical world. Figure 18 considers how MRTs support the conceptualisation and explanation of outcomes. Ultimately MRTs assist in providing possible explanations as to why interventions are effective thus providing insight into how efficacy can be improved. The value of realist evaluation is to help reveal why the winners win and the losers lose (Pawson 2017).

Figure 18 How MRTs help support conceptualisation and explanation of outcomes



Taken from Jagosh (2019)

Identification of MRTs in this thesis was guided by Shearn (2017) and Wong (2015) who propose a three staged process:

- i) Defining the concept

Definition of concept in the current thesis is complicated by a lack of clarity both about the nature of EOLC policy and about the intended outcomes. If, as was surmised in chapter one, the aim of EOLC policy is to improve the quality and consistency of EOLC, an immediate challenge is presented by a theme recurrently touched on in this thesis; what does good quality EOLC mean and how is it measured? Data reveals how quality is defined in many ways and varies depending on a wide range of social, cultural, economic and psychological variables.

- ii) Developing the proposition

The scoping study revealed that programme theories around EOLC policy were neither well defined nor well established, indeed no pre-existing theories were located in literature, necessitating that the initial RPT arrived at was developed uniquely for this thesis. The dearth of related studies meant that there was little guidance pointing towards MRTs previously used to promote conceptual understanding in this area.

The RPT proposed in chapter four hypothesised that EOLC policy worked to bring about outcomes by setting a standard and framework against which services could be guided and monitored. In the light of the more nuanced picture detailed in the 7 CMOs presented in chapter six, a new search was conducted, seeking to identify theories which would improve the explanatory power, heightening our understanding of how policy may help achieve better outcomes for those at EOL. A search for appropriate MRTs was conducted through a trawl of previous realist studies, together with a search of EOL and more generic literature on medical sociology. Drawing on the thinking of Shearn (2017) the three explicatory theories, suggested here, were selected on the basis that they:

- are applicable across each level of the social system, with the ability to explain phenomena at micro, meso and macro levels;
- focus on theory and concepts relevant to the stakeholders and subject matter of the current thesis;
- offer clarity and simplicity which will support theory generation;
- offer insights to help understand in what situations and with whom EOLC policy is most likely to produce the intended outcomes.

The three theories identified here (normalisation process theory, social capital and Foucault's (1998) concept of 'medicalisation'), are not the only ones with explanatory power, but were selected on the basis that they provide insights, across system levels, to some of the key causal processes highlighted in the CMOs.

- **Normalisation Process Theory (NPT)**

NPT was felt to have particular explanatory power, in that it focuses on the way new interventions and programmes become embedded.

- **Foucault and the medical gaze**

The way professionals, patients and carers/relatives respond to the options presented by EOL is influenced by a range of social, cultural, religious and economic factors. One particularly

powerful and dominant narrative intertwined in this contextual mix is that which presents a world view where medicine is often privileged and prioritised over social care. Foucault's (Foucault and Faubion 1994; Foucault 1998) thinking about power permeates systems and individuals at all levels.

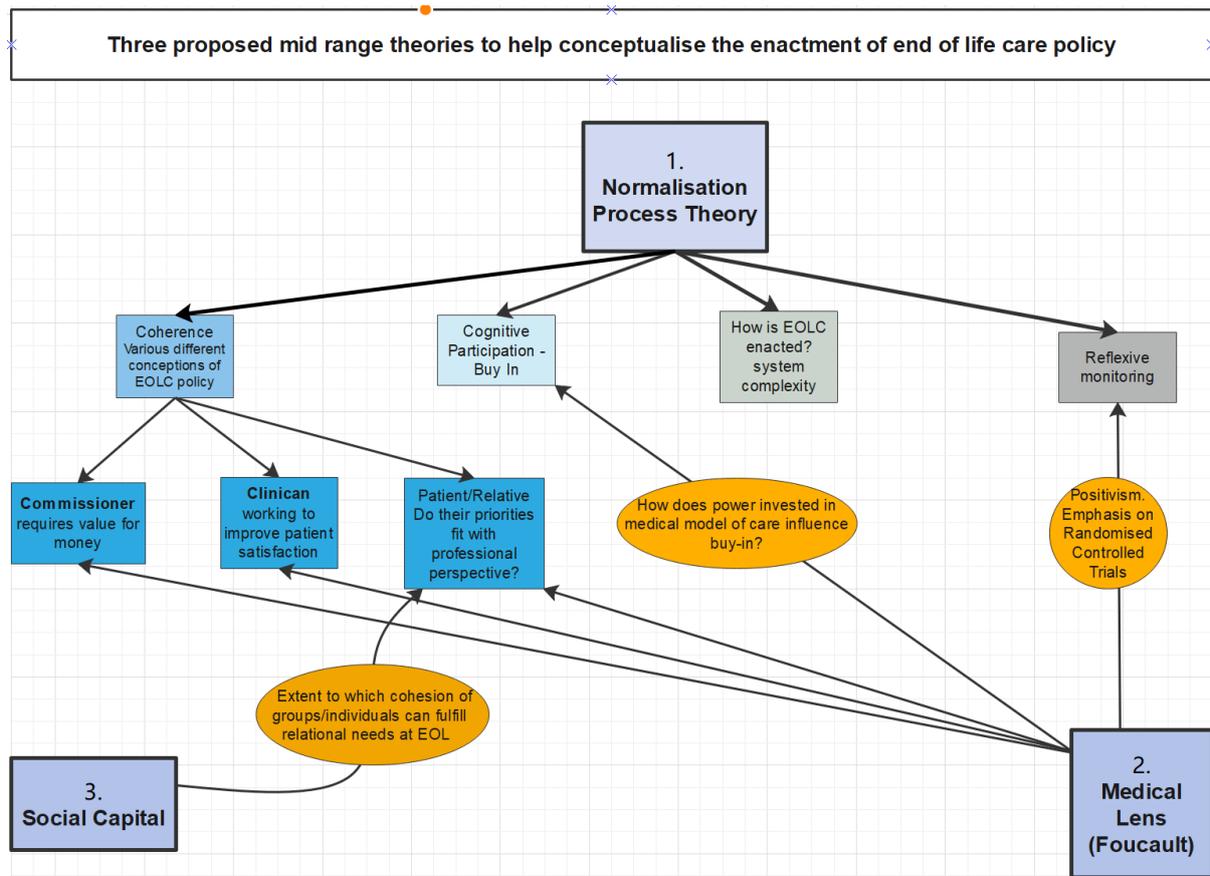
- **Social Capital**

The third MRT focuses on notions of social capital and draws on thinking of Kawachi and Berkman (2000) and Putnam (2000), and echoes the predominant patient view that priorities for them at EOL often revolved around their location within a social network and the desire to feel connected relationally as death drew close. Social capital is a concept often thought to inhere at the level of community (macro); though scholars talk of individual social capital, as being something located at the meso level that impacts on psychological well-being and behavioural mechanisms.

iii) Connecting propositions to develop theories

The final challenge is to use the identified MRTs to build connections between the different parts of the theory which will build rigour in the model and provide clearer guidance about 'how' causation is reliably achieved (why does it work?), the circumstances that lead to intended outcomes (i.e. in what circumstances does it work?), and 'who' does it work for?

Figure 19 How mid-range theories (MRTs) may support conceptualisation of theory



7.3 In what ways do identified MRTs provide explicatory power to the enactment of EOL policy?

7.3.1 Normalisation Process Theory

Normalisation Process Theory (NPT) provides a conceptual framework which sheds light on how new ideas are routinely embedded and operationalised, or not, into working practice. Some of the processes at play may shed light on how service managers and health professionals begin to operationalise EOLC policy. According to NPT there are four core constructs, represented in table 48 relating to the actions, views and understanding of participants and their relationship to the intervention:

Table 48 **How do NPT constructs relate to implementation of EOLC policy?**

Core Constructs of NPT in relation to EOLC policy	
i)	Coherence – How do participants understand and make sense of EOL policy? Is there coherence between the different perspectives?
ii)	Cognitive Participation – how participants buy into EOL policy
iii)	Collective Action – how participants enact EOL policy
iv)	Reflexive Monitoring – how participants appraise its effects

Adapted from (May et al. 2020)

NPT helps elucidate how national policy relating to EOLC can be of value and effectively implemented in context-dependent ways. As a theoretical model it articulates how and why a programme works and is therefore a valuable tool in planning and evaluating the implementation of policy and practice. NPT is made up of the four generative mechanisms outlined in Table 48 that work to embed policy within its social context. All four constructs work together dynamically, each part is contingent upon and interacts with the others.

Applying NPT to the implementation of EOLC policy begins with clarification of who the key actors are. In this PhD stakeholder groups were divided into:

- Policy makers – interviewed in the scoping study
- Service commissioners and managers
- Clinicians
- Relatives/carers
- Patients

Whilst policy implementation is largely the job of clinicians, service managers and commissioners the findings show the interconnections at each level and how the preferences and priorities of patients and relatives were influential in shaping the degree of motivation professionals showed towards enacting policy. The four components of NCP are reviewed in the following section, in relation to the findings of the thesis.

7.3.1.1 Coherence

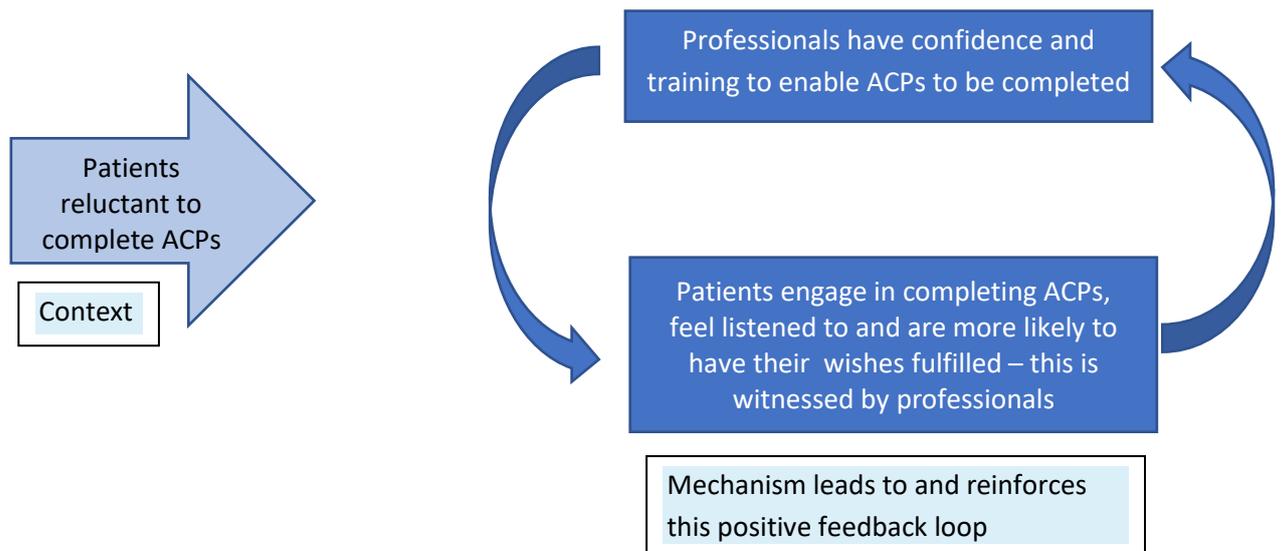
Finch et al (2015) propose that coherence relies on the building of a shared understanding of the aims, objectives and anticipated benefits of the intervention. Results considered in chapter six show

that whilst professionals agreed that policy is useful in that it provides a framework against which to set goals and standards, the considerable array of policy directives and aspirational statements mean that having a broadly shared understanding of what policy sets out to achieve or what success will look like remains tenuous. Moreover, the different stakeholders represented in the study have different insights into and interactions with policy.

For patients and relatives there was little spontaneous articulation in the case studies of policy, or how EOLC policy may impact on access to care. Indeed given that neither patients or relatives implement EOLC policy, they have little opportunity to be familiar with the aims or objectives of the policy – yet for policy to be effective there needs to be a shared understanding and agreement between professionals and patient/relatives as to what these priorities are. If patients are asking for one thing and clinicians are advocating another, there is a lack of coherence in the system. An example of this is witnessed in instances when patients struggle to access good quality relational care at EOL, whilst access to clinical care continues to be prioritised.

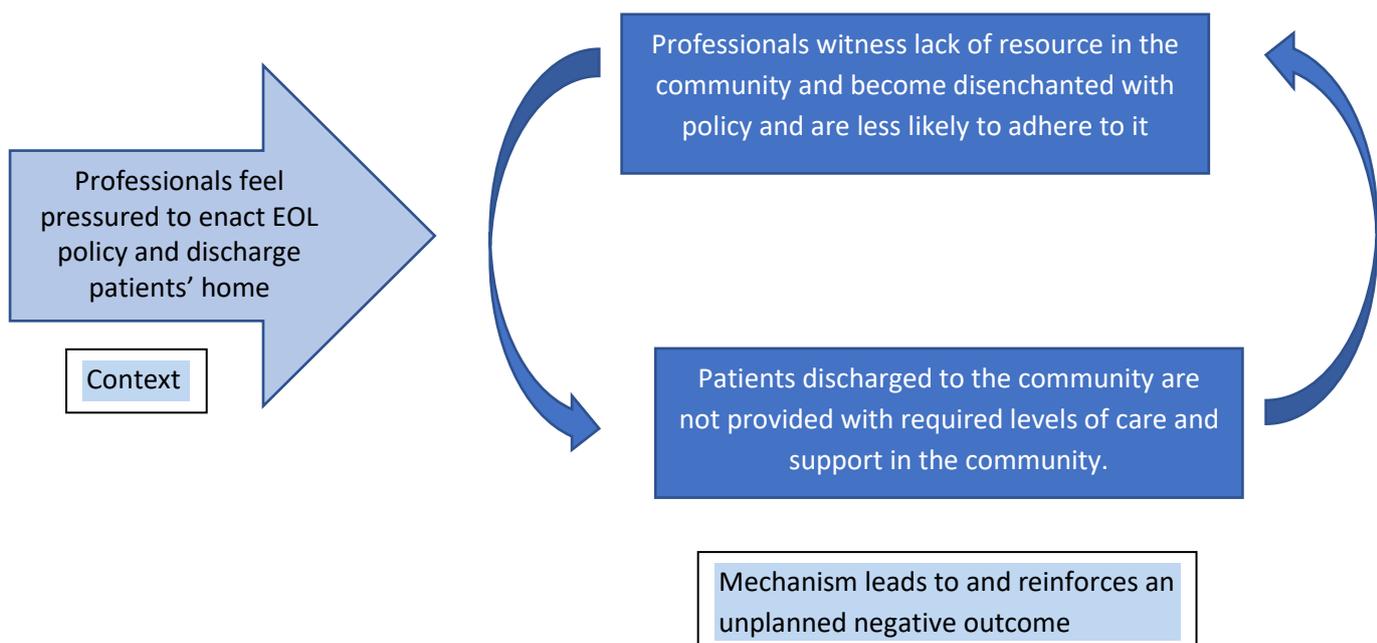
The case studies revealed the complexity inherent in determining priorities and how these are subject to considerable variation depending on a wide range of factors including individual circumstance, family support, religion and economic status. The huge challenge for national policy in reflecting the nuanced stance that each patient adopts was recognised. Despite this, where professionals witnessed positive outcomes as a result of processes to enact policy being set in place effectively, then this motivated them to formally engage in decisions and actions which reinforced policy. One such example was found in instances where: if professionals worked together to respond to the choices that patients articulated in an ACP, and if this resulted in increased patient satisfaction, then, going forward, professionals had more confidence to create ACPs (even for those patients who were initially reluctant to engage) and as a result enabled more patients to achieve EOL wishes. Byng et al (2005) refer to this as a positive feedback loop.

Example of positive feedback loop



Conversely, where professionals worked to achieve a particular goal articulated in EOLC policy, for example, enabling more patients to die at home, and where sufficient resources weren't in place in the community to provide adequate levels of care and support, this resulted in professionals becoming disenchanted with policy, in this case creating a negative feedback loop (Byng et al 2005). The finding from this study that budgetary and resource constraints meant that home deaths could not always be facilitated, was supported by Hashem's review of hospice at home services (Hashem et al 2020).

Example of negative feedback loop



Findings suggest that coherence is likely to be improved by joint, multi-professional working and whilst all case study sites had multi-professional EOL steering groups, the regularity with which they met varied, depending on the priority assigned to this area of work. In areas where they met regularly and had a clearly laid out process for monitoring EOL activities against policy goals (such as in case study A), a greater degree of both individual and shared understanding of what EOL policy was striving for was apparent. This process, a familiar part of NPT, of developing shared understanding, is described by Finch et al (2015) as 'internalisation' and is another example of how an initiative may contribute to a positive feedback loop.

7.3.1.2 Cognitive participation

Cognitive participation refers to the relational work that people contribute to building a community of practice who together may implement a complex intervention (Finch et al 2015). If EOLC policy is to be widely implemented there is a requirement for players in the system to recognise that it's their responsibility to take the work forward. Indeed in all three case study sites there were commissioners and clinicians who took ownership of this role. There were many examples too, where professionals worked flexibly, often beyond their role or remit, to ensure that policy aspirations were met, particularly in relation to fulfilling patient choice. In such instances examples of good practice were frequently cited.

A barrier to cognitive participation was evident when professionals were unclear of their role or lacked 'legitimation'. Continuous changes to NHS organisational structures, particularly with the establishment of STPs which was ongoing at the time of the study, were highlighted as a clear impediment to progress, creating an ongoing state of uncertainty and role confusion. Clarity of role therefore, is another example of a context which results in negative or positive feedback loops.

7.3.1.3 Collective action – how is policy enacted?

This construct refers to the work involved in implementing the intervention and the challenges encountered on route. There are a number of aspects to this construct of relevance here. Collective action refers to the ease with which practitioners operationalise the intervention – for example in the case of enacting EOLC policy a number of tensions emerged in relation to 'workability' particularly evident at macro and meso levels.

System Complexity and contextual integration (macro level)

The results presented in chapter six reveal a picture of a system bound in high levels of complexity where a broad range of contextual factors (see 6.2.6) need to be in place in order to trigger the mechanisms enabling EOLC policy to be followed and enacted. Complexity, it is said, does not lie solely in the intervention itself but is inextricably linked to its dependence on the wider system. Complex interventions do not neatly divide into discrete sets of actions with predictable, stable and linear consequences, 'rather they involve emergent, unpredictable, and non-linear associations between components and outcomes' (Moore 2020).

EOLC policy is not located within a vacuum but interacts both with (and on) a huge range of individuals and organisations which operate within a multi-layered system. Recognising the interplay of agency and structure and the impact of these on the way policy is enacted is challenging. One of the issues, revealed by the wide range of professionals working in the area of EOLC, was that whilst they put patient's wishes at the forefront, many of the most significant factors, on which service delivery was dependent, did not lie exclusively in their control. Whilst examples were given of innovative ways of making local improvements, many of the particular challenges mentioned, relating to: national staffing shortages; workforce pressures and the interface between health and social care, were considered to be problems residing at a national rather than local level.

Pawson (2006) proposes that there are four key contextual layers that pervade most systems:

- i) The individual capabilities and characteristics of key actors (in this case the four levels of stakeholder interviewed) ;
- ii) Interpersonal relationships (In this broadly based piece of research there are many different manifestations of these – the main one's being between: patients and clinicians, patients and relatives, patients and carers, carers and relatives, clinicians and commissioners);
- iii) The organisational setting (e.g. organisational cultures, senior leadership support, characteristics of people using the system, resource allocation, local priorities);
- iv) The infrastructural setting (e.g. prevailing NHS cultures and staff experiences at work).

Each of these layers were identified in the thesis and are represented in figure 17, section 7.2.

Greenhalgh and Papoutsis (2018a) highlight how these multiple layers of contextual complexity can cause confusion:

Complex systems have fuzzy boundaries; their interacting agents operate on the basis of internal rules that cannot always be predicted; and they adapt, interact and co-evolve with other systems
(Greenhalgh and Papoutsi 2018 p.2).

One of the outcomes of working within such complex systems is that tensions and paradoxes will inevitably arise and that linear causality between inputs and outcomes is hard to identify. Research enquiries located in complex systems must be able to tolerate uncertainty and remain committed to 'engage in disagreements.' (Greenhalgh and Papoutsi 2018). The complexity of systems has meant that cumbersome structural arrangements can obstruct and obfuscate the primary purpose of the health service; to work in the best interests of the patient's health and wellbeing.

Another consequence of working with complex systems that doesn't sit well with broad based policy is the tension that inevitably arises between working towards broad societal benefit on the one hand and catering for the nuances of individual need on the other. Commentators looking at other health policy areas addressing interventions working in highly complex systems (such as stroke policy) have highlighted the challenges of having to adhere to one rigid, universal policy which often lacks the flexibility to 'capture the complexity of individual responses' (Abrahamson and Wilson 2019, p.8).

The concept identified in NPT of 'contextual integration' is relevant here and refers to the way resources are allocated by following defined protocols, policies and procedures (Finch et al 2015). The ability to allocate resource depends not only on actual availability but also on how commodities are shared across different parts of the system and the ease of access that one part of the system has with another, enabling greater connection and flexibility. This is nowhere more noticeable than in the allocation of resource across health and social care. In instances where models had been developed that enable the sharing of resource across different parts of the system, as in the accountable care system in case study C, the reported outcome was more flexibility, clearer shared goals and greater transparency.

The case studies highlight that when the required contextual factors are in place, it was possible to achieve effective working practises characterised by partnership. The best examples of this look beyond the dislocation of systems, focussing less on organisational barriers and instead reconceptualise how services can be positioned around the patient. Responding to patient need drives professionals to overcome organisational constraints. Staff were enabled (either formally or

informally) to work collaboratively often on their own initiative. In addition to pooled budgets appropriate governance arrangements needed to be in place both to enable effective communication, to share data and to ensure that the decision-making process did not become too cumbersome. Effective partnership working was enabled when:

- Staff had the confidence to assert their own initiative and to be flexible in relation to job role.
- Different players across the system understood and were aware of the reliance of one part of the system on another.
- Additional support was provided to bring about more consistent commissioning. In London, for example, the work of the pan-London clinical network was identified as playing a role in facilitating joint work, encouraging sharing of tools and raising of minimum standards. Whilst the establishment of STPs will encourage more collaborative working and may contribute to larger scale shared systems, there may be a role for a more formal national contribution to help disseminate good practice, reduce replication and mandate national guidelines for minimum standards.

Is the policy workable? (meso level)

The question of workability is relevant both to commissioners and health professionals.

For commissioners, the ability to successfully fulfil the required role depends largely on whether they have the skills, access to data and necessary support to enable the commissioning of necessary services. For health professionals, who have to build accountability, there appears to be a greater onus on relationships with patients and the necessity to maintain confidence in the way EOLC policy is enacted. Various examples from the case studies demonstrate the conflict that professionals feel if they lose confidence in the efficacy of the advice or support they are offering. Frustration was voiced for example when the system was so fragmented that professionals weren't able to maintain oversight of the whole patient pathway, or where resources were so thin on the ground that the offering being made was considered unrealistic and impossible to achieve.

Relational integration is used in NPT to refer to the work people do to ensure the system operates efficiently to produce intended outcomes – one example from EOLC may be the electronic palliative care systems (EPaCS) that operate to ensure information about EOLC wishes is shared seamlessly across organisations. Case studies found that where systems work together and achieve interoperability, then patient information can be effectively shared, however many instances were

revealed where the system is clunky, with numerous barriers presented across geographical area, organisation and professional group. If professionals lack confidence that the information they gather from the patient, pertaining to their wishes at EOL, will not follow the patient along their journey, then this creates further disincentives to creating ACPs.

Another aspect of the ability to enact a programme in NPT is the idea of ‘skill set workability’ which refers to the importance that the right people are assigned the right jobs. In something as complex as the implementation of EOLC, being clear about which professionals are assigned to which tasks and ensuring they have the right skill set to achieve these tasks, is particularly challenging. EOL commissioners were seen to be a group with significant variation in skills, competence and support – impacting on their ability to manoeuvre their way effectively through the system.

Both commissioners and clinicians suggested that whilst policy was strong on aspiration, it was not always backed by adequate technical guidance and there was an assumption that the skill levels of those involved (particularly commissioners) was not always adequate. Results from the Lancaster study (2017), exploring the reasons for inequities in local EOL services, show that standardised information is not being used to commission services and there is confusion around responsibility for service provision.

The commissioning function for local health services was, at the time of fieldwork in 2019, at a point of considerable transition and flux as CCGs were being disbanded and becoming subsumed within STPs. Data collected highlights the important role that individual commissioners play in determining how services are planned and prioritised and how this is impacted by the knowledge commissioners bring to the job, and their ability and motivation to consult with related professionals (particularly clinicians). Whilst guidance for EOL commissioning exists it was clear from the research that not only were a wide range of different tools and data systems used – but also that commissioners come to post with varying levels of skills and experience. It is anticipated that STPs will commission at larger scale involving fewer, more highly qualified commissioners.

7.3.1.4 Reflexive monitoring

In order to assess the impact of the work being done to enact EOLC policy it is necessary to have ways to appraise and monitor progress. Finch et al (2015) refer to ‘systemization’ as the act of determining the value of a particular practice – methods for achieving this range from Randomised Control Trials (RCTs) to informal collection of anecdotal data. Respondents in this study agreed in the

value of data collection and monitoring – and highlighted some of the challenges relating to identifying appropriate KPIs, collecting data and putting it to good use. A particular issue identified was concern over the value attributed to quality of life, and experience of care, versus ‘harder’ clinical measures which may be easier to collect. Appraising the value of interventions is carried out continuously, both consciously and unconsciously and leads to adaptations and modifications. Recognition, for example, of the lack of integration of the system and the consequent fragmentation of the patient pathway at the EOL, has led to attempts to introduce a number of more integrated models of care.

An ongoing challenge is the difficulty of equating like with like and arriving at effective ways of measuring complex community based interventions (Minary et al. 2019). The veracity and robustness of data is often called into question. Sallnow (2018), for example, highlights the anomalous outcomes of evaluations looking at the value of schemes to reduce social isolation. She muses on the disparity between the findings of Charlesworth et al (2008) on the one hand, who undertook an RCT of a befriending intervention and concluded that befriending is not effective in improving wellbeing. And on the other, in stark contrast, a meta-analysis of social isolation carried out by Holt-Lunstad et al (2010a), which suggests that access to a social network results in a 50% mortality improvement. It is difficult, Sallnow (2018) concludes, to reconcile these two positions. Whilst the studies are asking different questions, of different populations, both are trying to understand the impact of social support and networks on isolated and vulnerable populations. Links can be drawn here with Foucault’s theories of ‘bio-power’, considered in the next section, and the suggestion that positivist versions of the truth, such as those drawn from RCTs, are favoured over qualitative data where more subjective, experiential data is privileged.

It is notable that there have been few attempts to measure the value of EOLC policy – perhaps reflecting some of the challenges identified in this thesis of both defining what policy is and the complexity of evaluating its impact.

In summary NPT is purported to add greater explanatory power to the research findings: that where EOLC policy is believed to be coherent, and professionals are able to engage and appreciate the value conveyed to patients, then prescribed policy will be followed. Participants will act together, reflexively monitoring the impact of their work through observation and feedback from patients. For this process to work, there needs to be coherence and congruence from all levels of stakeholders; in

other words patients, carers, managers and health professionals all need to engage with and believe that policy will result in outcomes that fit with patient preference.

Whilst NPT works well, particularly at the meso level, to add explanatory power, providing insight into the implementation of EOLC policy, it appears to fail to account for the pervasive influence of inherent power structures that influence individual behaviours and contribute to the coherence (or lack of it). Clarke et al (2013) suggest that NPT places too much emphasis on individual and collective agency, without explicitly locating this within the organisational and relational context in which the programme is being implemented. However, May et al (2018), in their review of NPT studies, suggest that its particular value is as a conceptual toolkit – used to address practical issues relating to implementation – stressing its versatility and the fact that it can be used in combination with other theories. The next section considers how exploring the findings in relation to commentators such as Foucault and his theories of power may help add further insight in helping to conceptualise the triggering of mechanisms.

7.3.2 Does consideration of inherent societal power structures add explanatory power to theories of EOLC policy implementation?

Michel Foucault, the French social theorist and postmodernist, has been persuasive in articulating theories of power as diffuse, 'every-day' and far reaching. I will argue here that an understanding of the often insidious nature of power throws a light on a number of mechanisms integral to the programme theory developed in section 7.2. Power is embodied in discourse, knowledge and 'regimes of truth' (Foucault 1991) and manifest in numerous social, political and cultural practices. 'Power is everywhere' and 'comes from everywhere' so in this sense is neither an agency nor a structure' (Foucault 1998, p. 63). Of particular relevance to the current thesis is Foucault's concept of 'biopower' which he uses to describe the process by which modern nation states regulate and control subjects through numerous different routes.

One way that Foucault argued the body was controlled and regulated by the state was through medical science. According to Foucault the aging body is a body of deterioration or defect. Senility and aging, within this context, are considered 'deficient', 'incompetent', or 'deteriorating' (Niamsri and Boonmongkon 2017). The bio-medical paradigm considers aging as something that should be fixed and put on hold for as long as viable. Foucault's concept of bio-power espouses the power of life over death, where the body is managed and disciplined in order to conquer ill health. Pertinent

here is the notion of 'truth' which, Foucault argues, is perpetuated by a range of societal discourses, sanctioned and approved by the state, and in this way come to be seen as 'true'. Gaventa (2003) highlights how 'regimes of truth' produced by scientific discourse and institutions are constantly reinforced and remodelled through societal mechanisms, including education and the media, reflecting the change and flux of political and economic ideologies. Truth is not absolute but is reflected in and endorsed by economic, political, social and cultural trends. Power, although not always repressive, plays a major role in instilling social discipline and conformity. At times it is so embedded and diffuse that it acts unconsciously, influencing individuals to act in particular ways without the need for coercion from others.

A Foucaultian analysis of EOLC policy suggests that the medical discourses and state-controlled narratives which are an integral part of policy are imbued with power which will impact on the various mechanisms identified in the CMOs. In relation to EOLC it is useful to consider the psychological/cultural influence of 'invisible power' and to explore how this impacts on relationships between patients and professionals, the nature of communication and the types of choices subsequently made by patients. EOLC policy is drawn up by those in positions of relative organisational power. National and local government, supported by local systems (including health and social care) drive through policies (using incentives, levers, pathways). Additionally, there is power inherent in the relationships between medical professionals and patients. Foucault saw medicine as a form of societal control; concerned with managing birth, death and illness. He developed the concept of 'the medical gaze' - describing how doctors modify the patient's story, selecting what they consider to be the relevant parts and fitting it into a biomedical paradigm. Information that does not fit with the medical paradigm is filtered out, and in this way, it is argued, medicine can create an abusive power structure (Misselbrook 2013). One of the strongest themes emerging from the case studies was the importance that both patients and carers attached to 'being listened to' – to having their experience, views, knowledge validated – fitting perhaps with the sense of not wanting their identity obscured by Foucault's medical gaze. Blaxter(2010) suggests that as care is transferred from the acute to community settings, including into people's homes, the level of potential for surveillance, in the Foucaultian sense, widens. Narratives and themes emerging from the research highlight a number of ways in which power was manifest through patient/professional relationships and these are explored in the remainder of this section.

7.3.2.1 Patient typologies and individual agency

Examples, of the 'passive', docile patient, happy to submit to the greater knowledge of the doctor, were numerous, however these existed alongside instances where individual agency was used to challenge and counter these top down manifestations of power. Also in evidence were individual patients, or in some cases relatives who were prepared to exert their own wishes, and still others who referred to health professionals more as friends and confidants, with whom they were able to 'share anything'.

Silence and a refusal to enter into dialogue was one way of exerting individual power. Whilst there was at times evident pressure to adopt 'normal' or socially sanctioned behaviours (for example to opt for home as the preferred place of death) – some patients had agency to articulate wishes which did not comply with preferred guidance, or to engage in a conversation where their own needs and preferences were clearly stated, rather than simply accepting medical advice – or indeed the guidance of relatives. The ability to challenge medical power has been facilitated by a number of factors including the rise of user groups (such as Patient and Public Involvement groups), consumerism and wider access to the internet (Busfield 2017) and examples of this were evident in the case studies. Busfield (2017) argues that a prevalent view of patients as 'docile and powerless' has been over-emphasised. However, assessing levels of individual agency was complicated by the fact that patient choice is strongly influenced by the patient's social and familial networks and conflict was often witnessed between patient wishes and those of loved ones.

The way in which power relationships are played out at the end of life is likely to reflect the way patients adjust their priorities as death approaches. Some patients preferred not to dwell on talking about their health, tending towards the introspective: wanting to put their life in order and make sense of significant life events. It was not uncommon for patients to reflect on their life story; perhaps looking for authentication and a sense of purpose - unravelling their individual narrative. In this desire they appeared to want to reinforce the connection with their social selves and the need for social affirmation. Once the end was in sight and people were resigned to imminent death their priorities were not so much focussed on available treatment choices which they were happy to defer to those around them with greater agency, but rather to be treated with kindness, compassion and empathy - to have their voices heard and through this to be reminded that they are first and foremost social beings.

7.3.2.2 Access to information: knowledge is power

In an age where much of our information is mediated through the internet, with the World Wide Web offering access to a huge panoply of information, it is interesting to reflect on how this impacts on elderly patients towards their EOL. In the cohort of patients in this study only a small minority referred, unprompted to use of the internet – indeed many had no access to it and relied on younger family members or professionals if internet access was required. Lack of access for the current generation of old people to the internet, which is increasingly relied upon by public services including GP surgeries – is an evident obstacle for older people in manoeuvring their way around the system. A review by AGE UK (West 2015) on digital technologies concludes that moving public services on line, without at the same time providing tailored support to older people, is deterring some from accessing services and putting them at greater risk.

Three out of ten people aged 65 to 74 and two-thirds of those aged 75 and over are not online. There is also a link to social disadvantage. For example, while only 15 per cent of people aged 65 to 74 in socio-economic group AB do not use the internet, this rises to 45 per cent in group DE (West 2015).

Whilst those who had no access to the internet did not themselves perceive it to be particularly problematic, it is likely that the inability to book appointments, order medicines and access information on line, in the way that the majority of the younger generation are able, does have a significant deleterious impact, particularly to those in lower income groups. This is an area requiring further scrutiny. Indeed, in Foucaultian terms, lack of access to the internet, amongst the elderly, can be seen as a means of those holding power reinforcing levels of control through social mechanisms – i.e. in developing systems that consciously or unconsciously exclude the elderly from acquiring information or interacting with local services, the elderly are rendered powerless.

7.3.2.3 Interrogating EOL choices from a Foucaultian perspective

The overview of English EOLC policy, highlighted the considerable attention paid to individual patient choice in the policy narrative (section 3.5.3), yet research findings suggest the appearance of choice may not always be reflected in what is available on the ground. I suggest that lying behind the rise of the agenda to promote choice is the desire to assert a narrative where choice per se is presented as beneficial. According to the narrative patients are offered choice by an apparently benevolent state which, despite the appearance of beneficence has a hidden agenda; either to pressure patients into

compliance with the proposed choices or, on occasion, to suggest publicly that services exist when the reality turns out to be quite different.

The ability to enact choice is not just based on free will alone, but is contingent on pervasive and often invisible power mechanisms. Patient choice is influenced by factors including family situation, physical and mental condition, socio-economic status, religious beliefs as well as prevalent societal and medical discourse. The danger of establishing patient choice as a central plank in EOL policy is that these complexities are easily overlooked and professionals, as was borne out in the research, can feel pressured to encourage patients into making inappropriate binary decisions which do not properly take account of complex contextual factors. ACPs are in danger of becoming another tick box exercise for professionals to complete as part of the ongoing balancing act which straddles individual patient welfare and compassionate care on the one hand, against the routine and bureaucratic nature of healthcare on the other (Borgstrom 2015). There is also a danger, if ACPs were to become a mandatory requirement, that patients may be required to participate against their will.

Neo-liberalism and the presentation of choice as a ‘solution’

Increased choice fits with the political ideology of neo-liberalism, premised on market-based values encompassing ‘competitiveness, consumerism, economic liberalisation, efficiency, privatisation and profit maximisation’ (Viens 2019 p.148). According to this paradigm market forces begin to shape how we understand health, defined more often in its most negative sense as an absence of disease – rather than a positive manifestation of good. The individual is empowered to take more responsibility, both through adopting health promoting behaviours and through the power to select and access an array of commodified services (Viens 2019).

Affording choice to patients and encouraging them to be part of the decision-making process, is presented as something to be celebrated. Borgstrom(2015), in her interrogation of choice at EOL suggests that within the policy rhetoric, choice (particularly in relation to Advance Care Planning) is presented as a solution to a number of the rising criticisms raised against the current system. The presentation of choice may be seen to equate to honouring and respecting the wishes of the individual:

Ascertaining and acting upon patient preferences ...{is} represented {as} a solution to providing dignity and care as more people die.... Providing the ability to choose and facilitating choice are seen as goals

within policy, as choice is perceived to embody and represent a 'good death', quality of care, and to some extent, the value of personhood...In this context, choice is deemed as a triumph over the potential for failure and lack of control that death and dying present (Borgstrom 2015 p.705).

Yet, the case studies reveal that the context of choice and its relationship with the power invested in individuals is complex and multi-layered. Choices are made in a social context and the capacity to make them is greater for those who are well educated and informed. The most vulnerable will need additional help to find solutions and draw on available public services (Leadbeater 2004).

7.3.2.4 Power and tolerance of risk

Also relevant to consideration of patient choice is the concept of risk. Medical practitioners, incentivised by the fear of being accused of and held responsible for negligent practice, strive to reduce risks. Yet, one evident tension emerging in the interviews was that patients often felt their capacity to make choices was taken out of their hands, particularly if chosen activities were perceived to put them at greater risk. In keeping with Foucault's idea of 'bio-power' the increasing aversion to risk shown towards older people, is an example of how a group may be regulated and controlled by the state to comply with a prevalent medical/social discourse.

The story, recounted in chapter one, from Atul Gawande's book *Being Mortal*, echoes some of the narratives collected in this thesis. The comparison between Atul's elderly grandfather in India, enabled in his 90's to ride out on his horse to survey his land, and some of the patients in this study who felt their independence and choice was eroded in the name of health and safety – is stark. Francis (2015) cites a study of Asylums (Goffman 1961) where he notes the similarities between prisons and nursing homes:

They were 'total institutions', preoccupied with minimising risk and facilitating staff routines at the expense of granting adult's autonomy and self-respect. Even now, there are many nursing homes in which clients are not allowed to walk alone in case they fall, eat certain foods they want in case they choke, use knives in case they cut themselves (Francis 2015. p.1).

A number of commentators (Francis 2015; Gawande 2014) assert that the modern day obsession with avoiding risk, takes power away from patient and stultifies the lives of the most vulnerable in our society. We have exalted longevity over what makes life worth living (Francis 2015). Mead and Copeland (2000) argue, from the consumer perspective, that risk is inbuilt into the experience of life, and consumers have the right to assess the level of risk they chose to take. However, the danger it seems, towards the end of life, is that both professionals and relatives may perceive the patient to be incapable of being responsible for their own conduct. Patient desire for independence is viewed

as reckless in the light of the many potential dangers to trip, fall and choke. Rather than being allowed to be their own expert, patients have choices taken away. Safety and longevity triumph over individual enjoyment or quality of life.

Risk aversion argues Neal (2000) is a symptom of our over-medicalised death-defying society. In days of old, he says, death was integrated into everyday life. Whilst death was sad, society accepted it with pragmatism; it was a normal part of life. Death now, has become segregated from normal life:

From being something expected and integrated within the domestic sphere, death has become increasingly segregated and hidden from view. This trend has contributed to the development of healthism and aversion to risk (Neal 2000 p.18).

7.3.2.5 Bio-power and the devaluing of social care and the social care workforce

A significant finding from the case studies was that patient relational care and the way carers (both formal and informal) were supported was prioritised less than clinical care – again echoing Foucault’s assertion of the dominant hold that medicine has over society. The direct impact of this was that carers tended to be undervalued and poorly recompensed. The breadth of this thesis has meant that this crucial area cannot be considered in great depth however Maslow’s (1943) seminal work on human needs may help inform future study in this area. Maslow proposed a hierarchy of need: physiological, safety, love and belonging, esteem, and self-actualization. His contention was that unless and until an individual’s most basic needs were met – higher level needs could not be actualised. The suggestion is that unless those looking after patients have their essential needs met they may struggle to reach out to the people they are caring for with kindness and compassion. Maben et al (2012) drew similar conclusions from a study exploring links between staff and patient experience – they found that on wards where staff were caring for acutely ill older people, those staff who reported feeling cared for and supported themselves, were better able to provide personalised care to the more needy patients.

7.3.2.6 The primacy of the medical model of health

Findings presented here suggest that the medical model of health, built on the paradigm of ‘evidence based medicine’ (EBM) prevails and that this hegemonic discourse has supported the raised status of clinical medicine (Murray, Holmes and Rail 2008). The accusation some direct at EBM is that it prevents other means of enquiry or knowledge from being taken into account and, at its

worst, perpetuates the power of certain groups in society at the expense of others (Murray et al. 2007). Certainly, the elevated status of clinical medicine when compared to social care suggest that personal patient experience and relational care are devalued by our current health and care system whilst transactional process and hard, clinical outcomes are prioritised.

Evidence based medicine supports a post-positivist epistemological stance, focusing on facts and an external, knowable reality (Sallnow 2018).

Indeed narratives emerging in this research, support Illich's (1976) assertion, touched on in chapter two, that modern medicine has in some senses emasculated us; robbing us of the power and ability to talk about and deal with death as a society. Indeed, a clinician recounted a powerful story of the fury of a son whose mother had died. 'I can't believe' he had shouted 'that in this day and age you let my mother die' (C.Clinician.8).

This seemingly relentless drive to live longer instils in us all a sense of immortality, where to let someone die is perceived as a failure, a betrayal of modern science. There is an expectation that progress equates to longer and longer life expectancy and recent reports from the Institute and Faculty of Actuaries (2019), suggesting that life expectancy projections are slowing down and in some cases even deteriorating, have been met in the press with condemnation (Collinson 2019). Yet given the rapidly changing demographic discussed in chapter one and the increasing demands this places on our health and social care system, how does the rhetoric of progress and its aspirations to continue to extend life expectancy ever further, translate into the realities of finite budgets and health economics – not to mention arguments about choice, quality of life, respect and dignity? The reframing of death and dying by modern medicine and the tenacious drive towards immortality, at times eclipses the impact this has on other areas of our lives - both in terms of the cost (materials and staff resource) and the human experience (quality of life), that were alluded to in many of the case study interviews. Professional clinicians and service managers are burdened with life and death decisions; how much money and resource should be invested in extending life? For how long? At what cost and with what impact on the quality of the life still lived? (Seymour and Gott 2011).

7.3.3 Can social capital contribute to strengthening relational care at the end of life?

The third MRT considered to add conceptual power to the current thesis is that of social capital. A number of commentators have reflected on the dangers of health policy putting too much emphasis on individual agency and overlooking the individual as a social being (Ahmed et al. 2014). There is

growing recognition that individuals need to be supported by using the assets of communities as well as the formal health and care system (Ham, Charles and Wellings 2018).

The notion of social capital although not described in those words, was alluded to by many respondents who espoused the importance of community support, networks and infrastructure from which practical, psychological, and social support systems were accessed. Social capital is a term popularised at the end of the twentieth century and although its precise definition is contested it refers loosely to the extent of connectedness and solidarity between groups in a particular local area or society (Kawachi and Berkman 2000; Putnam 2000; Wilkinson 2002). It resides in characteristics of social structures (such as levels of interpersonal trust, norms of reciprocity, links with civic society) which act to support individuals and can promote and facilitate collective action. Social capital, in this sense, is a form of social cohesion (Kawachi 2000) which is lodged not in the individual, but in the structure of social relationships. Links have been found between social capital and health, with evidence to suggest that individuals living in socially isolated areas, where social capital is high, report better health than in areas where it is low (Eriksson 2011). Three plausible pathways by which social capital impacts on health are proposed (Kawachi 2000):

- health-related behaviours through diffusion of health information or by exerting social control over marginal or deviant behaviours
- access to services
- psychosocial processes.

The concept of social capital builds on the Durkheimian sense of a cohesive society, marked by an abundance of 'mutual moral support' which allows members of communities to support each other when energy is low (Kushner and Sterk 2005). Whilst debates rage about the precise definition, the emphasis resides either in cognitive concepts (trust/moral reciprocity) or in the structural side (networks) of social capital (Moore and Kawachi 2017).

Drawing on the notion of social capital there has been a call (Sallnow et al. 2016; Kellehear 2013) to embrace a model of public health which places more emphasis on the social determinants of health and the influence of communities in the development of better health for all. A public health approach to palliative care, seeks to build and operationalise social capital, 'encompassing civic action, reform of healthcare institutions and local community action' (Sawyer 2019. p.10.) Within this model the focus is on empowering communities to support those dying, bringing to the fore

expressions of a compassionate society and in so doing challenging the 'professionalisation' of EOLC (Kellehear 2013).

In his call for a more compassionate, community based, model for EOLC Kellehear (2013) cites examples of volunteering projects to support the frail elderly and outreach programmes, linking school children with hospices, contributing to changing attitudes and broadened responsibility for EOLC within local communities. He cautions a growing disconnect between the basic family unit and their connection to broader community networks, the impact of which, he contends, is a growing dependence on professional input at EOL. Broader community involvement which promotes social, psychological and spiritual aspects, alongside physical health is seen to be the most robust strategy to living with a life-limiting illness:

Involving schools, workplaces, places of worship, the mass media or local businesses could help mobilise untapped sources of social and spiritual care and support as well as practical resources (Kellehear 2013. p.1074).

Examples found in the current thesis relating to the value of social capital include community development projects such as the 'compassionate neighbours' scheme' (chapter 6.2.6), together with numerous observations by individuals about the challenges of isolation and benefits of strong social networks.

Building social capital in end of life care

Whilst work in this area is new and evolving, early results demonstrate positive outcomes. Eriksson (2010) documents that particularly amongst individuals reporting high levels of cognitive social capital (trust and reciprocity), self-rated health is found to be correspondingly high. On the cautionary side there have been warnings (Kawachi and Berkman 2000; Eriksson 2011) that running alongside the potential benefits of creating a sense of cohesiveness and belonging, there may too be negative consequences concomitant with 'being left out'. However, despite salutary warnings the link between high levels of social capital and positive health outcomes leads commentators to support a new look at the nature and quality of interactions among people (Sallnow 2017; Kellehear 2016). Sawyer et al (2019) conducted a realist review of interventions to build social networks and social capital in people suffering from dementia at EOL and supported the call for a cultural shift, cutting across societal and organisational practices, challenging deeply held notions of responsibility and duty of care (Sawyer et al 2019, p.10).

Pertinent to this call for a cultural shift is Holt-Lunstad's (2010) meta-analysis of 148 studies looking at individual mortality data as a function of social relationships. Results showed that those with stronger social relationships had a 50% increased likelihood of survival than those with weaker social relationships. It appears that the beneficial health impact of building social connection may be as strong as medical intervention. Recognition of the value and importance of social capital (encompassing social cohesion and social interaction), particularly in isolated, elderly population groups may help authenticate the importance of community/civic interventions. Patients frequently spoke of the value they attached to support received from those around them (section 6.2.), yet those without access to social networks, whose social capital was low, were more likely to express feelings of isolation. The issue of risk and the apparent low tolerance that some clinical settings have for involvement of non-professionals and volunteers in EOLC was highlighted in the case studies and would need further exploration as civic society becomes more involved in EOLC.

Recent policy directives have included references to community engagement. The Ambitions for EOLC, (NPELCP, 2015) for example, includes a mention of the new public health approach under the ambition 'each community is prepared to help'. In addition to this, pockets of funding from the Cabinet Office, Hospice UK, The National Council for Palliative Care and PHE have encouraged the collecting and showcasing of good practice in new public health approaches (Sallnow 2018). A number of other policy and government initiatives, both big and small, have incorporated community engagement and social action discourse, including for example Cameron's work on The Big Society (Cameron 2009), and NICE guidance on community engagement (NICE 2016). Yet despite the growing importance attached to 'community' in much of the policy discourse there appears to be a disconnect between the clinical needs of the individual patient and the patient as a social being embedded within a social network, where needs and choices are influenced by a complex mix of social and economic variables. A more holistic approach to policy making, which pays more attention to wider structural influences, may go some way to building policies more congruent with the lived experience of patients and carers.

7.4 The rise of inequities and the impact of cuts in social care

Legislative changes which were part of the 2012 Health and Social Care Act (DH 2012) which invested greater decision making powers to local areas, through the creation of CCGs, have arguably further benefitted those who already hold power. Inequalities have been exacerbated adding to longstanding concerns that it is the more affluent who continue to be advantaged (McKenna and

Dunn 2015). Finlay's 'Improving Access to Palliative Care Services Bill' (2019) tried to introduce legislation which would have provided a mandate to bring about greater regional equality through setting minimum standards for 7 day access to palliative care, but in a parliamentary session paralysed by the political clamouring of Brexit, failed to progress past its second reading in the Lords.

The case studies provided evidence to show that where professionals were motivated, skilled and had access to resources, localism provided a platform to 'empower the powerful', with areas of good practice attracting growing funds and acclaim. However, conversely in other areas cuts to local government budgets have the potential to undermine some aspects of localism entirely – thus 'disempowering the powerless' (Hastings and Matthews 2014). A number of clinicians and commissioners suggested that mandatory benchmarks may help achieve minimum standards at a national level. More work needs to be done to interrogate what these minimum standards should be but could begin with recommendations regarding access to services, such as 24/7 community palliative care cover.

7.5 Towards a more holistic vision of care

The term 'person-centred care' used increasingly in health parlance describes '*a way of thinking and doing things that sees people using health and social care services as equal partners in planning, developing and monitoring care to make sure it meets their needs*' (Goodrich and Cornwell 2008 p.19). Although sometimes disregarded as 'management speak' – growing awareness of the importance of patient experience has promoted a new way of seeing things through the eyes of the patient; understanding their expectations, perceptions and experiences. Interviews conducted with patients and relatives in this study provided an insight into this patient perspective, often overlooked or misrepresented if only the professional perspective is sought. And one of the most striking outcomes of these narratives was the finding that whilst, from the patient point of view, their health needs were generally being met, the glaring gap in unmet need related to social support and relational care – with patients noting time and again the impact of isolation, loneliness and being treated with a perceived lack of humanity and compassion. Chochinov (2007) used the metaphor of a patient's thread, asserting that to deliver respectful care a doctor must see their patient as a person; to touch the thread that roots their patient as a social being to the real world. A failure to see the patient as a 'whole person', Chochinov warns, risks undermining their sense of self, representing a repudiation of personhood.

Examples cited throughout the research show how system infrastructure and service provision, continue to prioritise clinical outcomes over more social and relational factors. Findings suggest an imperative to revisit the prevalent bio-medical model and to find ways to challenge the current status-quo determining how need is prioritised and how resource allocation flows from this.

7.6 The role of policy in addressing the health and social care imbalance

Ambitions for Palliative Care (NPELCP 2015) suggests that the 6 six key ambitions for achieving consistently good EOL care are that:

- each person is seen as an individual
- each person has fair access to care
- maximising comfort and wellbeing are prioritised
- care is coordinated
- all staff are prepared to care
- each community is prepared to help .

Chapter six shows that for those patients who remain at home, and for the relatives who care for them there, a major barrier to fulfilling some or all of the six ambitions for palliative care (NPELCP 2015) is the fact that the social care system, particularly in relation to provision of and support for paid home care, is deemed not fit for purpose. Inconsistencies and lack of operational guidance as well as inadequate funding appear to be a major stumbling block in achieving policy goals.

A clearer policy drive reasserting the value of relational and patient centred care needs the backing of a public education initiative, focussing on cultural norms, building confidence in the appropriateness and suitability of enhanced non-professional forms of relational care at the EOL. There is a paucity of evidence demonstrating which interventions at policy level will make a positive difference to patient experience (Goodrich and Cornwell 2008). More research is needed to assess the lived experience of care provided at home (in relation to informal carers, paid carers and patients) and to use this to take a broad view of how funding for health and social care should be re-aligned, to fit better with patient priorities.

One challenge, raised by the findings presented here, is to find a way of bringing the choices available in the system more into line with patient priorities. The problem of how patient priorities should be reflected in public policy is challenging – demanding, perhaps, some sort of system of weighted prioritisation, whereby the perspectives of those at EOL (alongside the perspectives of

clinicians and policy makers) are incorporated into a formula for determining the spending of public funds. The pattern observed over the last decade of increasing the spend to clinical health and medical provision, whilst cutting the allocation to those relational issues – so highly valued by patients (including funding to social care) urgently needs to be addressed (Charlesworth 2019).

Whilst this thesis has questioned the relentless drive to extend length of life, the complexity of the numerous moral and ethical issues involved when developing policy around life expectancy should not be underestimated. Yet it is perhaps time to review the notion that extending length of life is an unquestionable sign of positive progress. In 2018 a government document was issued stating the ambition to increase life expectancy for the whole of the UK population. It pledged:

To improve healthy life expectancy so that, by 2035, we are enjoying at least five extra years of healthy, independent life, whilst closing the gap between the richest and poorest (DHSC 2018).

Policy makers should be cognisant of the views of some of those interviewed in this thesis, whose perceived quality of life had diminished to the point they no longer wanted to struggle on, and mindful too of the human and relational aspects of life that, for many, make it worth living.

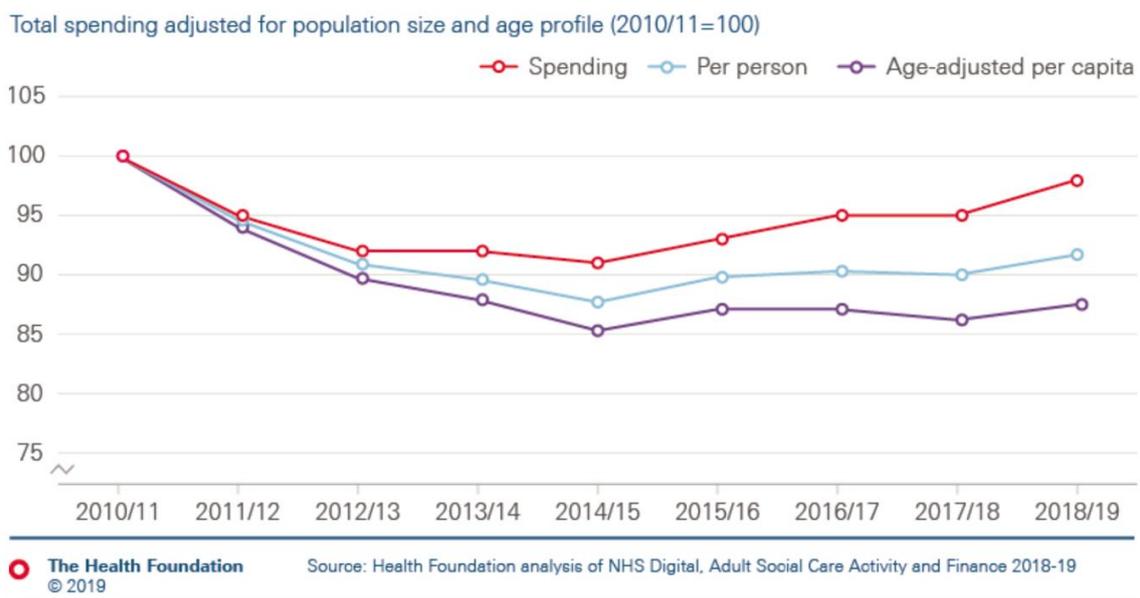
7.6.1 Funding health and social care

A recent independent commission established by the King's Fund has argued for the introduction of a simplified, single health and social care system where access to support is based on need per se – rather than whether the need is categorised as either 'health' or 'social care' (Barker 2014). It has been suggested that an important first step in providing a more equitable approach to responding to individual need is to provide for both health and social care from the same funding pot, using a set of criteria where neither sector is privileged over the other. Barker (2014) proposed a system where access to funded care gradually increases as needs rise, explicitly acknowledging the circumstance of EOL as a time where greater support should be available.

The picture that emerged from closer investigation of the experiences of EOL services, explored in this PhD, is often far removed from the aspiration to provide a joined up seamless service along the patient pathway. Confusion was voiced, by stakeholders at all levels, over how services were funded, commissioned and regulated with blurring of boundaries between statutory and voluntary sectors, the NHS, local authority and charitable enterprises. At the root of the fragmentation and significantly impacting on the way services are run, is the way funding has historically been distributed across

health and social care. Health-care spending accounts for £1 in every £5 spent by the government – amounting to more than £150bn across the UK in 2019/20 (Gershlick et al 2019), whilst public spending on adult social care, is around £18bn. Figure 20 (below) shows how social care funding over the last decade has fallen in real terms from a peak in 2010/11 – with a decrease between 2010 – 2019 of 4.9% (Charlesworth 2019). Additional pressures on the social care system with an aging population have meant that access to services has been substantially reduced (Gershlick et al 2019).

Figure 20 Trend in total spending on adult social care between 2010 and 2019



Source Gershlick et al 2019.

Demands for a fairer funding system for social care are growing louder and more clamorous (Humphries 2013, Gerschlick 2019, Charlesworth 2019) though root and branch reform remains elusive. Dilnot (2011) put forward a plan to cap the cost of care for older people, but whilst parliament agreed and legislation was passed in 2014, the issue became too politically fraught and has been postponed with ongoing posturing and prevarication from all parties (Charlesworth 2019).

An important first step, highlighted by results from the case studies, may be to address the iniquitous pay and conditions of staff working across health and social care with current rates of pay being much lower than equivalent roles in the NHS – with average care sector wages reported to be £6.78/hour – below that paid in most supermarkets (Skills for Care, 2019). One in five social care staff are on a zero hours contract, with high rates of staff turnover. The Health Foundation

(Gerschlick et al. 2019) recommend that as a priority staff pay in social care should be boosted and access to services be improved.

7.7 Chapter summary

This chapter has highlighted some of the complexity involved in answering the research questions about EOL policy; namely how does English national EOL policy and the way it is interpreted by the key stakeholders, help guide effective practice? Three mid-range theories have been proposed to help conceptualise theory and inform the implementation of effective policy. NPT was introduced as a tool to help identify, characterise and explain the key mechanisms involved in implementing EOL policy. Whilst it was suggested that NPT elucidates mechanisms at meso level, its explicatory powers at the micro and macro levels were less persuasive and theories developed by Foucault relating to power and the potential for social capital to build potentially beneficial social ties for those at EOL, were purported to add additional explicatory power. Also considered was the notion of system complexity and how policy implementation is bound inextricably into the different system levels. Finally, the importance of boosting the status and funding of social care was reviewed in the light of growing inequalities and system fragmentation.

Chapter 8: Conclusion

This final chapter begins with an overview of key findings, offers insight into the research methods and the challenges encountered through the course of the study, looks at study limitation and offers some personal reflection. It concludes with suggestions for future research together with recommendations targeted at policy makers, clinicians, commissioners and civic society.

8.1 Overview of findings in relation to research questions

A fictional Edith Sitwell, the redoubtable poet and writer, portrayed in a recent BBC radio drama, responded to a query about her health with the words: 'dying, but otherwise in very good health' (Cooper 2002). Having spent the last three years immersed in narratives around death and dying this matter of fact riposte struck a chord and seemed to resonate with many of the discourses collected through this study. The message conveyed of strength, resilience, and the resolute wish to carry on as normal even as death becomes more imminent, felt strangely familiar. Many of the patients I spoke to, rather than wishing to spend their last days wrapped in cotton wool, wanted to be able to turn on the washing machine, hold their loved one's hand, make sure their children were provided for. And others who even though they were reportedly EOL, repeatedly claimed to be in 'good health'. The narratives collected spoke of the importance of not over medicalising death and dying. The focus was rarely on a continued wish to fight the disease, and whilst there was a desire to be pain free, other priorities were to maintain independence, to be treated with kindness, not to be a burden and to stay connected, as far as was possible, with family and friends. There came a point where quality of life was more important to those reaching the end, than extension of life. The previous chapter discusses the importance of policy alignment; that policy coheres both with patient priorities and professional views. Yet the lack of coherence between stakeholder priorities and the reality of provision was starkly highlighted in the research findings.

Whilst the importance of and value attached to EOLC policy by professionals was evident, and there were examples demonstrating where it was applied effectively to help bring about more consistent outcomes, yet there were areas which need to be addressed if policy is to help achieve equitable and good quality services for all at EOL. Notably, policy must be aligned with the priorities and perspectives of stakeholders at all system levels, and must have the necessary resources invested, including adequate support and training for staff. The commissioning role was key and although

currently undergoing some level of re-alignment with the creation of STPs, fuller consideration of the skills needed by those in commissioning roles is seen as pivotal to help achieve equity across local areas. Additionally, the ability to monitor progress, using key performance indicators that accurately reflect quality outcomes and patient priorities, should be at the forefront of the policy agenda. At the macro and meso level the importance of integrated, joined up systems, where staff were enabled to work flexibly was emphasised, as was the urgent need to realign the health and social care sectors. Cuts in funding to social care over the last decade have exacerbated the inequities, with staff who care for the elderly at home being particularly poorly treated, under paid and undervalued. Finally, the potential to broaden responsibility for EOL, particularly promoting policies that enlist citizens to build local networks and mechanisms for supporting those at EOL is highlighted.

One of the strengths of this thesis is the attention paid not only to professionals but also to the voice of people approaching EOL and the relatives and carers looking after them. The nature of aging and dying is changing. We are living for longer with an increasing number of illnesses and complaints which impinge on our quality of life. As we are invested with the potential to stay alive for longer we must become more courageous about voicing what our priorities are. Most patients I spoke to were clear that being treated with kindness, dignity and compassion was a priority – yet in relation to the distribution of public funds it remains unclear how these priorities are responded to, indeed the dominance of medical discourse remains prevalent. Funding to the health care sector continues to rise whilst social care is felt to be overlooked and undervalued.

Researching EOL is an area of study fraught with numerous logistical, moral and ethical challenges – yet unless efforts are made to record their experiences there is a danger that the needs and priorities of this vulnerable group will go unrecorded and largely overlooked. The importance of listening to patients is as pertinent today as it ever has been and the findings demonstrate that all too often the needs of the patient are packaged into different service areas; clinical needs on the one hand and social needs on the other – often leading to a sense of fragmentation, frustration and obstruction.

The moral quandary, presented in chapter one, which motivated me to embark on this thesis, considered how the rising anxiety over soaring health-care costs on medications and clinical interventions, running alongside a fall in social care spending and examples of neglect of elderly social and relational care, fitted with priorities of those at EOL. The emerging theories, developed in

chapter seven, which contribute to the conceptualisation of the successful implementation of EOLC policy, point to the importance of ensuring that the priorities of the various stakeholders align with the ambitions of policy. A number of tensions emerged between the aspirations of policy and contextual challenges which may mean the mechanisms necessary to enact policy are less likely to trigger. In addition the various social theories introduced in the MRTs demonstrate how concepts of power, social capital, trust, coherence, system complexity and reflexive monitoring may all influence outcomes. Case study findings underline the complexity of effectively embedding the provision of equitable EOL policy and practice, suggesting that a multifaceted strategy is required, with input both into strategic structures at the top system level and more local, grass roots support to staff, carers and patients.

The task confronted by politicians and commissioners, in dividing up the budget to support public services, is enormously difficult; with the need to consider a huge raft of moral, ethical, economic and social arguments. Yet unless the views of stakeholders at all positions in the social hierarchy, from those at the top level of government, commissioners, clinicians, families through to the frail-elderly who are close to death, are fully considered – resulting policy, despite the rising sums of money invested, will fail to meet the needs and preferences of those it sets out to serve.

Writing this concluding chapter during the Spring of 2020 as the panic of the corona virus pandemic sweeps the nation, the findings of the thesis appear all the more relevant. Unprecedented numbers of deaths in care homes have fuelled the suspicion that securing Covid-19 testing and personal protective equipment (PPE) in the care home sector was considered less of a priority than provision across the NHS. Cowper (2020) in the HSJ considers how the gulf between the ‘two cultures’ of the NHS on the one hand and social care on the other have become increasingly polarised. As the pandemic spread in early March the government pledged to throw whatever was needed at the NHS whilst social care (initially anyway) remained largely ignored (Cowper 2020) – indeed it was only as increasing numbers of coffins were taken out of care homes that attention was turned to the sad plight of this forgotten sector. A Guardian editorial in April (Booth 2020) proclaimed a verdict of ‘culpable neglect’ in regard to the government’s treatment of the care sector, citing: lack of routine testing; shortage of PPE; residents being isolated from families and routinely asked to sign ‘do not resuscitate orders’. The article refers to the sense of anger, despair and betrayal felt by both those resident and working in social care.

Another area of concern to emerge during the Covid-19 pandemic, that resonates with findings from this thesis, has been reports of insensitive approaches made towards many of the frail elderly, particularly those in care-homes, encouraging them to complete DNAR forms, or of attempts to impose blanket DNAR orders on particular residents in care homes (Booth 2020). The pressure on beds in intensive care has rightly meant that efforts not to hospitalise those who have chosen not to have invasive treatments (including ventilation and resuscitation) have been redoubled, yet this research has shown how important it is that conversations around choice at EOL are both timely (i.e. that they take place at a time when the patient doesn't feel pressured and retains cognitive capacity) and handled with sensitivity – they should not be conducted as a knee jerk reaction in a crisis. A joint statement issued by the health regulator (CQC et al. 2020) confirmed that 'blanket policies' around DNAR orders were inappropriate yet emphasised the importance of older people, particularly those who are frail and suffering co-morbidities having an ACP in place.

Yet, alongside the huge pressures faced by both health and social care services it is evident that the strength of the response to the virus from civic society, in the form of establishing local community support networks and the rise in volunteering has been, and will continue to be, immense (Easton 2020). The potential for mobilising social capital and the huge power local movements can have, perhaps provide an opportunity to subvert some of the hegemonic power discourse discussed in the previous chapter. Indeed, one government minister conjectured:

This virus will be a measure of "social capital" in every country of the world, the strength of the glue that holds communities together (Easton 2020).

Perhaps most importantly this thesis reminds us of the priority attached by patients and their families to the social and relational aspect of death and dying, which whilst acknowledged in policy documents is not always recognised in practice.

8.2 Discussion of method

Chapter four presented a rationale for using RE to interrogate how EOLC policy may be used to bring about better quality, equitable EOLC. RE was considered an appropriate method of enquiry to maximise learning within the complex world of national policy and its application across institutional, organisational and individual barriers and boundaries. Its recognition of the complexity of the social world and acceptance that causality is often not linear – fitted well with the multi-layered nature of this enquiry. Whilst I am confident that the chosen method was appropriate it was

not without its challenges, some relating specifically to RE and others to more general issues relating to qualitative methods, elucidation of which may be helpful to inform future studies in this area. The next section begins with reflections specifically relating to RE methodology, before moving on to look more generally at challenges arising from qualitative and case study research, particularly with vulnerable groups.

8.2.1 Evaluating programme success – limitations in relation to outcome data

The initial rough programme theory (RPT) for this study was conjectured on the basis of the stated intended outcomes of EOLC policy. An articulated theory for how it was anticipated EOLC policy worked could not be identified from the literature. The supposition was that the mechanism worked through the creation of developing an aspirational template or set of markers – laying out what good practice looked like. The initial theorised outcome within the RPT was broad; namely that *‘equity of provision and quality was maximised from both a patient and systems perspective.’* However, the extent to which the relative success or failure of anticipated outcomes being achieved could be assessed was limited. For each case study site CQC inspections were reviewed, as were publicly available measures provided on the NEOLCIN website (NEOLCIN 2019) – however impressions of quality and equity within each case study were surmised mainly through self-reports, largely based on the experiences of patients, relatives and professionals and gleaned through analysis of the qualitative in-depth interviews. Whilst case study selection was guided by a range of factors (section 4.4.2) including relevant KPIs lodged on the NEOLCIN website – beyond this quantitative data was neither collected nor considered.

8.2.2 Definitions and understanding of CMOs

My understanding of and ability to use and identify CMO configurations, developed and evolved through the course of the research. A number of commentators (for example Dalkin et al. 2015) have recognised the potential for confusion in distinguishing between context and mechanism, particularly when working in complex environments with a myriad of different stakeholders, across a variety of sectors and settings. On reviewing the first set of conjectured CMOs, developed following the scoping study I became aware that I had, on occasions, fallen into this trap and confused mechanism with context. Dalkin suggests (2.1.5.3) that ‘mechanisms’ be separated into two parts; the intervention (referred to as ‘resources’) and the mechanism linked to individual reasoning or ‘agency’. Reviewing this thinking was helpful and as a result, in the second iteration of CMOs my central focus was on how this mechanism, (that is the decision making process that influences the extent to which EOLC policy is followed and implemented), was triggered. The ‘resource,’ in this

case, is the specific aspect of policy which applies to that CMO, and 'agency' relates to behaviours such as reasoning, motivation, level of engagement or commitment of the 'actor' in enacting policy. Through clarification of these definitions I became aware how I had in some cases conflated mechanism with context. For example, in the conjectured CMO for EOL commissioning (Appendix 4.12) I suggested that the 'resource mechanism' was:

Professionals are educated in and enabled to use the policy framework to commission and implement effective services.

In the revised commissioning CMO (6.2.5), 'the provision of education and support' to commissioners becomes a contextual factor which needs to be in place if the mechanism, is to be triggered. The revised mechanism becomes:

The commissioner believes that using policy benefits outcomes and as a result will be motivated to use policy to inform decisions around commissioning evidence based local services.

8.2.3 Linking context with mechanism

In some RE studies, CMOs are shown as linear arrangements. In such cases a particular contextual factor is the key causal determinant that triggers a mechanism - in turn bringing about an identified outcome (Rolfe 2019). Respondents in this study, as was reported in chapters 5 and 6, identified a wide range of contextual factors which they linked to outcomes and consequently multiple contextual factors are implicated in programme theory. However, the conjectured mechanisms proposed within the CMOs presented in chapter 6, were seen to operate at different levels (individual, organisational, societal) and different contextual factors are implicated to different degrees within each CMO. Like Rolfe (2019) and Byrne (2018) I found that amongst the many contextual factors identified, being able to assign the degree of causal impact that any one factor has, in relation to triggering the mechanism, was problematic. Pawson (2013) advises that researchers resist producing 'lists' of items when building CMOs, rather they should build propositions, where the different components are integrated - yet there appears to be scant guidance as to how this can be achieved.

8.2.4 Realist interviewing technique

Chapter four explores the RE style of interviewing, describing how its intention is to test the veracity of the proposed programme theory. The interviewing style is based on a 'teacher/learner

relationship' where the interviewer introduces the interview by subtly communicating the conjectured theory – giving the respondent the opportunity to either support or refute these ideas.

The subject matter of the interview is the researcher's theory and interviewees confirm, falsify, and refine this theory (Manzano 2016) .

The objective of a realist enquiry is not to elicit loosely guided narratives and ethnographies but rather to capture stories that relate specifically to the respondent's experience of the programme theory. Whilst this proved straight-forward with professional respondents it soon emerged that this style of interviewing was not easy, or perhaps even appropriate, when applied to interviewing patients (and to a lesser extent relatives) at EOL. When talking to patients, as with other respondents, I used a topic guide focussed around how patient priorities and experiences of their care align with EOL policy. My focus was to try to elicit what would either encourage or inhibit patients to choose treatment options which were aligned with national policy. Yet, as the interviews progressed, for both ethical and logistical reasons I found that interviews with patients could not be as 'interviewer' led as guidance suggests it should be (Manzano 2016).

Borgstrom (2017) considers how researchers, collecting narratives from people at EOL, may position themselves in relation to the data collected and looks at issues around reflexivity. Some commentators have demanded 'greater transparency in research accounts and call for a more nuanced understanding of how the researcher's own emotions become an integral part of analytical processes and knowledge production (Borgstrom 2017 p.3).

Aware of the power imbalance between interviewer and research subject, and the frailty of most of the patients I was interviewing, I made an early decision that although I would try to focus patient interviews around the topic guide, if they appeared resistant to talking about their health and priorities for care, then I would simply be led by their own agenda. In making this decision I was led in part by the knowledge that my focus and interests – that is, priorities for EOL, were not necessarily topics that some respondents wanted to talk about – and indeed EOL was never a term that I used in the interviews unless it was initially used first by patients. A couple of patients I spoke to, who had been identified by their GPs as being on their EOL register, when I asked, 'how are you?' declared themselves to be 'fit and healthy'. Although significant health issues then emerged as the interview progressed, it felt that the delicacy of the material under consideration, required an interviewing style which was more respondent led than RE guidance suggests. I was also influenced

by a belief that what patients told me, given that they had all been fully informed about the nature of the study, may be of value in conjecturing and refining theory.

Reflecting now, post field work, I suspect that my decision to want to make my interviews more discursive than 'transactional' was in part, an emotional response to the frail condition of many of my respondents and a sub-conscious desire to show a level of humanity, which was harder if following a prescribed template of questions. The reality was that for some patients, due to pain and fatigue, speaking was slow and laborious. With this in mind, whilst I was clear about the themes I was interested in, beyond this I tended not to be too directive.

In a number of interviews where I felt the topic guide was not going to elicit any meaningful response, I adopted the role more of a curious listener. The question I tended to ask was 'what is important to you now?' And then I would listen. It was interesting to observe a number of the themes that arose in these 'conversations'. Often, I was presented with accounts of major events in peoples' lives: the death of a husband, son, wife or daughter. Stories of immigration, of fitting in to a foreign country. Stories of children going astray or the importance of family. The sense I got was of people wanting to review the big events that had occurred in their life, to understand them and tie things together, so they could more easily accept the end. The other overriding impression was of the importance for many people of simply having a receptive ear. These observations, whilst clearly impressionistic, appeared an important part of the research process, particularly in relation to one of the major themes arising from all levels of stakeholder about the relative values assigned to social care on the one hand and health care on the other. At the end of most interviews patients thanked me for taking the time to listen to them or for providing company to break the monotony of their day:

It's nice to have your company. That's what people like me need is the company – even if it's just for an hour or two (B.Patient.3).

Do you have to go? I don't often have someone here who actually has the time to listen (C.Patient.8).

Reflecting on patient interviews following field work I suspect that my interview style with patients was more in keeping with Glaser and Strauss' (1967) visualisation of grounded theory, where the data collected is used to develop theory, rather than to refute or refine existing theory. I would suggest however that in interviews with vulnerable groups this may be a more appropriate method

than traditional RE methods and that emerging data can still be validly used to interrogate the degree of alignment between the perspectives of different stakeholders.

8.2.5 Honouring the patient voice

The interview technique I used encouraged patients and carers to reflect on a range of issues including current levels of support, their relationships with people caring for them and their state of mind. The resulting narrative was often spoken from the heart without checks on the political correctness. On analysing the data one interesting outcome of this was a dilemma I felt as a researcher as to how to appropriately deal with accounts that may be construed as offensive and yet to honour my role in relaying the veracity of what was being said. Within the very diverse communities in which the case studies took place one common theme emerged relating to ethnicity and the challenges presented of caring for a diversity of ethnic groups. Whilst it seemed acceptable for members of BAME community to reflect on the cultural inappropriateness of available services or perceived racism from health and care workers, processing comments made from white British patients and carers about how they or their relatives experienced the care received from non-British ethnic groups, presented greater challenge. Complaints about carers not speaking the required language or not knowing how to perform tasks seen to be routine amongst the white English respondents; buttering a piece of toast or boiling an egg were not infrequent. Whilst on one level such comments could be construed as racist slurs, they were often offered alongside the assurance that the carers were not bad people, indeed were often said to have the best intentions, but lacked a basic understanding of lifestyle preferences which would allow for adequate and dignified care and communication to take place. The use of 'google translate' on a mobile phone, for example, was seen to be a barrier to achieving true compassionate care to someone at EOL.

8.2.6 Logistics and uncertainty in interviewing at EOL

In common with other studies (Fischer et al. 2012; Borgstrom and Ellis 2017), focussing on the EOL, I found that field work was characterised by complexity. Challenges were encountered in relation to gaining access to patients, particularly those living at home, negotiating unpredictable illness trajectories and the sensitivity of the topics under discussion. Fieldwork had to be approached with flexibility, being sensitive to the condition of the patient on the day of the interview. On a couple of occasions, I arrived somewhere to interview a patient to discover that their condition had deteriorated and the interview was no longer viable. Gysels et al (2013) discuss how gaining informed consent from patients with serious health complications, particularly in the light of a relatively inflexible ethics process which required patients to digest considerable amounts of

information from the Participant Information Sheet (appendix 4.7a) can be difficult. I too experienced this process as onerous and clumsy (both from the patient and researcher perspective). Yet despite difficulties with consent and access, as well as fears that interview requests may be unnecessarily burdensome, the majority of patients reported it to have been a positive experience.

8.2.7 Ability to revisit respondents, test theories

Proponents of RE advocate an iterative model in which it is suggested that theories are in a constant state of flux, demanding ongoing refinement and testing. It is recommended that this be enabled (Manzano 2016) through revisiting research respondents to test the veracity of emerging theories. Such methods, present challenges with EOL populations who cannot easily be re-visited. A degree of iteration was introduced – for example, I returned to the Opening Doors Research Group (a group made up primarily of older people who act as advisers to researchers and provide an involved public perspective on applied health and social care research) to ‘sense check’ my findings on completion of field work. I also had a couple of calls and meetings with pivotal commissioners and policy representatives to clarify particular ideas as I processed the data.

8.2.8 Breadth of study

The breadth of this study, encompassing EOLC policy in all its manifestations, has been achieved perhaps at the expense of a deep understanding of any one particular policy area. Whilst it was an intentional and important objective to look at the whole system, asking how well policy is aligned between different stakeholders, the scale and breadth of the study increased the complexity both of the field work and the analysis. At times, when I was at danger of getting lost in the ‘wickedness’ and complexity of the multiple layers and perspectives, I drew comfort from the notion that truth is not absolute and singular. Greenhalgh and Papoutsi’s (2018) thinking on Complexity Science was particularly useful:

We need research designs and methods that foreground dynamic interactions and emergence – most notably, in-depth, mixed-method case studies that can act as concrete, context-dependent exemplars, including powerful ethnographic narratives paying attention to interconnectedness and incorporating an understanding of how systems come together as a whole from different perspectives (Greenhalgh and Papoutsi 2018).

Another consideration relating to breadth is that the study did not look at any one specific health condition. There will be unique and different issues relating to each condition suffered at EOL which

this study did not have the scope to consider. Alzheimer's and dementia, for example, are conditions of growing significance as the numbers of the population affected are growing and commentators warn of the need to identify and respond to rising need (Ellis, Winslow and Noble 2016).

8.2.9 Case study sites and governance procedures

Markers used to select case study sites

The methods I used to select the case study CCGs, were based on a desire to reflect a range of different outcome measures (across a spectrum of levels of perceived success relating to quality markers). However, as I became more familiar with the data these methods appeared more fallible. For example, the validity of the measure of 'death in preferred place of residence' as being a marker of good quality EOLC was called into question by a number of commentators. Nonetheless these measures continue to be collected nationally and as such distinguish different approaches and ways of working.

Case study boundaries and logistics

Case study sites were largely unboundaried. Although each case study was limited to the geographical area of the CCG, within this there was no limit put on the type of setting in which interviews were conducted. Interviews were conducted in people's homes, public spaces, NHS organisations, care homes, nursing homes, hospices and voluntary organisations. The impact of this in terms of logistics and the time spent seeking permissions from a large range of providers and the processes that needed to be followed, were not always commensurate with the amount of work conducted in each organisation. Whilst some systems were relatively straightforward to navigate others took weeks/months and involved filling in similar information, on different forms, with different headings, that then had to be checked and scrutinised by individuals working in the different organisations approached, in each case at considerable cost in terms of staff time. To undertake my three case studies I had to apply for separate permissions from:

- NHS Research Ethics Committee (REC)
- The host CCG
- A local mental health and community trust
- The ambulance service
- One hospice
- Three care homes

As the drive towards integrated working pushes forward, in a bid to reduce wasted time and resource, research managers may usefully consider how governance systems for research ethics can be used across different settings. The NHS REC system has achieved a route for accomplishing this across certain parts of the NHS though the system remains clumsy and cumbersome.

8.3 Limitations of study

The case study approach adopted privileged depth of understanding over generalisability. All three sites were based in urban areas, all with highly diverse communities and all with wards characterised by high levels of poverty. In addition, London has demographics which distinguish it from the rest of the English population, namely the age profile is younger than the national average, there is greater ethnic diversity and life expectancy is longer. Marmot et al (2020) report that across every deprivation quintile, life expectancy was higher than for any other area of England. The average life expectancy for women in the lowest deprivation quintile in London is 81 years compared to 76 years in the North East of England. The 'protective effect' of living in London is no doubt due to a number of variables some of which will have impacted on this piece of research and means that the results have limitations when generalising to geographic areas beyond London. London is also unique in relation to the profile of its workforce. The adult social care workforce in London has the lowest proportion of British born workers: estimated at 60% (Skills for Care 2019) – again this introduces a London bias into the findings. However, RE is based on the premise that the truth is multi-layered and the findings of this case study, although not purporting to represent a universal truth, provide a version of the truth, contributing a piece of a larger puzzle.

8.4 Personal reflections

I embarked on this thesis, coming from a background in health service social research, determined that I would produce actionable, real world recommendations. As I became more immersed in RE, a theory driven methodology, the tensions and challenges in achieving this grew more pronounced and I have fought to reconcile the requirements of academic research with the practical realities of the public service provision. Reflecting on these challenges as I conclude the work, I feel that whilst dragged, rather reluctantly, into the study and application of broader social theories and theoretical paradigms, now emerging on the other side - I am immensely grateful for the deeper insight and understanding that exploring outcomes through a variety of philosophical lenses has afforded.

In relation to the emotional labour of the study, whilst I imagined that interviewing people at the end of life may be harrowing, and indeed there were moments where the despair of a small number of respondents was hard to bear, on the whole I was humbled and inspired by the resilience, clarity and humanity displayed. Whilst this humanity can be obscured by the mess and complexity of the wider system – to see evidence of its strength at all system levels has been, for me, one of the positive outcomes of the study.

I was aware throughout that, in the largely qualitative methods used, my own views, perspective and character were likely to impact on research outcomes - both through influencing and leading respondents in interviews and through the filtering and interpretation of data during analysis. Bazeley (2013) talks of how personal processes have the capacity to influence results and raises the possibility that data is sought to confirm preconceived notions. I would concur this is a strong possibility; indeed it seems unlikely that my values have not impinged, in some way, on outcomes. Despite this, the various mechanisms introduced to enhance rigour, including regular supervision and sharing results with PPI groups have sought to counter too great a personal influence. Reflexivity is the process through which a researcher reflects on how they have influenced or biased the research outcomes (Carolan 2003). Notes that I made during the research process, in which I jotted down impressions and thoughts that occurred to me as the work progressed – helped me to monitor my own thinking as it changed and developed over the three years of study.

8.5 Recommendations:

The chapter concludes with a series of recommendations divided between policy, practice and research. I believe that the current COVID-19 crisis has provided a policy window where there is an opportunity to push the importance of attaching greater priority to social and relational care higher up the public service agenda. For this reason, unashamedly, I begin with a number of aspirational policy recommendations.

For policy makers (macro level)

- i) Review policy to explicitly address the imbalance between clinical care on the one hand and personal/relational care on the other. Prioritise improved pay and conditions for social care staff.
- ii) Reframe policy acknowledging that patients operate as social beings rather than individuals and that choices are made within a broader social context.

- iii) Develop a public education programme to build confidence in the value of talking about EOL planning and the notion that responsibility for EOL planning should not rest solely with professionals.
- iv) Stem the rise of local inequalities in EOLC, relating to both social group and geography. Specifically review requirements for the achievement of minimum national standards in relation to service provision for specific EOL related KPIs.
- v) Strengthen the mechanisms for incorporating patients' and carers input into service design, funding priorities and system reform – importantly this should take a broad view across both health and social care systems, allowing the relative impact of one pot of funding on another, to be more transparent.
- vi) Review levers and incentives for enacting EOL policy and assess their suitability for helping facilitate best practice.
- vii) Consolidate the range and scope of policy documents relating to EOLC and ensure that they are properly signposted, indexed and linked so that those who need to refer to, and follow through the guidance provided, are able to identify the most current advice.
- viii) Focus not only on aspiration but also operationalisation. Clarity is needed as to who, within the system, has responsibility for different levels of implementation.

For practitioners (meso-level)

Commissioners

- i) Produce a set of minimum standards for commissioning EOLC which may include stipulations relating to:
 - Required levels of access to essential EOLC services such as 24/7 palliative care
 - Further updated guidance on staff training, and for which groups, in EOL identification and communication
 - Recommend regular multi-professional EOL forums to help build a shared understanding of aims and objectives and work towards common goals.
- ii) Ensure clarity and consistency in relation to the STP commissioning function and the skills required.
- iii) Provide a clear set of guidelines, associated tool kits and training courses to those working in STP EOL commissioning posts, with a view to improving consistency both in relation to available competencies and allocated resource.
- iv) Provide training to commissioners to familiarise them with commissioning toolkits for EOLC services, including identification of mandatory KPIs.

- v) Provide commissioners with sufficient levers and incentives to assist the commissioning process to stipulate and secure minimum standards.
- vi) Promote the NEOLCIN website and the ability it affords to compare local and national data.

Health and social care staff

- i) Offer routine, mandatory support and education to staff across health and social care in key areas relating to palliative care and EOL (including recognition of EOL and communication skills to assist with advance care planning).
- ii) Continue to build recognition of the importance of the social and economic determinants of health.

For research

- i) Continue work identifying appropriate KPIs for patient outcomes and patient experience at the EOL.
- ii) Build the growing research base looking at the potential contribution civic society can make to the quality of the dying experience through initiatives such as compassionate communities.
- iii) Showcase successful examples of integrated working across health and social care.
- iv) Build the research base around the lived experience of care provided at home to those at EOL and for carers (both family and paid carers).
- v) Look at ways to facilitate gaining 'Research and Development' and ethics permissions to a multiplicity of sites, across both health and social care when conducting fieldwork – which both guarantees safety to sites and does not involve laborious and wasteful repetition of staff time.
- vi) Carry out more research on the lived experience of being at the end of life (both from patient and carer perspective).
- vii) Explore the impact of lack of access to digital technology on frail elderly.

8.5 Chapter summary

There is a paucity of research addressing the role that EOLC policy plays in bringing about more equitable services which are of good quality and meet patient priorities. This thesis has asked 'what type of policy works?', 'why does it work?' and 'in what circumstances?'. The findings reveal a system with multiple layers of complexity and many contextual variables which impact on outcomes.

It is hoped that whilst not presented as a universal truth the findings will go some way to contributing to a fuller understanding of how policy can be effectively used in helping to meet the needs and priorities of those at EOL.

Bibliography

- Abel, J. and Kellehear, A. (2018). Palliative Curriculum Re-imagined: A Critical Evaluation of the UK Palliative Medicine Syllabus. *Palliative Care: Research and Treatment* [Online], 11.
- Abrahamson, V. and Wilson, P. M. (2019). How unmet are unmet needs post-stroke? A policy analysis of the six-month review. *BMC Health Services Research* [Online], 19(1), 480.
- Academy of Medical Sciences (2016). *Improving the Health of the Public by 2040*. London: Academy of Medical Sciences.
- Addicot, R. (2010). *End of Life Care*. London: The King's Fund.
- Addington-Hall, J. (2002). Research sensitivities to palliative care patients. *European Journal of Cancer Care* [Online], 11(3), 220-224.
- Adshead, L. and Dechamps, A. (2016). End of Life Care: Everybody's Business. *Journal of Social Work Practice* [Online], 30(2), 169-185. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=118251015&site=ehost-live>.
- Ahmed, N., et al. (2014). Person centred care: From ideas to action (bringing together the evidence on shared decision making and self-management support). *London, England: The Health Foundation* [Online].
- Alderwick, H., et al. (2015). *Better Value in the NHS: The Role of Changes in Clinical Practice*. [Online]. Available from: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/better-value-nhs-Kings-Fund-July%202015.pdf
- Archer, M., et al. (2013). *Critical Realism: Essential Readings*. [Online]. Routledge.
- Arksey, H. and O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* [Online], 8(1), 19-32.
- Astbury, B. and Leeuw, F. L. (2010). Unpacking black boxes: mechanisms and theory building in evaluation. *American Journal of Evaluation* [Online], 31(3), 363-381.
- Awofeso, N. (2004). What's new about the "new public health"?. *American Journal of Public Health* [Online], 94(5), 705-709.
- Bailey, C., et al. (2016). 'The ICECAP-SCM tells you more about what I'm going through': A think-aloud study measuring quality of life among patients receiving supportive and palliative care. *Palliative Medicine* [Online], 30(7), 642-652.

- Ball, J., et al. (2014). Survey of district and community nurses in 2013. *Report to the Royal College of Nursing National Nursing Research Unit, King's College London: London* [Online].
- Barker, K., et al. (2014). A new settlement for health and social care: Final report of the Commission on the Future of Health and Social Care in England. *King's Fund* [Online].
- Berwick, D. (2013). A promise to learn—a commitment to act: improving the safety of patients in England. *London: Department of Health* [Online], 6.
- Bhaskar, R. (2010). *Reclaiming Reality: A Critical Introduction to Contemporary Philosophy*. [Online]. Routledge.
- Bhaskar, R. (1989). Critical Realism, Social Relations and Arguing for Socialism *Proceedings of the Socialist Conference at Chesterfield, UK*. [Online].
- Blaxter, M. (2010). *Blaxter, M. Health (Revised and Updated)*. Second edn. edn. Cambridge: Polity Press.
- Booth, R. (2020). UK healthcare regulator barnds resuscitation strategy unacceptable. *Guardian*, 01.04.2020.
- Borgstrom, E. (2016). National End-of-Life Care Policy in the English Context: The Problem and Solution to Death and Dying. In: Foster, L. W.,K ed. *Death and Social Policy in Challenging Times*. Palgrave Macmillan, pp. 35-53.
- Borgstrom, E. (2015). Planning for an (un) certain future: Choice within English end-of-life care. *Current Sociology* [Online], 63(5), 700-713.
- Borgstrom, E. and Ellis, J. (2017). *Introduction: Researching Death, Dying and Bereavement* [Online].
- Buck, D. (2018). *Local Government Spending on Public Health: Death by a Thousand Cuts* [Online]. Last updated: January 2018. Available from: <https://www.kingsfund.org.uk/blog/2018/01/local-government-spending-public-health-cuts>
- Buck, J., et al. (2018). Persistent inequalities in Hospice at Home provision. *BMJ Supportive & Palliative Care* [Online].
- Busfield, J. (2017). The concept of medicalisation reassessed. *Sociology of Health & Illness* [Online], 39(5), 759-774.
- Byrne, D. (2018). Researching complex large-scale nested interventions. *Doing Realist Research*. London: Sage [Online].
- Calanzani, N., Koffman, J. and Higginson, I. (2013). Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. *London: Marie Curie Cancer Care* [Online].

- Callahan, D. (2011). End-of-Life Care: A philosophical or management problem?. *Journal of Law, Medicine and Ethics* [Online], 39(2), 114-120 [Accessed 6 December 2017].
- Callahan, D. and Wasunna, A. A. (2008). *Medicine and the Market: Equity V. Choice*. [Online]. JHU Press.
- Cameron, D. (2009). The big society. *Hugo Young Lecture* [Online], 10(11), 09.
- Campbell, C., et al. (2015). A good patient? How notions of 'a good patient' affect patient-nurse relationships and ART adherence in Zimbabwe. *BMC Infectious Diseases* [Online], 15(1), 404.
- Care Quality Commission (2016). A different ending: Addressing inequalities in end of life care. *Newcastle upon Tyne: CQC* [Online].
- Carers UK (2019). *Assessments Factsheet: Your Guide to Getting Help and Support in England* [Online]. Available from: https://www.carersuk.org/images/Factsheets/Assessments_-_England_factsheet_April2019.pdf [Accessed 02//03/2020].
- Carey, I., et al. (2015). Improving care for patients whose recovery is uncertain. The AMBER care bundle: design and implementation. *BMJ Supportive & Palliative Care* [Online], 5(1), 12-18.
- Carolan, M. (2003). Reflexivity: a personal journey during data collection. *Nurse Researcher* [Online], 10(3), 7-15.
- Centre for Health and Social Care Research (2016). *State of the Nations Report: Terminal Illness Care in England, Northern Ireland, Scotland and Wales*. Sheffield: Sheffield Hallam University and Marie Curie.
- Charlesworth, A. (2019). We need a social care system that is as much a source of national pride as the NHS. *BMJ (Clinical Research Ed.)* [Online], 365, l4349.
- Charlesworth, A. (2018). *Health Foundation Response to Government Announcement of Additional NHS Funding* [Online]. Last updated: 20/06/2018. Available from: <https://www.health.org.uk/news/health-foundation-response-government-announcement-additional-nhs-funding>
- Charlesworth, G., et al. (2008). Befriending carers of people with dementia: randomised controlled trial. *BMJ (Clinical Research Ed.)* [Online], 336(7656), 1295-1297.
- Charmaz, K. (2011). Grounded theory methods in social justice research. *The Sage Handbook of Qualitative Research* [Online], 4(1), 359-380.
- Chill, C. (2016). *Are Care Plans Worth it?* [Online]. Available from: <http://www.pulsetoday.co.uk/views/debates/arecareplansworthit/20033278.article>

- Chitnis, X., et al. (2012). *The Impact of the Marie Curie Nursing Service on Place of Death and Hospital use at the End of Life. Research Report.* Nuffield Trust.
- Chochinov, H. M. (2007). Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ (Clinical Research Ed.)* [Online], 335(7612), 184-187.
- Clark, D. (2002). Between hope and acceptance: The medicalisation of dying. *British Medical Journal* [Online], 324(7342), 905-907 [Accessed 8 December 2017].
- Clarke, A. (2006). Qualitative interviewing: Encountering ethical issues and challenges. *Nurse Researcher* [Online], 13(4), 19.
- Clarke, D. J., et al. (2013). Implementing a training intervention to support caregivers after stroke: a process evaluation examining the initiation and embedding of programme change. *Implementation Science* [Online], 8(1), 96.
- Coast, J. (2014). Strategies for the economic evaluation of end-of-life care: Making a case for the capability approach. *Expert Review of Pharmacoeconomics and Outcomes Research* [Online], 14(4), 473-482 [Accessed 6 December 2017].
- Collinson, P. (2019). Life expectancy falls by six months in biggest drop in UK forecasts. *Guardian, (Lifestyle)* 07/03/2019.
- Colquhoun, H. L., et al. (2014). Scoping reviews: time for clarity in definition, methods, and reporting. *Journal of Clinical Epidemiology* [Online], 67(12), 1291-1294.
- Coombs, M. and Long, T. (2008). Managing a good death in critical care: can health policy help?. *Nursing in Critical Care* [Online], 13(4), 208-214. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=105670058&site=ehost-live>.
- Corbin, J. and Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry* [Online], 9(3), 335-354.
- Corbin, J. and Strauss, A. (2008). Basics of qualitative research: Techniques and procedures for developing grounded theory. [Online].
- Coulter, A., et al. (2016). Building the House of Care for people with long-term conditions: the foundation of the House of Care framework. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners* [Online], 66(645), 288-90.
- Cox, S., Handy, J. M. and Blay, A. (2012). Palliative care in the ICU 2C06. *Journal of the Intensive Care Society* [Online], 13(4), 320-326 [Accessed 6 December 2017].
- CQC (2016). '*A Different Ending*': *Addressing Inequalities in End of Life Care. Overview Report.* [Online]. Newcastle upon Tyne: CQC. Available from:

http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf;
<http://www.cqc.org.uk/content/different-ending-end-life-care-review>.

CQC, et al. (2020). *Joint Statement on Advance Care Planning* [Online]. Last updated: 03.004.2020. Available from: https://www.cqc.org.uk/news/stories/joint-statement-advance-care-planning?utm_source=Unknown+List&utm_campaign=b399e0b3a2-EMAIL_CAMPAIGN_2020_04_07_08_13&utm_medium=email&utm_term=0_-b399e0b3a2-&mc_cid=b399e0b3a2&mc_eid=%5bUNIQID%5d [Accessed 29.05.2020].

Creswell, J. W. and Creswell, J. D. (2017). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. [Online]. Sage publications.

Dalkin, S. M., et al. (2015). What's in a mechanism? Development of a key concept in realist evaluation. *Implementation Science : IS* [Online], 10, 49. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4408605/>.

Davies, J. M., et al. (2016). Using routine data to improve palliative and end of life care. *BMJ Supportive & Palliative Care* [Online], 6(3), 257-262.

De Silva, D. (2012). *Helping People Share Decision Making*. [Online]. The Health Foundation. Available from: <http://www.health.org.uk/publication/helping-people-share-decision-making>.

De Vleminck, A., et al. (2016). How Do General Practitioners Conceptualise Advance Care Planning in Their Practice? A Qualitative Study. *PLoS ONE* [Online], 11(4). Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4838248/>.

Deloitte (2014). *Transforming Care at the End-of-Life: Dying Well Matters*. [Online]. London : Deloitte. Available from: <https://www2.deloitte.com/content/dam/Deloitte/uk/Documents/life-sciences-health-care/transforming-care-at-the-end-of-life.pdf>

Denzin, N. K. and Lincoln, Y. S. (2008). *Strategies of Qualitative Inquiry*. [Online]. Vol. 2. Sage.

Department of Health (2014). One chance to get it right, improving people's experience of care in the last few days and hours of life. *Leadership Alliance for the Care of Dying People* [Online].

Department of Health (2012a). *Fast Track Pathway Tool for NHS Continuing Healthcare*. November edn. Department of Health.

Department of Health (2012b). *First National VOICES Survey of Bereaved People: Key Findings Report*.

The Health and Social Care Act 2012c

Department of Health (2010). *Equity and Excellence: Liberating the NHS*. The Stationery Office, London.

- Department of Health (2009). *The NHS Constitution: All You Need to Know about how the NHS Constitution Affects You as a Provider Or Commissioner of NHS Care*. [Online]. NHS.
- Department of Health (2008). *End of Life Care Strategy - Promoting High Quality Care for all Adults at the End of Life*. [Online]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf
- Department of Health (2003). *Building on the Best Choice, Responsiveness and Equity in the NHS*. [Online]. DH. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/272092/6079.pdf
- DHSC. (2018). *National Framework for NHS Continuing Healthcare and NHS -funded Nursing Care*. March edn. Department of Health and Social Care.
- Dilnot, A. (2011). *Fairer Care Funding: The Report of the Commission on Funding of Care and Support*. [Online]. Vol. 1. The Stationery Office.
- Dixon, J., et al. (2015). Equity in the provision of palliative care in the UK: review of evidence. [Online].
- Dixon, J., King, D. and Knapp, M. (2016). Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People. *BMJ Supportive & Palliative Care* [Online].
- Dixon-Woods, M., et al. (2004). The problem of appraising qualitative research. *Quality & Safety in Health Care* [Online], 13(3), 223-225.
- Easton, M. (2020). *Coronavirus: How to Behave in an Epidemic*. BBC News [Online]. Last updated: 22/03/2020. Available from: <https://www.bbc.co.uk/news/uk-51991566> [Accessed 25/03/2020].
- Economist Intelligence Unit (2015). The 2015 Quality of Death Index. Ranking palliative care across the world. *London: The Economist Intelligence Unit* [Online].
- Edwards, N. (2018). ***Integrated Care: What does it Mean for Commissioning?*** [Online]. Available from: <https://www.nuffieldtrust.org.uk/news-item/integrated-care-what-does-it-mean-for-commissioning#holding-providers-to-account-setting-standards>
- Ellis, J., Winslow, M. and Noble, B. (2016). Social policy and care of older people at the end of life. In: *Death and Social Policy in Challenging Times*. [Online]. Springer, pp. 17-34.
- End of Life Care Coalition (2017). *End of Life Care in Sustainability and Transformation Plans: An Analysis* [Online]. Available from: <http://endoflifecampaign.org/wp-content/uploads/2017/10/STP-one-pager.pdf>

- Engelhardt, J. B., et al. (2006). Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *Planning* [Online], 11, 93-100.
- Eriksson, M. (2011). Social capital and health—implications for health promotion. *Global Health Action* [Online], 4(1), 5611.
- Fernstrom, K. M., et al. (2016). Development and validation of a new patient experience tool in patients with serious illness. *BMC Palliative Care* [Online], 15(1), 99.
- Findik, U. Y., Unsar, S. and Sut, N. (2010). Patient satisfaction with nursing care and its relationship with patient characteristics. *Nursing & Health Sciences* [Online], 12(2), 162-169.
- Finlay, I. (2019). Access to Palliative Care Bill. *2nd Reading June 2019*.
- Fischer, D. J., et al. (2012). Conducting research with end-of-life populations: Overcoming recruitment challenges when working with clinical agencies. *Applied Nursing Research* [Online], 25(4), 258-263.
- Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology* [Online], 20(2), 181-194.
- Foucault, M. (1998). The will to knowledge: The history of sexuality vol. I. [Online].
- Foucault, M. and Faubion, J. D. (1994). Michel Foucault, Power, Essential Works of Foucault 1954-1984. *London: Penguin* [Online].
- Francis, G. (2015). *Adventures in Human being: A Grand Tour from the Cranium to the Calcaneum*. [Online]. Basic Books.
- Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary*. [Online]. Vol. 947. The Stationery Office.
- Galushko, M., Romotzky, V. and Voltz, R. (2012). Challenges in end-of-life communication. *Current Opinion in Supportive and Palliative Care* [Online], 6(3), 355-364 [Accessed 6 December 2017].
- Gaventa, J. (2003). *Power After Lukes: A Review of the Literature*. Brighton: Institute of Development Studies.
- Gawande, A. (2014). *Being Mortal: Medicine and what Matters in the End*. [Online]. Metropolitan Books.
- Georghiou, T. and Bardsley, M. (2014). *Exploring the cost of care at the end of life*. [Online]. Nuffield. Available from: <https://www.nuffieldtrust.org.uk/research/exploring-the-cost-of-care-at-the-end-of-life>.

- Gerschlick, B., et al. (2019). *Health and social care funding: Priorities for the new government*. In: The Health Foundation ed.
- Ghaljaie, F., Naderifar, M. and Goli, H. (2017). Snowball Sampling: A Purposeful Method of Sampling in Qualitative Research. *Strides in Development of Medical Education* [Online], 14(3), 0-0.
- Gibbins, J., et al. (2013). Overcoming barriers to recruitment in care of the dying research in hospitals. *Journal of Pain and Symptom Management* [Online], 45(5), 859-867.
- Gilgun, J. F. (2005). "Grab" and good science: Writing up the results of qualitative research. *Qualitative Health Research* [Online], 15(2), 256-262.
- Gilmore, B., et al. (2019). Data Analysis and Synthesis Within a Realist Evaluation: Toward More Transparent Methodological Approaches. *International Journal of Qualitative Methods* [Online], 18, 1609406919859754.
- Gilson, L. (2012). Introduction to health policy and systems research. *Health Policy and Systems Research: A Methodology Reader*. Geneva: Alliance for Health Policy and System Research: WHO [Online], 19, 39.
- Given, L. M. (2015). *100 Questions (and Answers) about Qualitative Research*. [Online]. SAGE Publications.
- Glaser, B. and Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. 139. [Online].
- Gomes, B., et al. (2013a). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care* [Online], 12(1), 7.
- Gomes, B., et al. (2013b). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *The Cochrane Database of Systematic Reviews* [Online](6), 1-279. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4473359/>.
- Goodrich, J. and Cornwell, J. (2008). Seeing the person in the patient. *The Point of Care Review Paper* [Online].
- Government of Kerala (2019). *Kerala State Policy on Palliative Care* [Online]. Available from: <https://palliumindia.org/cms/wp-content/uploads/2019/12/Kerala-Palliative-care-policy-Eng-2019-Dec.pdf> [Accessed 13/03/2020].
- Green, J. and Thorogood, N. (2018). *Qualitative Methods for Health Research*. [Online]. Sage.
- Greenhalgh, T. and Papoutsis, C. (2018a). *Studying Complexity in Health Services Research: Desperately Seeking an Overdue Paradigm Shift* [Online].

- Greenhalgh, T. and Papoutsi, C. (2018b). Studying complexity in health services research: desperately seeking an overdue paradigm shift. *BMC Medicine* [Online]. Available from: <https://bmcmmedicine.biomedcentral.com/track/pdf/10.1186/s12916-018-1089-4> [Accessed 07/02/2020].
- Greenhalgh, T., Thorne, S. and Malterud, K. (2018). Time to challenge the spurious hierarchy of systematic over narrative reviews?. *European Journal of Clinical Investigation* [Online], 48(6), e12931.
- Greenhalgh, T., et al. (2015). Protocol--the RAMESES II study: developing guidance and reporting standards for realist evaluation. *BMJ Open* [Online], 5(8), e008567-2015-008567.
- Guy's and St Thomas' NHS Foundation Trust (2018). *The Amber Care Bundle* [Online]. Available from: <https://www.ambercarebundle.org/homepage.aspx>
- Gysels, M., et al. (2013). Diversity in defining end of life care: an obstacle or the way forward?. *PLoS One* [Online], 8(7), e68002.
- Haines, A. (2004). Report of the Public Health Sciences Working Group convened by the Wellcome Trust: Public Health Sciences: Challenges and Opportunities. [Online].
- Ham, C., Charles, A. and Wellings, D. (2018). **Shared responsibility for health: the cultural change we need.** *The King's Fund*.
- Harrison, H., et al. (2017). Case Study Research: Foundations and Methodological Orientations. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* [Online], 18(1). Available from: <http://www.qualitative-research.net/index.php/fqs/article/view/2655/4079>.
- Hashem, F., et al. (2020). Understanding what works, why and in what circumstances in hospice at home services for end-of-life care: Applying a realist logic of analysis to a systematically searched literature review. *Palliative Medicine* [Online], 34(1), 16-31.
- Heath, I. (2016). How medicine has exploited rationality at the expense of humanity: an essay by Iona Heath. *BMJ: British Medical Journal (Online)* [Online], 355.
- Henry, G. T., Julnes, G. and Mark, M. M. (1998). Realist Evaluation: An Emerging Theory in Support of Practice. *New Directions for Evaluation* [Online], 78, 1-109.
- Hight, G., et al. (2014). Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICe): a mixed-methods study. *BMJ Supportive & Palliative Care* [Online], 4(3), 285-290.
- Holt-Lunstad, J., Smith, T. B. and Layton, J. B. (2010). Social relationships and mortality risk: a meta-analytic review. *PLoS Medicine* [Online], 7(7), e1000316.

- Hospice UK (2018). *Facts and Figures about Hospice Care* [Online]. Available from: <https://www.hospiceuk.org/about-hospice-care/media-centre/facts-and-figures> [Accessed 03/10/2019].
- House of Commons Committee of Public Accounts (2018). *NHS Continuing Healthcare Funding: Thirteenth Report of Session 2017–19*. HC.
- Howdon, D. and Rice, N. (2018). Health care expenditures, age, proximity to death and morbidity: Implications for an ageing population. *Journal of Health Economics* [Online], 57, 60-74.
- Hughes, D. (2017). **District nurse numbers under pressure**. , .
- Hughes-Hallett, T., et al. (2011). Funding the right care and support for everyone. Creating a fair and transparent funding system. *The Final Report of the Palliative Care Funding Review* [Online].
- Hughes-Hallett, T., Murray, S. A. and Cleary, J. (2013). *Dying Healed : : Transforming End-of-Life Care through Innovation*. [Online]. Doha] : WISH. Available from: <http://www.wish-qatar.org/app/media/386>; <https://www.imperial.ac.uk/global-health-innovation/our-research/our-publications/wish-reports-2013/>.
- Hui, D., et al. (2014). Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care”: a systematic review. *Journal of Pain and Symptom Management* [Online], 47(1), 77-89.
- Hunter, J. and Orlovic, M. (2018). *End of Life Care in England: A Briefing Paper*. London: IPPR.
- Huynh, E., et al. (2017). Values for the ICECAP-Supportive Care Measure (ICECAP-SCM) for use in economic evaluation at end of life. *Social Science & Medicine* [Online], 189, 114-128.
- Illich, I. (1976). Limits to medicine: medical nemesis: the expropriation of health. *London: Marion Boyars* [Online], 174.
- Imison, C., et al. (2011). Transforming our healthcare system. *London: The King's Fund* [Online].
- Jagosh, J. (2020). Retroductive theorizing in Pawson and Tilley's applied scientific realism. *Journal of Critical Realism* [Online], 19(2), 121-130.
- Jagosh, J., et al. (2015). A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC Public Health* [Online], 15(1), 725.
- Jagosh, J., et al. (2011). Assessing the outcomes of participatory research: protocol for identifying, selecting, appraising and synthesizing the literature for realist review. *Implementation Science* [Online], 6(1), 1.
- Kawachi, I. and Berkman, L. (2000). Social cohesion, social capital, and health. *Social Epidemiology* [Online], 174(7).

- Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine* [Online], 106(12), 1071-1075.
- Kendall, M., et al. (2006). How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers. *Family Practice* [Online], 23(6), 644-650.
- Kendall, M., et al. (2007). Key challenges and ways forward in researching the "good death": qualitative in-depth interview and focus group study. *BMJ (Clinical Research Ed.)* [Online], 334(7592), 521.
- Keogh, B. (2013). *Review into the Quality of Care and Treatment Provided by 14 Hospital Trusts in England: Overview Report*. London: NHS.
- Kernick, D. and Mannion, R. (2005). Developing an evidence base for intermediate care delivered by GPs with a special interest. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners* [Online], 55(521), 908-910.
- Kornhaber, R., et al. (2016). Enhancing adult therapeutic interpersonal relationships in the acute health care setting: an integrative review. *Journal of Multidisciplinary Healthcare* [Online], 9, 537-546.
- Krakauer, E. L. and Rajagopal, M. R. (2016). End-of-life care across the world: a global moral failing. *The Lancet* [Online], 388(10043), 444-446 [Accessed 6 December 2017].
- Kushner, H. I. and Sterk, C. E. (2005). The limits of social capital: Durkheim, suicide, and social cohesion. *American Journal of Public Health* [Online], 95(7), 1139-1143.
- Kvale, S. (2006). Dominance Through Interviews and Dialogues. *Qualitative Inquiry* [Online], 12, 480-502. Available from: https://www.sfu.ca/cmns/courses/2012/801/1-Readings/Kvale_dominance%20through%20interviews.pdf.
- Lancaster, H., et al. (2018). Commissioning of specialist palliative care services in England. *BMJ Supportive & Palliative Care* [Online], 8(1), 93-101.
- Lau, R. and O'Connor, M. (2012). Behind the rhetoric: Is palliative care equitably available for all?. *Contemporary Nurse: A Journal for the Australian Nursing Profession* [Online], 43(1), 56-63. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=104304501&site=ehost-live>.
- Leadership Alliance for the Care of Dying People (June 2014). *Once Chance to Get it Right; Improving People's Experience of Care in the Last Few Days and Hours of Life*. London: Crown Copyright.
- Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *Journal of Family Medicine and Primary Care* [Online], 4(3), 324-327.

- Levac, D., Colquhoun, H. and O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science* [Online], 5(1), 69.
- Lloyd, A., et al. (2016). Why do older people get less palliative care than younger people?. *European Journal of Palliative Care* [Online], 23(3), 132-137. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=115983278&site=ehost-live>.
- Lloyd, L. (2011). What do we know about the congruence between what older people prioritize at the end of life and policy and practices. *Living with Aging and Dying* [Online], 63-72.
- Maben, J., et al. (2012). 'Poppets and parcels': the links between staff experience of work and acutely ill older peoples' experience of hospital care. *International Journal of Older People Nursing* [Online], 7(2), 83-94.
- Malhotra, A., et al. (2015). *Choosing Wisely in the UK: the Academy of Medical Royal Colleges' initiative to reduce the harms of too much medicine*. [Online]. Vol. 350.
- Manzano, A. (2016). The craft of interviewing in realist evaluation.. 2016;(3): 342-360. *Evaluation* [Online], 22. Available from: https://www.researchgate.net/publication/300065986_The_craft_of_interviewing_in_realist_evaluation [Accessed 07/02/2020].
- Marchal, B., Dedzo, M. and Kegels, G. (2010). A realist evaluation of the management of a well-performing regional hospital in Ghana. *BMC Health Services Research* [Online], 10(1), 24.
- Marchal, B., et al. (2012). Is realist evaluation keeping its promise? A review of published empirical studies in the field of health systems research. *Evaluation* [Online], 18(2), 192-212.
- Marie Curie (2018). *What is Palliative Care?* [Online]. Available from: <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care>
- Marie Curie (2016). *Palliative care and the UK nations: An updated assessment on need, policy and strategy Implications for England*. [Online]. Marie Curie. Available from: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/marie-curie-reports/state-of-the-nations-mariecurie-report-england.pdf> [Accessed 02/05/2019].
- Marie Curie and Alzheimer's Society (2014). *Living and dying with dementia in England: Barriers to care*. Marie Curie UK.
- Marmot, M., et al. (2020). *Health Equity in England: The Marmot Review 10 years on*. Institute of Health Equity.
- Martinsson, L., Lundstrom, S. and Sundelof, J. (2018). Quality of end-of-life care in patients with dementia compared to patients with cancer: A population-based register study. *PLoS One* [Online], 13(7), e0201051.

- Maslow, A. H. (1943). A theory of human motivation. *Psychological Review* [Online], 50(4), 370.
- Maxwell, J. A. (2012). *Qualitative Research Design: An Interactive Approach*. [Online]. Vol. 41. Sage publications.
- May, C., et al. (2015). *Normalization Process Theory on-Line Users' Manual, Toolkit and NoMAD Instrument*. [Online]. Available from: <http://www.normalizationprocess.org> [Accessed 22/04/2020].
- May, C. R., et al. (2018). Using Normalization Process Theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implementation Science* [Online], 13(1), 80.
- Mayne, J. (2012). Making causal claims. [Online].
- McAteer, J., et al. (2018). Bridging the academic and practice/policy gap in public health: perspectives from Scotland and Canada. *Journal of Public Health (Oxford, England)* [Online].
- McEvoy, P. and Richards, D. (2003). Critical realism: a way forward for evaluation research in nursing?. *Journal of Advanced Nursing* [Online], 43(4), 411-420.
- McKenna, H. and Dunn, P. (2015). Devolution: What it means for health and social care in England. *The King's Fund, London* [Online].
- McMillan, J., et al. (2006). Ethics and opportunity costs: have NICE grasped the ethics of priority setting?. *Journal of Medical Ethics* [Online], 32(3), 127-128.
- Mead, S. and Copeland, M. E. (2000). What recovery means to us: Consumers' perspectives. *Community Mental Health Journal* [Online], 36(3), 315-328.
- Mears, A. (2014). Gaming and targets in the English NHS. *Universal Journal of Management* [Online], 2(7), 293-301.
- Merriam, S. B. (1998). *Qualitative Research and Case Study Applications in Education. Revised and Expanded from " Case Study Research in Education."* [Online]. ERIC.
- Miles, M. B., Huberman, A. M. and Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook*. 3rd. Ed: *Thousand Oaks, CA: Sage* [Online].
- Mills, A., Durepos, G. and Wiebe, E. (2010). *Encyclopedia of Case Study Research*. [Online]. Vol. 1. Sage.
- Minary, L., et al. (2019). Which design to evaluate complex interventions? Toward a methodological framework through a systematic review. *BMC Medical Research Methodology* [Online], 19(1), 92.

- Mingers, J. (2006). Philosophical foundations: Critical realism. *Realising Systems Thinking: Knowledge and Action in Management Science* [Online], 11-31.
- Misselbrook, D. (2013). Foucault. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners* [Online], 63(611), 312.
- Moody, D., Lyndon, H. and Stevens, D. (2017). *Toolkit for general practice in supporting older people living with frailty*. In: NHS England ed. [Online].
- Moore, L. (2020). *Evaluating Complex Systems Approaches to Improving Health*. The Health Foundation. Complex Systems Webinar [Online]. Last updated: 20.03.2020. Available from: https://www.health.org.uk/sites/default/files/2020-03/COMPLEX%20SYSTEMS%20FINAL%20DECK_FINAL.pdf
- Morgan, D. (2008). Snowball Sampling
- In: Given, L. ed. *The SAGE Encyclopedia of Qualitative Research Methods*. Sage Publications Inc, pp. 816-817.
- Mulhall, A. (2003). In the field: notes on observation in qualitative research. *Journal of Advanced Nursing* [Online], 41(3), 306-313.
- Munday, D., Petrova, M. and Dale, J. (2009). Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England. *BMJ (Clinical Research Ed.)* [Online], 339, b2391.
- Murray, S. A., et al. (2008). Implementing a service users' framework for cancer care in primary care: an action research study. *Family Practice* [Online], 25(2), 78-85.
- Murray, S. J., et al. (2007). No exit? Intellectual integrity under the regime of 'evidence' and 'best-practices'. *Journal of Evaluation in Clinical Practice* [Online], 13(4), 512-516.
- Murray, S. J., Holmes, D. and Rail, G. (2008). On the constitution and status of 'evidence' in the health sciences. *Journal of Research in Nursing* [Online], 13(4), 272-280.
- Murray, S. A., et al. (2005). Illness trajectories and palliative care. *BMJ (Clinical Research Ed.)* [Online], 330(7498), 1007-1011.
- National Advisory Group on Patient Safety (2013). *A Promise to Learn, a Commitment to Act. Improving the Safety of Patients in England*. London: DH.
- National Audit Office (2008). *End of Life Care*. | London: TSO.
- NCPC (2010). Following the Money: Findings from NCPC's survey to monitor the first year of investment in end of life care 2009/10. *Published by the National Council for Palliative Care Now Part of Hospice UK*, Briefing 18.

- Neal, M. (2000). Risk aversion: The rise of an ideology. *Journal of Organizational Change Management* [Online], 19(4), 13-31.
- Nesta (2019). *Death, Dying and Loss. it's all Part of Life, so Let's Talk .. how Compassionate Neighbours are Addressing this Challenge* [Online]. Last updated: 04/03/2019. Available from: <https://www.nesta.org.uk/blog/death-dying-and-loss-its-all-part-of-life-so-lets-talk/> [Accessed 17/03/2020].
- Neuberger, J. (2013). *Review of Liverpool Care Pathway for dying patients*. [Online]. DOH. Available from: <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>.
- Neuman, W. L. (2013). *Social Research Methods: Qualitative and Quantitative Approaches*. [Online]. Pearson education.
- NHS Digital (2018). [Online]. Available from: <https://qof.digital.nhs.uk/search/index.asp>
- NHS England (April 2016). *NHS England Specialist Level Palliative Care: Information for Commissioners*.
- NHS England (2018). *Areas Introducing Personal Health Budgets in End of Life Care* [Online]. Available from: <https://www.england.nhs.uk/personal-health-budgets/areas-introducing-personal-health-budgets-in-end-of-life-care/east-lancashire/>
- NHS England (2014a). *Five year forward view*. [Online]. Available from: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>.
- NHS England (2014b). *NHS England's Actions for End of Life Care*. NHS England.
- NHSE (2017). **CCG improvement and assessment framework 2017/18**. Page updated 14th June 2018 edn. NHSE.
- NHSI (2016). **the Value of Patient Time: Last 1000 Days** [Online]. Available from: <https://improvement.nhs.uk/resources/value-patient-time-last-1000-days/>
- Niamsri, P. and Boonmongkon, P. (2017). Bio-power, medical gaze and negotiation: Narrative experiences of anti-aging practices among Thai women. *Kasetsart Journal of Social Sciences* [Online], 38(1), 62-67.
- NICE (2016). **Community engagement: improving health and wellbeing and reducing health inequalities**. , March(NICE guideline {NG44}).
- NICE (2011). *End of Life Care for Adults: Quality Standard (QS13)* [Online]. Last updated: March 2017. Available from: <https://www.nice.org.uk/guidance/qs13> [Accessed 17/11/2017].

- NICE (2009). *Appraising life extending end of life treatments*. [Online]. Web: NICE. Available from: <https://www.nice.org.uk/guidance/gid-tag387/documents/appraising-life-extending-end-of-life-treatments-paper2>.
- NIHR (2004). NIH State-of-the-Science Conference Statement on Improving End-of-Life Care. 2004;21:1e26. *NIH Consensus State Sci Statements*. National Institute of Health Research, pp. 21:1e26.
- NPELCP (2015). *Ambitions for palliative and end of life care: a national framework for local action 2015-2020*. In: National Palliative and End of Life Care Partnership ed. [Online]. National Palliative and End of Life Care Partnership. Available from: <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>; <http://endoflifecareambitions.org.uk/>.
- Office for National Statistics (2019). *National Life Tables, UK:2016 to 2018* [Online]. Last updated: 25.09.2019. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies/bulletins/nationallifetablesunitedkingdom/2016to2018> [Accessed 08.04.2020].
- Office for National Statistics (2015). *National Survey of Bereaved People (VOICES), 2014*. [Online]. London: ONS. Available from: http://www.ons.gov.uk/ons/dcp171778_409870.pdf; <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2014/stb-voices-2014.html>.
- O'Hara, G. (2013). The Complexities of 'Consumerism': Choice, Collectivism and Participation within Britain's National Health Service, c. 1961–c. 1979. *Social History of Medicine* [Online], 26(2), 288-304.
- Palinkas, L. A., et al. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research* [Online], 42(5), 533-544.
- Papoutsis, C., et al. (2018). Interventions to improve antimicrobial prescribing of doctors in training (IMPACT): a realist review. *Health Services and Delivery Research* [Online], 6(10).
- Pastrana, T., et al. (2010). Outcome indicators in palliative care—how to assess quality and success. Focus group and nominal group technique in Germany. *Supportive Care in Cancer* [Online], 18(7), 859-868.
- Pawson, R., et al. (2005). Realist review—a new method of systematic review designed for complex policy interventions. *Journal of Health Services Research & Policy* [Online], 10(1_suppl), 21-34.
- Pawson, R. and Tilley, N. (2004). *Realist Evaluation*. [Online]. online: Paper funded by the British Cabinet Office. Available from: http://www.communitymatters.com.au/RE_chapter.pdf.

- Pawson, R. (2017). Middle Range Theory and Program Theory Evaluation: From Provenance to Practice 1. In: *Mind the Gap*. [Online]. Routledge, pp. 171-202.
- Pawson, R. (2006). *Evidence-Based Policy: A Realist Perspective*. [Online]. Sage.
- Pawson, R. (2013). *The Science of Evaluation: A Realist Manifesto*. [Online]. London; London: Sage; Sage.
- Pawson, R., et al. (2004). *Realist Synthesis: An Introduction ESRC Research Methods Programme*. [Online]. RMP Methods Paper 2 edn. University of Manchester.
- Pawson, R. and Tilley, N. (1997). *Realistic Evaluation*. London: Sage.
- Petrova, M., et al. (2016). Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from. *BMJ Supportive & Palliative Care* [Online].
- PHE, N. R. (2018). *Reducing Unwarranted Variation to Improve Health Outcomes and Value* [Http://Fingertips.Phe.Org.Uk/Profile/Atlas - of - Variation](http://fingertips.phe.org.uk/profile/atlas-of-variation) [Www.England.Nhs.Uk/Rightcare](http://www.England.Nhs.Uk/Rightcare) *Atlas of Variation for Palliative and End of Life Care in England: Reducing Unwarranted Variation to Improve Health Outcomes and Value*. Public Health England.
- Porter, S. (2015). Realist evaluation: an immanent critique. *Nursing Philosophy* [Online], 16(4), 239-251.
- Public Health England (2019). *End of Life Care Profiles* [Online]. Available from: <http://fingertips.phe.org.uk/profile/end-of-life/data#page/0/gid/1938132902/pat/6/par/E12000007/ati/102/are/E09000002> [Accessed 01/05/2019].
- Public Health England (2017). *End of Life Care Profiles: Technical Guidance* [Online]. Available from: <http://fingertips.phe.org.uk/profile/end-of-life>
- Putnam, R. D. (2000). *Bowling Alone: The Collapse and Revival of American Community*. [Online]. Simon and schuster.
- Quilter-Pinner, H. and Antink, B. (2017). Devo-health: Where next. [Online].
- Raleigh, V. (2018). What is happening to life expectancy in the UK?. [Online]. Available from: <https://www.kingsfund.org.uk/publications/whats-happening-life-expectancy-uk>.
- RCP and Marie Curie (2016). *End of Life Care Audit – Dying in Hospital. Executive Summary 2016*. Royal College of Physicians.

- Robert, G. and Fulop, N. (2014). The role of context in successful improvement. *Perspectives on Context. A Selection of Essays Considering the Role of Context in Successful Quality Improvement*. London: Health Foundation [Online], 31.
- Robson, C. and McCartan, K. (2016). *Real World Research*. [Online]. John Wiley & Sons.
- Rolfe, S. (2016). *Assessing the Impacts of Community Participation Policy and Practice in Scotland and Englan*. University of Glasgow.
- Rolfe, S. (2019). Combining Theories of Change and Realist Evaluation in practice: Lessons from a research on evaluation study. *Evaluation* [Online], 25(3), 294-316.
- Rolls, L., et al. (2011). Older people living alone at the end of life in the UK: Research and policy challenges. *Palliative Medicine* [Online], 25(6), 650-657. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=104680811&site=ehost-live>.
- Royal College of Practitioners (2011). *The GSF Prognostic Indicator Guidance: The National GSF Centre's Guidance for Clinicians to Support Earlier Recognition of Patients Nearing the End of Life* [Online]. Available from: <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf> [Accessed 02/03/2020].
- Rycroft-Malone, J., et al. (2010). A realistic evaluation: the case of protocol-based care. *Implementation Science* [Online], 5(1), 38.
- Sallnow, L. (2018). *Collective social capital: a study of new public health and end-of-life care*. University of Edinburgh.
- Sallnow, L., Kumar, S. and Numpeli, M. (2010). Home-based palliative care in Kerala, India: the neighbourhood network in palliative care. *Progress in Palliative Care* [Online], 18(1), 14-17.
- Sallnow, L., et al. (2016). The impact of a new public health approach to end-of-life care: a systematic review. *Palliative Medicine* [Online], 30(3), 200-211.
- Sanchez, J. M. S., et al. (2014). Impact of a legislative framework on quality of end-of-life care and dying in an acute hospital in Spain. *International Journal of Palliative Nursing* [Online], 20(5), 225-231.
- Saunders, B., et al. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity* [Online], 52(4), 1893-1907.
- Sayer, A. (1992). *Method in Social Science: A Realist Approach*. 2nd edn. London: Routledge.
- Scriven, M. (1994). The fine line between evaluation and explanation. *Evaluation Practice*, 15, 75-77.

- Seymour, J., Witherspoon, R. and Gott, M. (2005). *End-of-Life Care: Promoting Comfort, Choice and Well-being for Older People*. [Online]. Policy Press.
- Seymour, J. and Gott, M. (2011). The challenges of health technology for ageing and dying. *Living with Ageing and Dying: Palliative and End of Life Care for Older People* [Online], 42-52.
- Shah, K. K., Tsuchiya, A. and Wailoo, A. J. (2014). Valuing health at the end of life: an empirical study of public preferences. *European Journal of Health Economics* [Online], 15(4), 389-399. Available from:
<http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=103819536&site=ehost-live>.
- Shaw, J., et al. (2018). Mechanisms, contexts and points of contention: operationalizing realist-informed research for complex health interventions. *BMC Medical Research Methodology* [Online], 18(1), 1-12.
- Shearn, K., et al. (2017). Building realist program theory for large complex and messy interventions. *International Journal of Qualitative Methods* [Online], 16(1), 1609406917741796.
- Siriwardena, N. and Clark, D. (2004). End-of-life care for ethnic minority groups. *Clinical Cornerstone* [Online], 6(1), 43-48. Available from:
<http://www.sciencedirect.com/science/article/pii/S1098359704900063>.
- Sivell, S., et al. (2015). Considerations and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: a consensus paper. *BMJ Supportive & Palliative Care* [Online].
- Skills for Care (2019). *The State of the Adult Social Care Sector and Workforce in England*. Skills for Care. Report number: September.
- Sleeman, K., et al. (2018). Is end-of-life care a priority for policymakers? Qualitative documentary analysis of health care strategies. *Palliative Medicine*, July(269216318786333), 1-13.
- Solutions Research (2016). *Public Perceptions and Experiences of Community Based End of Life Initiatives*. London: Public Health England.
- Spradley, J. ed. (2016). *Participant Observation*. [Online]. New York: Waveland Press.
- Stame, N. (2004). Theory-based evaluation and types of complexity. *Evaluation* [Online], 10(1), 58-76.
- Stow, D., Matthews, F. E. and Hanratty, B. (2018). Frailty trajectories to identify end of life: a longitudinal population-based study. *BMC Medicine* [Online], 16(1).
- Stoye, G. (2018). **what does the NHS Funding Announcement Mean for Health Spending in England?** [Online]. Last updated: 18/06/2018. Available from:
<https://www.ifs.org.uk/publications/13077>

- The Institute and Faculty of Actuaries (2019). *Longer term influences driving lower life expectancy projections*.
- The National Council for Palliative Care (2014). *The End of Life Care Strategy: New Ambitions*. NCPC.
- The University of Edinburgh (2019). *Supportive and Palliative Care Indicators Tool (SPICT™)* [Online]. Last updated: April. Available from: file:///C:/Users/User/OneDrive/phd/method/SPICT_April%202019.pdf [Accessed 02/03/2020].
- Thomas, K. P.,D. (2013). *RCGP Commissioning Guidance in End of Life Care*. London: RCGP.
- Thoonsen, B., et al. (2016). Training general practitioners contributes to the identification of palliative patients and to multidimensional care provision: secondary outcomes of an RCT. *BMJ Supportive & Palliative Care* [Online].
- Threapleton, D. E., et al. (2017). Care Toward the End of Life in Older Populations and Its Implementation Facilitators and Barriers: A Scoping Review. *Journal of the American Medical Directors Association* [Online], 18(12), 1000-1009.e4. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=126351206&site=ehost-live>.
- Tilden, V. P. and Thompson, S. (2009). Policy Issues in End-of-Life Care. *Journal of Professional Nursing* [Online], 25(6), 363-368 [Accessed 6 December 2017].
- Unison (2015). *Unison Survey Reveals Scale of Stress among Ambulance Workers* [Online]. Available from: <https://www.unison.org.uk/news/article/2015/04/unison-survey-reveals-scale-of-secret-stress-among-ambulance-workers/> [Accessed 20/05/2020].
- University of Birmingham (2018). *ICECAP-O (ICEpop CAPability Measure for Older People)* [Online]. Available from: <https://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/ICECAP-O/index.aspx>
- University of Edinburgh (2017). *Supportive and Palliative Care Indicators Tool (SPICT™)*. April 2017 edn. University of Edinburgh.
- Urquhart, C. (2012). *Grounded Theory for Qualitative Research: A Practical Guide*. [Online]. Sage.
- Van Belle, S. B., et al. (2010). How to develop a theory-driven evaluation design? Lessons learned from an adolescent sexual and reproductive health programme in West Africa. *BMC Public Health* [Online], 10(1), 741.
- Viens, A. (2019). *Neo-Liberalism, Austerity and the Political Determinants of Health* [Online].
- Walshe, K., et al. (2018). Devolving health and social care: learning from Greater Manchester. *Devolving Health and Social Care: Learning from Greater Manchester* [Online].

- Wand, T., White, K. and Patching, J. (2010). Applying a realist (ic) framework to the evaluation of a new model of emergency department based mental health nursing practice. *Nursing Inquiry* [Online], 17(3), 231-239.
- Wanless, D. (2004). *Securing Good Health for the Whole Population*. [Online]. HM Stationery Office London.
- Weiss, C. H. (1997). Theory-based evaluation: Past, present, and future. *New Directions for Evaluation* [Online], 1997(76), 41-55.
- Welch, V. A. and Tricco, A. C. (2016). Reporting guidelines for realist evaluations seek to improve clarity and transparency. *BMC Medicine* [Online], 14(1), 109.
- West, S. (2015). *Later life in a digital world*. In: Age UK ed.
- Westhorp, J. (2014). *Realist Impact Evaluation: An Introduction*. [Online]. A methods lab publication edn. ODI.org. Available from: <https://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/9138.pdf>.
- White, T. (2014). **Doctors would choose less aggressive end-of-life care for themselves**. *Stanford Medicine*, May 28.
- Wilkinson, R. G. (2002). *Unhealthy Societies: The Afflictions of Inequality*. [Online]. Routledge.
- Williams, L., Rycroft-Malone, J. and Burton, C. (2017). Bringing critical realism to nursing practice: Roy Bhaskar's contribution. *Nursing Philosophy* [Online], 18(2), e12130.
- Wilson, D. M., Shen, Y. and Birch, S. (2017). New Evidence on End-of-Life Hospital Utilization for Enhanced Health Policy and Services Planning. *Journal of Palliative Medicine* [Online], 20(7), 752-758. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=123949413&site=ehost-live>.
- Wimbush, E., Montague, S. and Mulherin, T. (2012). Applications of contribution analysis to outcome planning and impact evaluation. *Evaluation* [Online], 18(3), 310-329.
- Winch, P. (1958). *The Idea of a Social Science and its Relation to Philosophy*. New York: Routledge.
- Witt, J., et al. (2018). *Introducing the Outcome Assessment and Complexity Collaborative (OACC) Suite of Measures. A Brief Introduction 2017* [Online].
- Wittgenstein, L. (1958). *Philosophical Investigations*. 2nd edn. London: Blackwell.
- End of life care: fifth report of session 2014-15. Report, together with formal minutes relating to the report.9780215084149 . Available from: <http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf>;

[http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2010/end-of-life-care/;](http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2010/end-of-life-care/)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/467810/Cm_9143_Accessible.pdf

Wong, G., et al. (2016). RAMESES II reporting standards for realist evaluations. *BMC Medicine* [Online], 14(1), 96.

Wrigley, F. (2018). **London requires more patient care plans to provide bespoke care.** *Health Service Journal*, 26th March.

Yin, R. (2014). *Case Study Research: Design and Methods*. Fifth edn. edn. London: SAGE Publications.

Yin, R. K. (2017). *Case Study Research and Applications: Design and Methods*. [Online]. Sage publications.

Appendices

Appendix 2.1 Economic indicators used in EOLC (Coast 2014)

- i.) Wefarism looks at how 'utility' (happiness and preferences) can be maximised – the focus of investigation is concerned with how well the desires on the part of patients and families are met. There is a suggestion that patients and family place more emphasis on the value of certain decisions during the limited end of life period and for this reason interventions acquired may fetch a higher price. In this approach perspectives of all those closely involved with dying patient are worthy of consideration. Critics of this approach suggest that focussing just on utility may miss other aspects of care and that preferences have been shown to undergo significant change as the amount of time left to live decreases.
- ii.) The second, and most common approach, relates to the idea of 'health maximization' (also known as 'extra-welfarism') and is expressed using QALYs (Quality Adjusted Life Years) as a measure. A QALY, equal to 1 year of life in perfect health, is calculated by estimating length of life remaining and weighting this against a quality of life score (on a scale of 0 to 1) (NICE 2020). The focus is on the health improvement of the individual and therefore more in line with general population measures of health status. The emphasis is on measures of health and the focus of benefit assessment is purely health improvement: either through reduction in morbidities or extending length of life. This may not be appropriate for EOLC, where the concern may be providing care rather than health improvement.

One problem in applying QALYs to EOL interventions results from the nature of this 'quality' adjustment, which is traditionally based on health interventions. In the case of EOLC however, outcomes viewed as effective may be particularly impacted by interventions traditionally provided through social services; the evaluative framework therefore may need to be adapted to encompass the broad methods advocated for evaluating social service interventions.
- iii.) The third position encompasses the health maximization approach but goes further to include notions of 'capability' as advocated by Amartya Sen (1987). Sen focuses on the importance of evaluating interventions according to their impact on an individual's capability well-being, that is, what a person is able to do or be in their lives. Sen provides an example of how capability well-being manifests itself, citing the case of two individuals at the end-of-life both requiring palliative care but living in different areas, one in an area where there is hospice provision and one where there is not. The individual in the first area may choose not to use the hospice care available, preferring to remain with family members; the second, who may not have family, would have used hospice care if it had been available in his local area. Neither individual received hospice care and appear similar therefore if 'use of services' is the only criteria considered, but in terms of capability (ability to access hospice care) the second patient is clearly worse off. An appropriate focus for the evaluation of end-of-life care might therefore be to consider different care strategies in terms of the capabilities that allow a person, and their family and friends, to have a good experience of end of life.

Appendix 3.1 Timeline for key guidance and strategy documents, together with initiatives on End of Life Care

2000

The NHS Cancer Plan (2000) and the National Service Framework for Older People (2001) emphasise the importance of palliative or end of life care.

2004-2007

The NHS End of Life Care Programme ran from 2004 to 2007. This SHA-led programme was supported by £12 million investment and aimed to help enable people at the end of life to have more choice about where they can be cared for and die.

2006/7

A first [National Care of the Dying Audit](#) was undertaken by the Marie Curie Cancer Care Palliative Care Institute and the Royal College of Physicians (2006). This assessed the quality of care given to 2672 patients who died in 94 hospital Trusts in 2006/07.

2007

Advance Care Planning: A Guide for Health and Social Care Staff. February 2007. End of Life Care Programme publication supported by NCPC.

[This publication aimed clarify the definition of Advance Care Planning and related terms, to provide practical guidance on core competences, education and training of different professional groups and related ethical and legal implication and to suggest next steps.](#)

2008

Department of Health (2008). End of Life Care Strategy: Promoting high quality care for all adults at the end of life. London: HMSO. [The first formal government strategy for EOLC – laid out challenges and aspirations for care of the dying. The Government committed an additional £383 million to implement the strategy; the Liverpool Care Pathway, or an equivalent tool, was recommended for wider use than for patients with cancer—it should be used in hospitals, care homes, hospices and in people’s homes.](#)

2009

Dying Matters Coalition Established. Aim to raise profile of dying and change attitudes.

DH 2009 EOLC strategy: quality markers and measures for EOLC

http://webarchive.nationalarchives.gov.uk/20130104173044/http://www.dh.gov.uk/en/Publicationandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681

These Quality Markers were designed for commissioners and providers, to accompany the DH's End of Life Care Strategy. They include markers for professionals in a variety of settings to encourage communication across all of these sectors.

2010

National End of Life Intelligence Network established. [Aim: to drive forward End of Life Strategy.](#)

White Paper: Equity and Excellence. [Lays out government policy direction on empowering choice including in end of life care.](#)

Supporting People to Live and Die Well. NHSIQ. The National End of Life Care Programme.

General Medical Council guidance: Treatment and care towards the end of life: good practice in decision making (2010). [This guidance for doctors from the General Medical Council provides a framework for good practice when providing treatment and care for patients who are reaching the end of their life.](#)

2011

Palliative Care Funding Review (Hughes-Hallet 2011): [recommendations for fairer funding of palliative care. 2 year pilots set up.](#)

NICE. Quality Standard for End of Life Care. [This quality standard covers care for adults \(aged 18 and over\) who are approaching the end of their life.](#)

Transparency in Outcomes (DH). [The first steps to develop a framework for quality in adult social care outcomes framework. Aim to improve social care outcomes including for people at end of life.](#)

The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services) [Collects information on bereaved people’s views on the quality of care provided to a friend or relative in the last 3 months of life, for England. The survey has now been run for 5 years and was commissioned by the Department of Health in 2011 and 2012, and NHS England from 2013. It is administered by the Office for National Statistics \(ONS\)](#)

Find your 1% campaign launched spearheaded by Dying Matters. [The Find your 1% campaign aims to support GPs and other health and social care staff in identifying the 1% of people who are likely to be in their last 12 months of life, in order to talk about, plan for and meet their end of life care needs and preferences.](#)

2012

The Health and Social Care Act (Department of Health 2012). [Enacted widespread reforms and promoted patient choice.](#)

First national VOICES survey of bereaved people: key findings report (DH 2012) [Annual systematic account of care experiences at end of life](#)

2013

Neuberger (2013). ‘More care, less pathway: a review of the Liverpool Care Pathway.’ *Department of Health*. [Recommended that the Liverpool Care Pathway should be phased out.](#)

Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. [Reported serious failings in care.](#)

NHSE, NHSIQ, HEE, PHE – [assumed new respective responsibilities for ELC under the Health and Social Care Act.](#)

2014

NHS England, (2014). Actions for End of Life Care: 2014-16. [online] London: NHS England, p.7. Available from: <http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>.

‘One chance to get it right: Improving people’s experience of care in the last few days and hours of life.’ Leadership Alliance for the Care of Dying People (2014) .

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Response to Independent review of LCO. Set out five priorities for EOLC.

LCP phased out by July 2014

Actions for End of Life Care: 2014-16 (NHS England)

<https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

NHS Choice Framework 2014/15 – [brought together information about how patients can make informed choices](#)

World Health Assembly – the governing body of the World Health Organisation - [passed a resolution requiring all governments to recognise palliative care and to make provision for it in their national health policies.](#)

NHS published Five Year Forward Plan (SYFP). [Focus on right care, right time, right place](#)

2015

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. National Palliative and End of Life Care Partnership. www.endoflifeambitions.org.uk

[This document is an attempt to bring together a number of disparate reports through a broad partnership of organisations across England working to improve health and care at the end of life. The document sets out ambitions for palliative and end of life care, based on collective experience and the analysis of the many reviews and reports in this area, and present a framework for local action.](#)

The Choice in End of Life Care Programme Board. ‘What’s important to me. A Review of Choice in End of Life Care.’ Feb 2015

National Council for Palliative Care and National Voices. (March 2015) Every Moment Counts: A narrative for coordinated patient centred care towards the end of life.

https://www.nationalvoices.org.uk/sites/default/files/public/publications/every_moment_counts.pdf

Dying Without Dignity. Parliamentary and health Service Ombudsman

<https://www.ombudsman.org.uk/publications/dying-without-dignity>

National Council for Palliative Care (2015) Time for Action: Why end of life care needs to improve, and what we need to do next

file:///C:/Users/User/OneDrive/PHD/literature.%20scoping%20review/pdfs%20of%20papers/Time%20for%20Action%20FINAL_0.pdf

July 2016

Our commitment to you for end of life care. One Year on: [The Government Response to the Review of Choice in End of Life Care \(Sept 2017\) DH](#)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/645631/Government_response_choice_in_end_of_life_care.pdf

[NHS Outcomes Framework 2016 to 2017 at-a-glance](#)

Sets out the framework and indicators that will be used to hold NHS England to account for improvements in health outcomes – including EOLC

[Future of an ageing population](#) Foresight report looking at the challenges and opportunities of an ageing society. This report brings together evidence about today's older population, with future trends and projections, to identify the implications for the UK. This evidence will help government to develop the policies needed to adapt to an ageing population.

2017

The National End of Life Care Intelligence Network (NEoLCIN) [present key data about end of life care to assist Sustainability and Transformation Partnerships \(STPs\) as they develop their plans for services.](#)

NEoLCIN have published this data as an [End of Life Care Sustainability and Transformation \(STP\) Tool - Version 3](#) with a [Metadata Guide - Version 3](#).

PHE: *Cost-effective commissioning of end of life care Understanding the health economics of end of life care*

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/612377/health-economics-palliative-end-of-life-care.pdfalliative and end of life care

2018

Hunter, J., Orlovic, M. (May 2018) [End of Life Care in England: A briefing paper](#). Institute for Public Policy Resarch

2019

Age UK (May 2019) End of Life Care. [Policy Position Paper](#)

National Audit of Care at the End of Life (NACEL) 2019. (HQIP 2019) The National Audit of Care at the End of Life (NACEL) is a comparative audit of the quality and outcomes of care in England and Wales experienced by the dying person and those important to them during the last admission leading to death. It looks at care in acute, community hospitals and mental health inpatient providers.

Appendix 3.2 Demographic data for gender, deprivation and ethnicity in older English population and how this may impact on both mortality data and place of death

Gender

Women continue to outlive men with data from 2018 showing there were twice as many females as males over the age of 90 (ONS 2019). The implications of this are reflected in the mortality statistics shown in table Of the 110,132 deaths in England in 2019 in those aged over ninety, 73,156 were women and only 36,976 men (ONS 2020 from NOMIS 21 Feb 2020). Conversely in the 75-79 age group more men died than women; 33,488 men compared to 27,169 women. These gender disparities have important implications for resource planning, particularly in relation to availability of beds in hospitals, nursing homes and hospices.

Table i.) English mortality statistics (2018) – by sex and age

Age	Total	Male	Female
total (all ages)	505,859	250,012	255,847
Aged 75-79	60,657	33,488	27,169
Aged 80-84	80,916	41,692	39,224
Aged 85-89	93,487	42,463	51,024
Aged 90 and over	110,132	36,976	73,156

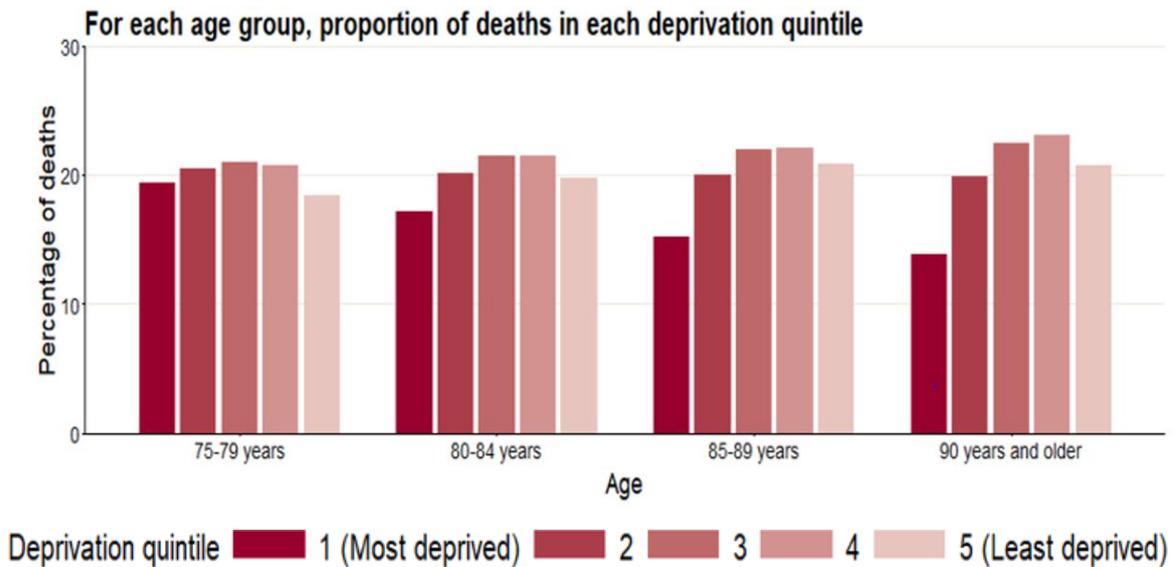
Source: <https://www.nomisweb.co.uk/>

ONS Crown Copyright Reserved [from Nomis on 21 February 2020]

Deprivation

Age of death differs with deprivation quintile (PHE 2017) with people in the most deprived quintile dying earlier than those in the less deprived quintiles. Figure i) shows how by the age of 90, numbers dying from the most deprived quintile are significantly lower.

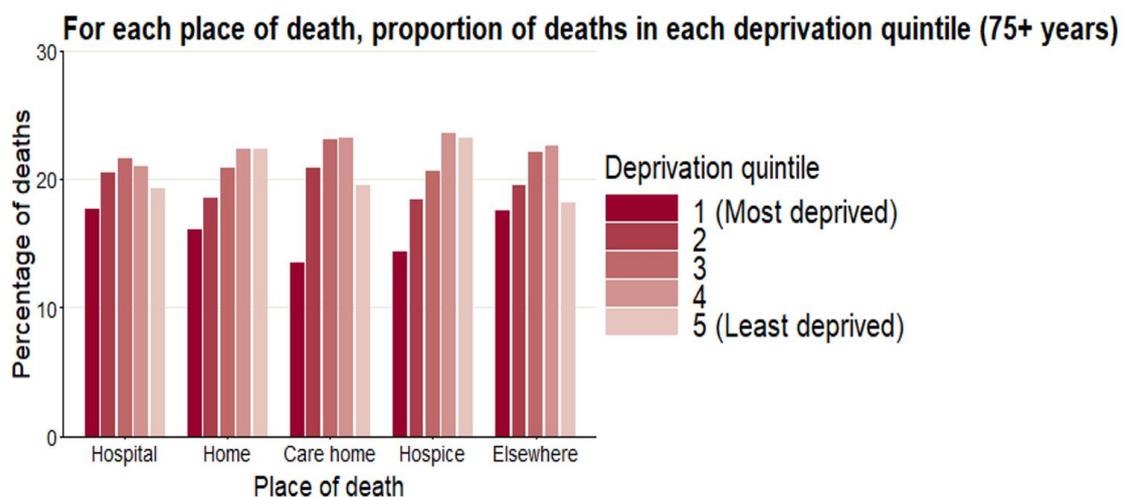
Figure i) Proportion of deaths by age amongst people 75 years of age and older in each deprivation quintile in England in 2017



Source: Public Health England (June 2017) <https://www.gov.uk/government/publications/death-in-people-aged-75-years-and-older-in-england-in-2017/death-in-people-aged-75-years-and-older-in-england-in-2017>

Not only is age of death linked to level of deprivation, data also shows that place of death varies with level of deprivation. Figure ii) below shows that in the 75-84 age group those who were more affluent were more likely to die at home or in a hospice compared to the most deprived quintile.

Figure ii) Proportion of deaths by place of death amongst people 75 years of age and older in each deprivation quintile in England in 2017

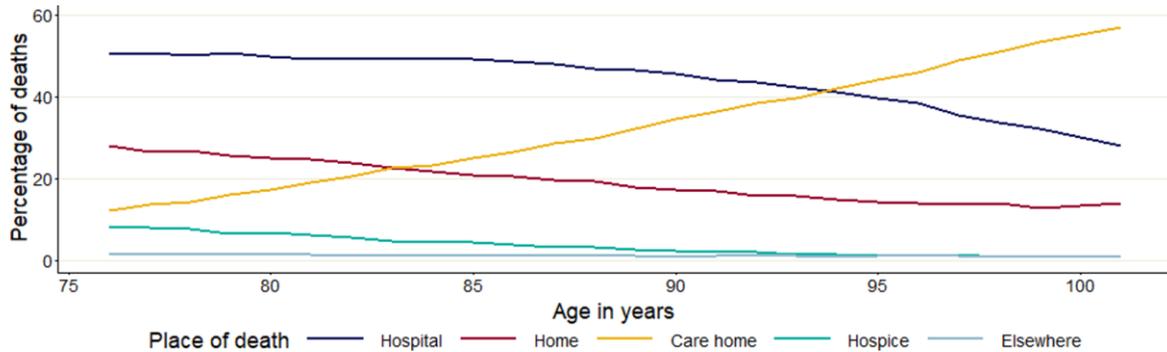


Source: Public Health England (June 2017) <https://www.gov.uk/government/publications/death-in-people-aged-75-years-and-older-in-england-in-2017/death-in-people-aged-75-years-and-older-in-england-in-2017>

Place of death is linked to age and gender

The reality of being able to die at home is that it is more likely to be facilitated for those not living on their own. The graph in figure iii) below shows that as people age they are less likely to die at home and more likely to die in a care home.

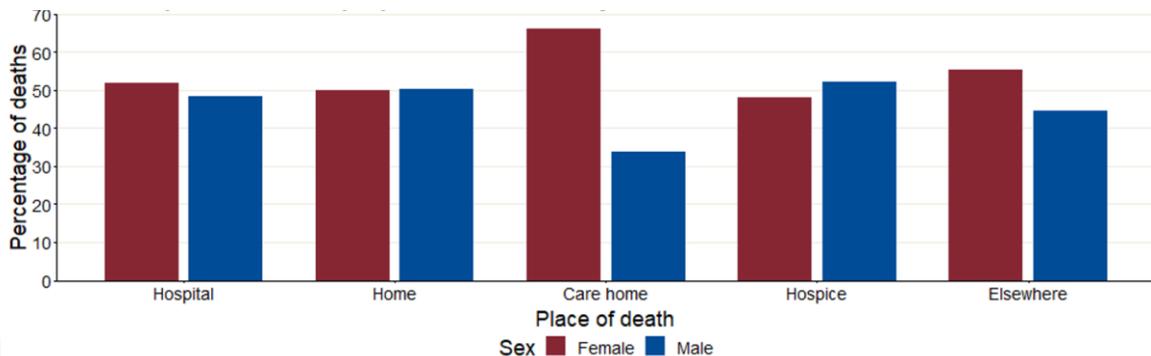
Figure iii) Proportion of deaths between the ages of 75-100 by place of death



Source: PH England (June 2019) <https://www.gov.uk/government/publications/death-in-people-aged-75-years-and-older-in-england-in-2017/death-in-people-aged-75-years-and-older-in-england-in-2017>

Gender too is linked to place of death. Women who live longer than men are more likely to end up living on their own before moving into a care home where they die. Figure iv) shows that in 2017 two thirds more women than men died in a care home.

Figure iv). Place of death by gender. 2017 data.



Source: PH England (June 2019) <https://www.gov.uk/government/publications/death-in-people-aged-75-years-and-older-in-england-in-2017/death-in-people-aged-75-years-and-older-in-england-in-2017>

Ethnicity

Age profile of BAME population groups in the UK is currently slanted towards younger groups due to migration patterns over the last half century. In England, according to the 2011 census, 86% of the population were white, 7.5 % were Asian, 3.3% Black ethnic groups and 2.2% mixed/multiple ethnic groups. However this distribution changes for those in older age brackets, as is reflected in the table below with Asians, aged between 75 to 79 constituting only 1.2 % of numbers in this age group.

Table ii) . Distribution of older population for England and Wales by ethnicity and age band

Percentage and number of people within each broad ethnic group that falls into each age group (2011 census data)												
	All		Asian		Black		Mixed		White		Other	
Age	%	Number	%	Number	%	Number	%	Number	%	Number	%	Number
Age 75 to 79	3.2	1,777,547	1.2	49,198	1.4	26,074	0.6	6,816	3.5	1,690,772	0.8	4,687
Age 80 to 84	2.4	1,338,005	0.6	26,010	0.8	14,236	0.4	4,578	2.7	1,290,136	0.5	3,045
Age 85 and over	2.2	1,254,688	0.4	14,956	0.4	7,618	0.3	3,625	2.5	1,226,440	0.4	2,049
Source: Gov.uk												

From: RAMESES II reporting standards for realist evaluations

1		In the title, identify the document as a realist evaluation
SUMMARY OR ABSTRACT		
2		Journal articles will usually require an abstract, while reports and other forms of publication will usually benefit from a short summary. The abstract or summary should include brief details on: the policy, programme or initiative under evaluation; programme setting; purpose of the evaluation; evaluation question(s) and/or objective(s); evaluation strategy; data collection, documentation and analysis methods; key findings and conclusions Where journals require it and the nature of the study is appropriate, brief details of respondents to the evaluation and recruitment and sampling processes may also be included Sufficient detail should be provided to identify that a realist approach was used and that realist programme theory was developed and/or refined
INTRODUCTION		
3	Rationale for evaluation	Explain the purpose of the evaluation and the implications for its focus and design
4	Programme theory	Describe the initial programme theory (or theories) that underpin the programme, policy or initiative
5	Evaluation questions, objectives and focus	State the evaluation question(s) and specify the objectives for the evaluation. Describe whether and how the programme theory was used to define the scope and focus of the evaluation
6	Ethical approval	State whether the realist evaluation required and has gained ethical approval from the relevant authorities, providing details as appropriate. If ethical approval was deemed unnecessary, explain why
METHODS		
7	Rationale for using realist evaluation	Explain why a realist evaluation approach was chosen and (if relevant) adapted
8	Environment surrounding the evaluation	Describe the environment in which the evaluation took place
9	Describe the programme policy, initiative or product evaluated	Provide relevant details on the programme, policy or initiative evaluated
10	Describe and justify the evaluation design	A description and justification of the evaluation design (i.e. the account of what was planned, done and why) should be included, at least in summary form or as an appendix, in the document which presents the main findings. If this is not done, the omission should be justified and a reference or link to the evaluation design given. It may also be useful to publish or make freely available (e.g. online on a website) any original evaluation design document or protocol, where they exist
11	Data collection methods	Describe and justify the data collection methods – which ones were used, why and how they fed into developing, supporting, refuting or refining programme theory Provide details of the steps taken to enhance the trustworthiness of data collection and documentation
12	Recruitment process and sampling strategy	Describe how respondents to the evaluation were recruited or engaged and how the sample contributed to the development, support, refutation or refinement of programme theory
13	Data analysis	Describe in detail how data were analysed. This section should include information on the constructs that were identified, the process of analysis, how the programme theory was further developed, supported, refuted and refined, and (where relevant) how analysis changed as the evaluation unfolded

RESULTS		
14	Details of participants	Report (if applicable) who took part in the evaluation, the details of the data they provided and how the data was used to develop, support, refute or refine programme theory
15	Main findings	Present the key findings, linking them to contexts, mechanisms and outcome configurations. Show how they were used to further develop, test or refine the programme theory
DISCUSSION		
16	Summary of findings	Summarise the main findings with attention to the evaluation questions, purpose of the evaluation, programme theory and intended audience
17	Strengths, limitations and future directions	Discuss both the strengths of the evaluation and its limitations. These should include (but need not be limited to): (1) consideration of all the steps in the evaluation processes; and (2) comment on the adequacy, trustworthiness and value of the explanatory insights which emerged In many evaluations, there will be an expectation to provide guidance on future directions for the programme, policy or initiative, its implementation and/or design. The particular implications arising from the realist nature of the findings should be reflected in these discussions
18	Comparison with existing literature	Where appropriate, compare and contrast the evaluation's findings with the existing literature on similar programmes, policies or initiatives
19	Conclusion and recommendations	List the main conclusions that are justified by the analyses of the data. If appropriate, offer recommendations consistent with a realist approach
20	Funding and conflict of interest	State the funding source (if any) for the evaluation, the role played by the funder (if any) and any conflicts of interests of the evaluators

Title of Study: How does End of Life Care and the views of stakeholders fit with the ambitions of national policy? Insights from a case study

April 2018

This interview outline is intended as a guide only. Different aspects of the interview will be emphasised depending on background and special areas of interest of the interviewee.

Introduction – Reminder of right to withdraw from study and contextual background.

Definitions

- What is your working definition of EOLC?

National Policy

- How does national policy and strategy help guide and determine local practice? What are the key challenges?
- Is there enough power/weight at a national level to influence practice? Why?
- What are the implications of: the new care models? Vanguard?
- What evidence is collected to inform policy and practice? Is data collected put to good use?
- How are decisions around cost and benefit variously understood and assessed? What is the value of using 'currencies' in discussion around cost?
- How to reduce/tackle variations in local practice?

Challenges

- What are the key challenges to delivering effective EOLC at the local level?
- Do we have the right balance of curative versus palliative care? Probe: ethics of financial outlay on drugs/technologies at EOL
- How is good practice measured? What monitoring indicators are used?
- Who determines what good looks like at the end of life?
- Gaps in research? Where is more evidence needed?

Data Collection

- What data should be collected locally and nationally?
- Do we do enough to assess 'quality of death' from patient perspective? Why? Probe: how to improve this?

Aspirational

If it was up to you to determine future policy and strategy for end of life care what would your priorities be?

Closure: Reminder about what will now happen with data and dissemination of findings

How does End of Life Care in England and the views and experiences of stakeholders, fit with the ambitions of national policy? Insights from a case study.

Date: 13/07/2018. Version 1

Introduction – researcher to provide background to the study.

Definitions

- What is your working definition of EOLC?

Local Practice

- Can you describe what end of life services there are in your local area (CCG?)
- What is balance between statutory and voluntary provision in your area?
- What is the provision of EOLC training across different professional groups?
- How is need assessed? Probe
- What are the factors/influences that impact on decisions made around prioritising EOL services at local level (CCG or STP)?
- In what ways, if any, does national policy and strategy help guide and determine local practice?
- What tools if any do you use
- Is there adequate leverage at national level to influence practice?
- What are the implications of: the new care models? Vanguard?
- Are there gaps in evidence?
- How are decisions around cost and benefit variously understood and assessed? What is the value of using 'currencies?' in discussion around cost?
- How to reduce/tackle variations in local practice?

- To what extent do you think the aspirations of National Policy are being met? (Probe: being treated as an individual; being involved in decisions; having fair access to services; having care that is coordination; being comfortable?)

Challenges

- What are the key challenges to delivering effective EOLC at the local level?
- How are decisions made between different services (palliative, acute, community)? Probe: ethics of financial outlay on drugs/technologies at EOL against costs of palliative care.
- Are you familiar with the use of currencies in commissioning services? Do you use them in commissioning EOLC? How? What are benefits/challenges of using currencies?
- Are currencies a useful way to assess funding needs for specific conditions? Why?
- How is good practice measured? What monitoring indicators are used?
- Who determines what good looks like at the end of life?

Data Collection

- What data is collected to inform policy and practice? Is data collected put to good use?
- What data should be collected locally and nationally?
- Do we do enough to assess 'quality of death' from patient perspective and clinician perspective? Why? Probe: how to improve this?

Aspirational

If it was up to you to determine future policy and strategy for end of life care what would your priorities be?

Thoughts on national commissioning guidelines/national EOLC frameworks for commissioning?

How does End of Life Care in England and the views and experiences of stakeholders, fit with the ambitions of national policy? Insights from a case study.

Date: 13/07/2018. Version 1

Introduction – researcher to provide background to study.

Definitions

- What is your working definition of End of Life?

Local Practice

- Can you describe what end of life services you are involved with.
- How is need assessed? Would you say that needs are generally met? Why? Thinking about your patients what improvements could be made? *Probe to get more detail.*
- Are you aware of the factors/influences that impact on decisions made around prioritising EOL services at local level (CCG or STP)?
- In what ways, if any, does national policy and strategy help guide and determine local practice?
- Is there enough leverage at a national level to influence practice? Why?
- What are the implications of: the new care models? Vanguard?
- How to reduce/tackle variations in local practice?
- To what extent do you think the aspirations of National Policy are being met? (Probe: being treated as an individual; being involved in decisions; having fair access to services; having care that is coordination; being comfortable?)
-

Challenges

- What are the key challenges to delivering effective EOLC at the local level?
- Do we have a good balance between different services offered (community, acute, palliative)? Probe: ethics of financial outlay on drugs/technologies at EOL against costs of palliative care.
- Are currencies a useful way to assess funding needs for specific conditions? Why?
- How is good practice measured? What monitoring indicators are used?
- Who determines what good looks like at the end of life?
- What are the workforces challenges? (Probe: supporting staff, staff shortages, education)

Data Collection

- What data should be collected locally and nationally?
- What data/evidence is collected to inform policy and practice? Is data collected put to good use?
- Are there gaps in evidence?
- Do we do enough to assess 'quality of death' from both patient and clinician perspective? Why? Probe: how to improve this?

Aspirational

If it was up to you to determine future policy and strategy for end of life care what would your priorities be?

Research study investigating the care experiences of older people needing more support and care. Does national policy help guide local practice?

Date: 13/07/2018

- Introduction – background to study
- What is your experience of the care you have received (or the treatment of the person you are caring for) over the last few months? This may be care from doctors, nurses, volunteers, therapists, social workers etc.
- It may be helpful to think about a specific episode and ask:
 - Who came to see you?
 - What did they do?
 - Was that how you wanted it?
 - Is that what normally happens?
 - Who else comes to see you
 - What are the things they look forward to most?
 - What are the things they find most helpful? What else would be helpful?

Prompts:

- What aspects of the care that you have received/are receiving, have been/are the most helpful to you or the person you are caring for)? Do you have a care plan in place? Advanced Care Plan? Advanced Care Directive?
- Have there been things that have got in the way of you/your relative receiving better care? Can you tell me about them?
- Do you feel that there was any care/ support that was not provided, or that you feel could have been done better?
- Have all your needs been addressed in equal measure or have some been easier to meet than others? (Probe: keeping you comfortable/reducing pain/providing clinical (medical) treatments/providing social support/providing assistance for helping you to eat/supporting family and carers/spiritual support/other)?
- What does good care mean to you?
- To what extent do you feel you/your relative/friend are:
 - treated as an individual?
 - involved in decisions?
 - have fair access?
 - care is coordinated?

- comfort is achieved?

1. When thinking about your care/ the care of your relative/friend do you make any distinction between health care (doctors/nurses) and social care (people who help with washing, cooking, counselling, cleaning etc)

Aspirational

If it was up to you to determine what type of care is offered to people in your situation what would your priorities be?

Appendix 4.3 Example of CINAHL literature searches

<i>Search result strategies and hits by database</i>		
<i>Search</i>	<i>Mesh terms</i>	<i>Number of hits</i>
CINAHL		
<i>Date performed: 5th January 2017</i>		
1. Age	<i>MM (Aged OR elderly OR geriatric) OR TX (Aged OR elderly OR geriatric) OR AB (Aged OR elderly OR geriatric)</i>	1,218,985
2. EOL	<i>MM (Terminal Care OR Hospice Care OR "End of life") OR TX (car* AND (terminal OR hospice OR "end of life" OR dying OR death) OR AB (car* AND (terminal OR hospice OR "end of life" OR dying OR death)</i>	138,516
3. Resources	<i>resources OR health care rationing OR health care costs OR healthcare economics OR cost benefit analysis OR cost allocation OR (costs and cost analysis) OR cost control OR cost of illness OR health priorities OR</i>	95,664
4. Policy	<i>(policy or policies or law or laws or legislation) OR strategy OR (uk or united kingdom or britain or england or wales or scotland or northern ireland) OR department of health</i>	743,060
5. Care	<i>care OR medical overuse OR patient centered care OR standard of care OR advanced directives OR comfort of care OR hospice care OR holistic health</i>	1,080,573
6.	<i>1 and 2 and 4 and 5 Screened for UK or Western or English Language or relevance</i>	1,741 <i>screened by title and 258 selected</i>
7.	<i>1 and 2 and 3 and 4 and 5 Limit publication date 2008 Limit English Language</i>	248

Cochrane Database 10/03/2018		
EOL AND Policy	as above Limit publication date 2008	127
EOL and Age and Care	as above	580 of which 78 were selected

Scopus 10/03/2018		
EOL AND Age AND Care and resources	as above Limit publication date 2008	65
EOL and UK Policy	as above Limit publication date 2008	66

King's Fund (10/01/2018)		
End of life reading list		68
Search carried out by KF	Policy and 'end of life'	115

AgeInfo Data base (30/03/2018)		
End of Life		327 Screened and 35 selected

Total papers reviewed		
After multiple copies were deleted final number of references saved in Refworks 391 – of these all abstracts were reviewed and 176 full pdfs downloaded.		

Project Title: How does End of Life Care and the views of stakeholders fit with the ambitions of national policy? Insights from a case study

25/09/2018 Version 2

Name of investigator: Rhiannon Barker, Centre for Health Service Studies, University of Kent

Name of chief supervisor: Professor Patricia Wilson, Centre for Health Service Studies, University of Kent

Email: rb648@kent.ac.uk

Participant identification number for this project:

IRAS: 247340

Please initial each box

1. I confirm that I have read and understand the information sheet dated 28/03/2018 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
3. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher/s, but my personal information will not be included and I will not be identifiable.
4. I understand that my name/my organisation's name will not appear in any reports, articles or presentation without my consent.
5. I understand that any interviews will be audio-recorded and transcribed and that data will be protected on encrypted devices and kept secure.
6. I understand that data will be kept according to University guidelines and all personal data destroyed once the study is complete.

7. I agree to take part in the above study.



Name of Participant Date Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher /person taking the consent _____
Date _____ Day/month/year

One copy of this form will be given to the participant and the original kept in the files of the researcher at the University of Kent

Research study investigating the care experiences of older people needing more support and care. Does national policy help guide local practice?

Version 2. 25.09.18

Name of investigator: Rhiannon Barker, Centre for Health Service Studies, University of Kent

Name of chief supervisor: Professor Patricia Wilson, Centre for Health Service Studies, University of Kent.

Email: rb648@kent.ac.uk Phone: 07941 262800

Participant identification number for this project:

IRAS:247340

Please initial each box

8. I confirm that I have read and understand the information sheet dated 13/07/2018 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

9. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

10. I understand that everything I say is confidential unless I tell you something that indicates that I, or someone else, is at risk of harm in which case you would discuss this with me before telling anyone else.

11. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.

12. I understand that any interviews will be audio-recorded and typed up and that data will be protected and kept secure.

13. I understand that data will be kept according to University guidelines and all personal data destroyed once the study is complete.

14. I agree to take part in the above study.



I do/do not* wish to receive a summary of the results.

*delete as applicable

Name of Participant

Date

Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Name of Researcher

Date

Signature

One copy of this form will be given to the participant and the original kept in the files of the researcher at the University of Kent

GP Address

I

RAS research reference number: 247340

Date

Dear...

Study Title: Research study investigating the care experiences of older people needing more support and care. Does national policy help guide local practice?

We are writing to let you know about some research we are supporting that is looking at the experiences of older people needing more support and care. We are interested to know how well we do locally and whether we manage to look after people in a way that both matters to them and meets what the government sets out to achieve.

Attached you will find an information sheet giving more details about the research. If you are interested in taking part, or simply want to find out more, please fill in the attached form and return it in the stamped addressed envelope provided to Rhiannon Barker, the researcher, who will contact you to discuss what it would involve so you can decide whether you want to take part. It is only through talking to people about their experiences that we can try to ensure the services we provide are meeting your needs. If you are interested in telling the researcher about some of your experiences she will come and visit you, in your home or other usual place of residence.

If you feel unable, or aren't interested in taking part, please be assured that the care you receive will not be altered in any way. Rhiannon Barker, the researcher carrying out this work will call next week to answer any questions you may have and to confirm whether or not you are interested in participating in this study

Best wishes,

GP and researcher

HRA project ID: 247340**Proforma for proposed telephone call to form part of substantial amendment****Version 1: 10/04/2019****If there is an answer phone Rhiannon Barker (RB) to say:**

'Hello my name is Rhiannon Barker, I'm just calling to check that you have received the information sent to you through the GP surgery (give surgery name) last week, about the research looking at care needs of older people. I won't call again but if you would like to participate please give me a call to discuss on 07941 262800. If you don't want to participate then of course that's fine and you need take no further action.'

If someone picks up:

RB: *Hello – is that 'name of patient'?*

If it is:

I'm sorry to bother you, my name is Rhiannon Barker. I'm calling to check that you have received the information sent to you through the GP surgery about the research looking at the care needs of old people.

If they are not sure read out the title:

'Research study investigating the care experiences of older people needing more support and care. Does national policy help guide local practice?'

If response: *Yes*

Then RB: *I was wondering if you have any questions you would like to ask?*

If: *'yes' – RB to answer questions*

If: *'no – I don't have any questions'*

Then RB: *You are under no pressure to participate but I was wondering if you have had the opportunity to think about whether you would be able to talk to me so I could ask you more about your experiences of care over the last few months?*

If: *'no' I don't want to participate'*

Then RB: *That's absolutely fine – thank you so much for your time.*

If: *'yes'*

Then RB: *That's great thank you! Is it best for me to come and talk to you at home? When would suit?*

If someone answers the call who is not the patient:

Hello, my name is Rhiannon Barker. I sent 'name of patient' a letter from the GP surgery the other day asking if they would be interested in participating in some research to learn more about their recent experiences of the care they have received. Would I be able to talk to them or to you about this?

If 'no' then RB: **That's absolutely fine – thank you so much for your time.**

... if 'yes' then proceed as above.

Research study investigating the care experiences of older people needing more support and care. Does national policy help guide local practice?

Researcher: Rhiannon Barker, Centre for Health Service Studies, University of Kent

Date: 03/03/2019 Version 3

Summary

We would like to talk to you to learn more about how you have found the treatment and care you or your relative/friend have received over the last few weeks. We are interested in your experiences, both good and bad. Information we get from you will be used to help plan care that is delivered in a way most likely to improve the quality life.

What is the purpose of the research?

The research is looking at how well provided for older patients are when they need more support and care. Older, from the point of view of this research, is defined as people over 75 years old.

The government wants all people needing more care to feel that they:

- Are treated as individuals
- Are being involved in decisions about their care;
- Have fair access to the care they need
- That care is coordinated between different agencies and that comfort is maximised.

We want to talk to you to see how well you think this is being done and to ask if these are the things that are important to you.

Who is undertaking the work?

The study is being carried out by Rhiannon Barker, a PhD student at the University of Kent. The research supervisors are Professor Patricia Wilson and Professor Claire Butler.

Why have I been invited?

You are being asked to take part because a professional who is involved in your care thinks that your experiences may be relevant to this study. If you have a close relative or carer who helps you, we would also like to learn about their experiences.

What will taking part involve?

Taking part in the research means you will have the opportunity to tell the researcher about your experiences of care and the treatment you or your relative/friend have received over the last few weeks and months.

The researcher will visit you wherever you are currently living. This is not a formal interview but more like a conversation. We want to allow you to express your experiences without

overtiring you. We may be with you anything between 30 to 60 minutes. It is entirely up to you how long you spend talking about your experiences.

If you agree to take part, we will contact you or your relative/carer to arrange to visit on a day and time that suits. We completely understand that you may need to cancel or change the agreed interview at the last minute if you don't feel up to it.

We also want to learn about the experiences of the close relatives or friends who care for you, providing that both they, and you, are happy for this to happen. We will ask you whether there is an appropriate friend or relative we could talk to and if you are happy to talk together or are more comfortable speaking separately.

Do I have to take part?

No. It is up to you whether or not you take part. Before we start the interview we will ask you to sign a consent form. If you decide to take part you can change your mind at any time without giving a reason. A decision not to take part will not affect your care and treatment in any way.

Are there benefits of taking part?

The research may help people in a similar situation to you in the future although there are no immediate benefits of this research to you. However, some patients can find it helpful talking about the experiences they have had. The research is intending to make a valuable contribution towards ensuring that the care received by frail, elderly people across England is consistent, of high quality and fits with what is important to patients.

What are the possible disadvantages of taking part?

You may find talking tiring or you may find it upsetting to reflect on your experiences. You can stop talking at any time. We will provide you with phone numbers for local services providing support if you feel you need it.

Will my taking part in this project be kept confidential?

We would like to record the conversation to help us remember what you say. The recording will be typed-up and all names will be removed. The recording will then be deleted. We may use direct quotes when writing up the research but any names will be removed so you will not be recognised individually. All information collected will be kept strictly confidential. The paperwork will be stored in a protected way and only the researcher and her supervisors will have access to this information.

If you tell us something that indicates there is a risk of harm to yourself or someone else, then we will need to consider telling someone about this risk. We will not speak to anyone without discussing with you first.

What will happen to the results of the research?

This study will help us understand your experiences and will help us to see how well that fits with what national policy is trying to achieve. We will share what we have found out with

everyone who was involved in the study, including you and if appropriate those caring for you. In order to reach a wider audience the results might be published in academic journals

and presented at academic or professional conferences. You will not be identified in any way.

DPR: Data protection, confidentiality, anonymity and right to withdraw

The University of Kent is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Kent will keep identifiable information about you until completion of the study period, anticipated to be 01.10.2020.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at <https://www.kent.ac.uk/infocompliance/> and/or by contacting the university compliance team on +44(0)1227 823671 or at <https://www.kent.ac.uk/infocompliance/dp/contact.html> .

How do I take part?

If you are willing to take part, please complete and return the attached consent form and return in the stamped addressed envelope. Or if you prefer email preferred contact details to rb648@kent.ac.uk. Once I hear back from you with your preferred contact method I will be in touch to organise a time to come and talk to you.

Questions or concerns?

The study has been reviewed and approved by London-Stanmore Research Ethics Committee (24730). If you have any general queries or concerns please contact the researcher directly.

Researcher: Rhiannon Barker Email: rb648@kent.ac.uk. Tel: 07941 262800

If the issue is not resolved successfully please contact Professor Wilson, P.M.Wilson@kent.ac.uk, 01227 816093. Where this has not been successful, complaints should be addressed to the Director of Research Services, Dr Simon Kerridge, S.R.Kerridge@kent.ac.uk, 01227 823229.

Follow up

I will call next week to make sure that they have received this letter, to answer any questions you may have and to confirm whether or not you are interested in participating in this study.

Appendix 4.7b Participant Information Sheet for clinicians and managers in case study

Study Title: How does End of Life Care in England and the views and experiences of stakeholders, fit with the ambitions of national policy? Insights from a case study

Researcher: Rhiannon Barker, Centre for Health Service Studies, University of Kent

Date: 25/09/2018. Version 2. IRAS Reference: 247340

Invitation to participate

You are invited to participate in a case study for research being undertaken at, and funded by, the Centre for Health Service Studies, University of Kent. The study is being conducted as part of a PhD. This case study is looking at End of Life Care and involves semi-structured interviews (topic guide attached) with a purposeful sample of managers, clinicians, patients and relatives/carers. The purpose of these interviews is to help identify and map key challenges in End of Life Care (EOLC) and to explore the experiences of those involved at all system levels.

Aims of Research

This study will explore current UK End of Life Strategy and Policy (both national and local), examining to what extent national policy influences and guides local practice. Through three CCG case studies it will ask if national policy is effective in helping to shape consistent EOLC which fits both with national ambitions and with the views of stakeholders.

The study will look at the way local resources are allocated and through this will examine how service priorities are set within budgetary frameworks. Exploring different EOLC pathways within health and social care, the study will examine the rationale behind aspects of health and care decision making. The perspectives of older people at the end of life, their family and carers, clinicians and policy makers will be interrogated.

What will it involve for me?

Interviews will be conducted at your convenience either face to face or by phone and will last no longer than forty five minutes. Interviews will be based on the attached topic guide. It is not intended that all respondents will necessarily answer all the questions in the topic guide; different aspects will be focussed on depending on your areas of interest and expertise. Participation is entirely voluntary and ethics permission for this stage of the research has been sought from and approved by the HRA (IRAS ref: 247340).

Benefits to the NHS

Key recommendations will be provided for professionals and policy makers that, it is hoped, will feed into the debate concerning how EOL policy and guidance at both national and local levels can contribute to achieving more equitable and consistent EOLC.

GDPR: Data protection, confidentiality, anonymity and right to withdraw

As a university we use personally-identifiable information to conduct research, including to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

The University of Kent's Data Protection Officer can be contacted at:
<https://www.kent.ac.uk/infocompliance/dp/staff-info/staff-info.html>

All data collected will be anonymised and no quotes attributed without permission having been sought.

How do I take part?

If you are willing to take part, please complete and return the attached consent form by email to rb648@kent.ac.uk or by post to Rhiannon Barker, CHSS University of Kent, Canterbury, Kent, England, CT2 7NZ,

If I do not hear from you in the next two weeks I will contact you by email and/or telephone to confirm if you are willing to take part or not.

Questions or concerns?

The study has been reviewed and approved by London-Stanmore Research Ethics Committee (ref: [247340](#)). If you have any general queries or concerns please contact the researcher directly.

Researcher: Rhiannon Barker Email: rb648@kent.ac.uk. Tel: 07941 262800

If the issue is not resolved successfully please contact Professor Wilson, P.M.Wilson@kent.ac.uk, 01227 816093. Where this has not been successful, complaints should be addressed to the Director of Research Services, Dr Simon Kerridge, S.R.Kerridge@kent.ac.uk, 01227 823229.

Research study investigating the care experiences of older people needing more support and care. Does national policy help guide local practice?

Name of investigator: Rhiannon Barker, Centre for Health Service Studies, University of Kent

Name of chief supervisor: Professor Patricia Wilson, Centre for Health Service Studies, University of Kent.

Contact email: rb648@kent.ac.uk Phone: 07941 262800

I, **(insert name)** would be happy to participate in the above study.

My preferred method of contact is
(please insert phone or email contact details)

I would prefer the arrangements to be made via a relative or carer. Please insert their name and contact details here:

.....

I would like (insert name of relative/carer) to be part of the discussion

Or please tick this box if you would prefer to participate alone

Signature:

Date:.....



Ms Rhiannon Barker
50 Dale Street
London
W4 2BL

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

15 October 2018

Dear Ms Barker

HRA and Health and Care

Study title:	How does End of Life Care and the views of stakeholders fit with the ambitions of national policy? Insights from a case study
IRAS project ID:	247340
REC reference:	18/LO/1443
Sponsor	University of Kent

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

How should I continue to work with participating NHS organisations in England and Wales? You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the “*summary of assessment*” section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a ‘green light’ email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

Page 1 of 7

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your nonNHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including: □ Registration of research

- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Nicole Palmer

Tel: 01227824797

Email: n.r.palmer@kent.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **247340**. Please quote this on all correspondence.

Yours sincerely

Kelly Rowe

Assessor

Email: hra.approval@nhs.net

*Copy to: Ms Nicole Palmer, University of Kent, Sponsor contact
Ms Sarah Walker, Hillingdon CCG, Lead NHS R&D contact*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UoK Henderson Insurance Doc 2]	1	01 June 2018
HRA Schedule of Events [Validated SOE]	1.0	23 August 2018
HRA Statement of Activities [Validated SOA]	1.0	23 August 2018
Interview schedules or topic guides for participants [Topic guide for clinicians 13072018]	1	13 July 2018
Interview schedules or topic guides for participants [Topic guide for managers in EOLC 13072018]	1	13 July 2018
Interview schedules or topic guides for participants [Topic guide for patients relatives carers 13072018]	1	13 July 2018
IRAS Application Form [IRAS_Form_25072018]		25 July 2018
Letters of invitation to participant [Letter of invitation to patient 25092018]	3	25 September 2018
Letters of invitation to participant [response form for patients 250918]	2	25 September 2018
Other [UoK Henderson Insurance Doc]	1	01 June 2018
Participant consent form [consent form for patients relatives carers 250918]	2	25 September 2018
Participant consent form [consent form for professionals 250918]	2	25 September 2018
Participant consent form [consent form for participants taking part in observed meetings]	2	25 September 2018
Participant information sheet (PIS) [Information sheet for patients relatives and friends 250918]	2	25 September 2018
Participant information sheet (PIS) [Information sheet for clinicians and managers 250918]	2	25 September 2018
Participant information sheet (PIS) [Information sheet for observing meetings 250918]	3	25 September 2018
Research protocol or project proposal [Protocol v7 180718]	7	18 July 2018
Summary CV for Chief Investigator (CI) [RB CV IRAS 130718]	1	13 July 2018
Summary CV for supervisor (student research) [P Wilson IRAS CV 2018]	1	18 July 2018
Summary CV for supervisor (student research) [C Butler IRAS CV 160718]	1	16 July 2018

Summary, synopsis or diagram (flowchart) of protocol in non technical language [phases of work 240718]	1	24 July 2018
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Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

If a study led by Northern Ireland or Scotland, complete assessment criteria as instructed, and complete other sections as normal.

Overwrite “No Comments” when it is appropriate to add comments

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. The statement of activities confirms there are no funds available to site from the sponsor.

5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical	Not Applicable	No comments
Section	Assessment Criteria	Compliant with Standards	Comments
	Trials Regulations assessed		
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

Participating NHS sites will be recruiting sites; the initial approach to patients will be by site staff with consent and interviews undertaken by external researchers possibly at site.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A local collaborator is expected at participating sites in order to arrange any access for external researchers.

GCP training is not a generic training expectation, in line with the [HRA/HCRW/MHRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

As this study is taking place in GP practices you are advised to contact the primary care management function to follow local processes.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Notification of Non-Substantial/Minor Amendments(s) for NHS Studies

This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.

If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

Instructions for using this template

- For guidance on amendments refer to <http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/>
- This template should be completed by the CI and optionally authorised by Sponsor, if required by sponsor guidelines.
- This form should be submitted according to the instructions provided for NHS/HSC R&D at <http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/which-review-bodies-need-to-approve-or-be-notified-of-which-types-of-amendments/> . If you do not submit your notification in accordance with these instructions then processing of your submission may be significantly delayed.

1. Study Information

Full title of study:	How does End of Life Care and the views of stakeholders fit with the ambitions of national policy? Insights from a case study
IRAS Project ID:	Ref: 247340
Sponsor Amendment Notification number:	Amendment 2
Sponsor Amendment Notification date:	14/05/2019
Details of Chief Investigator:	
Name [first name and surname]	Rhiannon Barker
Address:	Centre for Health Service Studies, University of Kent George Allan Wing, Canterbury

Postcode:	CT2 7NF
Contact telephone number:	07941262800
Email address:	Rb648@kent.ac.uk
Details of Lead Sponsor:	
Name:	Ms Nicole Palmer Lead for Research Ethics and Governance University of Kent
Contact email address:	n.r.palmer@kent.ac.uk
Details of Lead Nation:	
Name of lead nation <i>delete as appropriate</i>	England
If England led is the study going through CSP? <i>delete as appropriate</i>	No
Name of lead R&D office:	Sarah Walker Hillingdon CCG Address Boundary House, Cricket Field Road, Uxbridge, UB8 1QG Work Email

2. Summary of amendment(s)

This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.
If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

No.	Brief description of amendment <i>(please enter each separate amendment in a new row)</i>	Amendment applies to <i>(delete/ list as appropriate)</i>		List relevant supporting document(s), including version numbers <i>(please ensure all referenced supporting documents are submitted with this form)</i>		R&D category of amendment <i>(category A, B, C)</i> <i>For office use only</i>
		Nation	Sites	Document	Version	
1	<p>Addition of 'participation identification centres' in the three case study CCGs to allow for patient interviews to be conducted through community-based professionals within each of the three trust linked to the CCGs. These are:</p> <ul style="list-style-type: none"> i) Central and North West London Foundation Trust (for Islington and Hounslow CCG) ii) North East London Foundation Trust (for Newham CCG) iii) Central London Community Healthcare (for Hounslow) <p>The protocol (version 9) already states that professionals from a range of different settings will be used to help identify patients – but these settings are</p>	England	All sites	<p>Protocol</p> <p>Information Sheet</p>	<p>9 (03032019)</p> <p>3 (03032019)</p>	
		All sites				

Declaration(s)

Declaration by Chief Investigator

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment(s) to be implemented.

Signature of Chief Investigator: ...

Rhiannon Barker

Print name:

...Rhiannon Barker.....

Date:13/05/2019.....

Optional Declaration by the Sponsor's Representative (as per Sponsor Guidelines)

The sponsor of an approved study is responsible for all amendments made during its conduct.

The person authorising the declaration should be authorised to do so. There is no requirement for a particular level of seniority; the sponsor's rules on delegated authority should be adhered to.

- I confirm the sponsor's support for the amendment(s) in this notification.

Signature of sponsor's representative:



Print name:.....Nicole Palmer

Post:Research Ethics & Governance Officer

Organisation:.....University of Kent

Date:.....14.05.19

**Health Research
Authority****London - Stanmore Research Ethics Committee**

Ground Floor
NRES/HRA
80 London Road
London
SE1 6LH

Tel: 0207 104 8241

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

26 April 2019

Ms Rhiannon
Barker 50 Dale
Street w4 2bl
London
W4 2BL

Dear Ms Barker

Study title: How does End of Life Care and the views of stakeholders fit with the ambitions of national policy? Insights from a case study

REC reference: 18/LO/1443

Protocol number: N/A

Amendment number: 1

Amendment date: 03 March 2019

IRAS project ID: 247340

Approval was sought for changes to the patient recruitment. It was suggested that to improve response rate one follow-up phone call should be made from the surgery to the patient or carer to whom the letter was sent, clarifying that the letter was received, answering any queries and clarifying whether or not the patient was happy to participate.

The above amendment was reviewed at the meeting of the Sub-Committee held on 31 March 2019.

Ethical opinion

The researchers were contacted via email to reply to queries and provided the following clarifications.

The Sub Committee identified that the Participant Information Sheet is totally blank and requested a copy of the document is submitted for REC review. The members further noted that the researchers are planning to make a follow up phone call and requested that a script for the phone call is produced so that all phone calls take the same form.

Ms Rhiannon Barker replied by providing the pro-forma with a suggested script for the phone call and the full Participant Information Sheet.

The members of the Sub Committee were satisfied with the responses submitted by the researcher and were content to issue a Favourable Opinion for the Amendment. **The Sub Committee recommended that the phrase “or to you” in the line “Would I be able to talk to them or to you about this?” in the Participant Information Sheet is removed.**

Approved Documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Letters of invitation to participant	3	03 March 2019
Notice of Substantial Amendment (non-CTIMP)		
Other [phone call pro forma 100419]	1	10 April 2019
Participant information sheet (PIS)	3	03 March 2019
Participant information sheet (PIS) [Information Sheet for patients relatives and friends 03032019 version 3]		03 March 2019
Research protocol or project proposal	3	03 March 2019

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-andimproving-research/learning/>

18/LO/1443:	Please quote this number on all correspondence
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Yours sincerely



PP

Mrs Sunder Chita Chair

E-mail: nrescommittee.london-stanmore@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Rhiannon Barker

Attendance at Sub-Committee of the REC meeting on 31 March 2019

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Sunder Chita (Existing Chair)	Health Service Research Manager	Yes	
Dr Geraldine Edge	Consultant Anaesthetist	Yes	
Mrs Rosemary Hill (Chair)	Statistician	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Patrick Walsh	REC Manager
Miss Charlotte Ferris	Approvals Administrator



London Ambulance Service **NHS**
NHS Trust

Clinical Audit and Research Unit

Headquarters Annexe

Ground Floor, 8-London SE1 0BW20

Pocock Street

Tel: 020 7783 2504
sarah.kingsbury@lon
d-amb.nhs.uk

Project reference: 247340

REC reference: 18/LO/1443

30th January 2019

Dear Rhiannon

How does End of Life Care and the views of stakeholders fit with the ambitions of national policy?
Insights from a case study

I am pleased to inform you that your proposed research project, *“How does End of Life Care and the views of stakeholders fit with the ambitions of national policy? Insights from a case study”* now has full Trust Research & Development (R&D) approval to be carried out in the London Ambulance Service NHS Trust.

As agreed, we are only issuing approval for you to conduct telephone interviews; you will not be able to access London Ambulance Service sites to conduct interviews, and as such we will not be issuing you a Letter of Access.

Favourable ethical opinion

This approval is subject to the favourable ethical opinion of HRA and Health and Care Research Wales (HCRW) regulatory approval remaining in place for the entire duration of the project.

Local approvals

Trust R&D approval for your project is subject to the approval of local London Ambulance Service management remaining in place for the entire duration of the project.

Legislation

You must adhere at all times to the principles and standards of the Department of Health's *Research Governance Framework (2nd edition)*. You are also reminded of your obligation to collect, use, store and protect all research data in accordance with the Data Protection Act 1998, the Human Rights Act 1998, and all other legislation that applies to your project.

RL6 No issues – other approvals obtained

Updated December 2018

Page 1 of 2

Circumstances to notify to the R&D Co-ordinator

During the course of the project you must inform Sarah Kingsbury, R&D Co-ordinator immediately:

- If your research deviates from that laid out in the approved proposal, for any reason, at any time.
- If you encounter any problems or unexpected delays.
- Of any adverse incidents or near misses arising from the project. These will be dealt with according to current London Ambulance Service policy.

You must also comply with the rules on adverse event reporting as published by the Health Research Authority.

Amendments

If you wish to make an amendment to your project, for example to recruit at new London Ambulance Service sites or change the protocol in any way, please contact the R&D Co-ordinator prior to implementing the amendment to arrange for Trust R&D approval to be issued. You may also need to submit an amendment to the Research Ethics Committee that approved your project.

Final report and publications procedure

Finally, you are reminded of the procedure for the review of final reports and of publications arising from the project. Adherence to this procedure is a condition of the London Ambulance Service giving permission for you to proceed with your project.

The final report must be forwarded to me as soon as it is completed. This will then be reviewed by our Clinical Audit and Research Steering Group (CARSG) and feedback will be given. You must not publish or disseminate your final report until CARSG have given their approval to do so. Similarly, all papers, articles or presentations arising from the research must be forwarded to me prior to submission so that I can arrange review and approval by CARSG.

I wish you every success in your project.

Yours sincerely,



Dr Rachael Fothergill

Head of Clinical Audit and Research

ST JOSEPH'S HOSPICE

MARE STREET, HACKNEY, LONDON E8 4SA

STATEMENT OF PLACEMENT AS HONORARY APPOINTEE

EMPLOYER: University of Kent
Centre for Health Service Studies

HONORARY APPOINTMENT EMPLOYER: ST JOSEPH'S HOSPICE

NAME AND ADDRESS OF EMPLOYEE: Rhiannon Barker
50, Dale Street
London
W4 2BL

JOB TITLE: Honorary Researcher

FIXED CONTRACT FROM: 01/07/2019 to 31/12/2019

1. The honorary appointment is without remuneration from St Joseph's Hospice. Travelling expenses, course fees etc will not be met by St Joseph's Hospice unless prior written approval has been given by St Joseph's Hospice.

2. All information concerning patients and staff is strictly confidential and you will be asked to sign a Confidentiality Statement on commencement at St Joseph's Hospice.

3. You are required to devote all your working time to your research and educational work within the Hospice, to carry out your duties diligently with professional skill and devotion, and to uphold and maintain in your work the ethical and moral standards of St Joseph's Hospice.

4. Nothing in these conditions creates or deems to create a contract of employment between you and St Joseph's Hospice and you will not be entitled to any payment on the cessation or discontinuance of your honorary placement.

5. Whilst on this honorary placement within St Joseph's Hospice, you will comply with its policies and procedures. These are contained in the Staff Handbook, which you are requested to read. The Staff Handbook can be found on the Loop: Find a policy: Human Resources: Staff Handbook.

6. During this honorary appointment, you may be required to assist in the investigation of untoward incidents and, if requested, to supply a written statement and give evidence as a witness on behalf of St Joseph's Hospice.

7. You are expected to ensure a safe working environment and be aware of responsibilities under the Health & Safety at Work Act, taking appropriate action in the event of an accident to patients, staff, self or any other person in the work area.

8. St Joseph's Hospice accepts no responsibility for damage to or loss of personal property.

This honorary appointment permits the appointee to carry out research activity at St. Joseph's hospice only where it is related to the specific research project "how does End of Life Care and the views of stakeholders fit with the ambitions of national Policy? Insights from a case study.

Only research activity approved by the UK Health Research Authority (HRA) for this specific project is permitted (IRAS projects ID 247340, REC reference: 18/LO/1443).

If the above research project ends, closes or has its approval withdrawn then this contract will terminate with immediate effect

This honorary appointment is conditional on continued enrolment as a PhD scholarship student in the Centre for Health Service Studies at the University of Kent.

Signed on behalf of St Joseph's Hospice:

Print Name: Janet Simkins

Post held: HR Director

I hereby accept the appointment outlined in the above Honorary Contract on the terms and subject to the conditions referred to therein.

Please sign both copies and return one to the Human Resources Department, St Joseph's Hospice, Mare Street, Hackney, London E8 4SA.

Signed: 

Date: 13/09/2019.....

Having confirmed that the necessary additional pre-engagement checks have been completed, I am satisfied that the above named researcher is suitable to carry out the duties associated with their research activity outlined in this Research Passport.			
Signed:		Date:	
Name: SARAH WALKER		Job Title: ASSOC. Director Transl	
Organisation: IBOG; -t		Department: NINTI	
Email: sarah.walker@nint			
Section 8 - For Office Use Only			
This section should be completed by the NHS R&D Office that received the initial application. The NHS R&D office must countersign and date retained photocopies of the documents. The grey section must be completed before the form is returned to the applicant.			
CV reviewed?		Training?	No
Evidence of qualifications?	No <input checked="" type="checkbox"/>	Appendix pages reviewed?	Numbers IRA 524173 Schepinet activities
Professional registration details reviewed?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	Occupational health clearance reviewed?	No N/A
Criminal record disclosure reviewed?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	Date of disclosure:	re: 1/8/18 P0000 NY9 XQF
For regulated activity as defined in the Safeguarding Vulnerable Groups Act 2006, as amended (in particular by the Protection of Freedoms Act 2012), did the criminal record disclosure confirm a satisfactory check against the appropriate ISA barred list(s)			Yes <input checked="" type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Enter Electronic Staff Record Number (if issued):			
Confirmation of var Research Passport:			
Project specific <input type="checkbox"/> Three-year <input checked="" type="checkbox"/> Other End date <input type="checkbox"/> Date <input type="checkbox"/>			
Signed:		Date:	
Name: sarah.walker@nint			
NHS Organisation Name and contact details HILLINGDON CCG sarah.walker77@nhs.net 01895 203000			
Date Honorary Research Contract/letter of access issued (delete as appropriate)			

Appendix 4.9g Confirmation of research permission from Central and North West London

From: SAHOTA, Navdeep (CENTRAL AND NORTH WEST LONDON NHS FOUNDATION TRUST) <navdeep.sahota2@nhs.net>
Sent: 10 June 2019 13:20
To: R.J.Barker <rb648@kent.ac.uk>
Subject: RE: IRAS: 247340 PIC Site Confirmation of Capacity and Capability at Central North West London NHS Foundation Trust.

Hi Rhiannon,

Yes you can begin your study liaise with your contacts.

Please let me know if you require anything else and when you have completed your research at CNWL.

Best of luck with the project!

Kind regards,
Navdeep Sahota



Navdeep Sahota

Research Facilitator

Direct: 020 3317 2643 Team: 020 7685 5949



Appendix 4.10 Reports considered as part of data triangulation process in each case study site

Site 1	Site 2	Site 3
Most recent CQC report, including EOL care report	Most recent CQC report, including EOL care report	Most recent CQC report, including EOL care report
Data from NEOLCIN website	Data from NEOLCIN website	Data from NEOLCIN website
Care Home Data Pack Report	EOL Masterclass CCG Update. 09/11/2019	'Percentage of deaths with three or more emergency admissions in last 90 days of life' London Clinical Network 2018
CCG Paper 2017/19: 'Locally Commissioned Service Specification for Rolling Last Years of Life (LYoL) LCS Specification for GP'	GP Masterclass Ceilings of Treatment	'CCG Action Plan for Delivery of End of Life Strategy' 2018
Integrated Pioneer Programme Paper	Coordinate my Care: An MDT approach	'Organisational development towards integrated care: a comparative study of Admission Avoidance, Discharge from hospital and End of Life Care pathways in three CCGs" 2018
STP Last Phase of Life Steering Group minutes 2019	'Compassionate Care – Improved End of Life Care at Hospital'	'EOLC pathway in ... CCG'
STP Last Phase of Life Business Case		'Pilot: An Appropriate Pathway of Care for Frailty and End of Life Care in ... CCG' 2018
Urgent and Emergency Care Workstream: High Level 5 Year Delivery Plan for 2017/18		

Reference details withheld for identification purposes

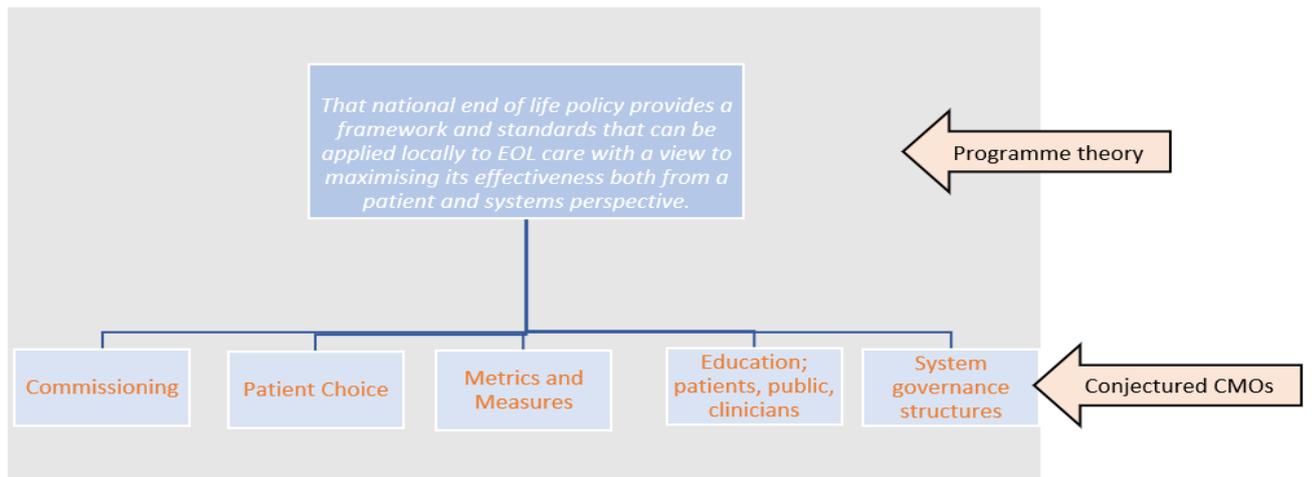
Appendix 4.11 Example of template used to refine CMOs

If patients are properly communicated with, in a timely fashion and provided with meaningful, informed choices – regardless of their ethnicity, religion and socio-economic group

Context ‘If this is in place’	Mechanism ‘Then this may be triggered’	Outcome ‘To produce this outcome’
<p>Sub-Category</p> <p>If patients are properly communicated with, in a timely fashion and provided with meaningful, informed choices – regardless of their ethnicity, religion and socio-economic group</p>	<p>Sub-Category</p> <p>Then, commissioners, clinicians and other service providers will use policy to fulfil patient wishes</p>	<p>Sub-Category</p> <p>Better patient experience and person-centred care at the EOL</p>
<p>Code</p> <p>Communication</p> <p>ACPs</p> <p>Coordinate My Care</p> <p>Electronic Palliative Care Systems</p> <p>Ethnicity</p> <p>Religion</p> <p>Socio-economic group</p> <p><i>‘It helps to have these discussions as early as possible.’</i> (C.Clinician.8)</p>	<p>Code</p> <ul style="list-style-type: none"> - Patient choice - Enacting policy <p><i>‘many doctors and nurses do it extremely well and we manage a lot of ‘good deaths’.</i> (B.Clinician.1)</p> <p><i>‘Before it was difficult but now its not. I pre-empt the conversation by saying I need to talk about things which might not be easy – but I need to know so that we can plan in advance to ensure that your loved one gets the care you want.’</i> (A.Non-Clinical.2)</p>	<p>Code</p> <ul style="list-style-type: none"> - Quality of life - Patient experience - Person centred - Listening <p><i>‘Yes the doctor came and asked my mum about what she wants to do at the end. She said she wants to die in her own home and she doesn’t want them to turn the machine off. She want’s to die naturally – or as best as she can. It was a good conversation. You get to know what she wants. And I know that my mum wants to live. She doesn’t want death to be hastened.’</i> (A.Carer.2)</p> <p><i>‘We do initial assessment on patients and create an ACP. Those with months to live we may offer referral to social services and the local hospice - and make sure we are aware of general needs. The actual plan will depend on their level of need</i></p>

		<i>and how much time they have to live.'</i> (B.Clinician.3)
<p>Notes:</p> <ul style="list-style-type: none">• Refinements or relationship to programme theory• Data from case study shows importance that choice presented is meaningful – if this is not the case clinicians observe poor patient experience and lose faith/		

Figure 1: Key factors influencing the Programme Theory



1. Conjectured CMO mechanism for EOL national policy

Context Mechanisms	programme mechanism (resource)	Agency (reasoning)	Some possible outcomes
If this is already in place....	If this is provided as an 'intervention'...	Then this will happen	Leading to....
<ul style="list-style-type: none"> - that there are adequate resources (both staff and financial) to allow for policy to be enacted - that policy fits with priorities of key stakeholders - that the relevant parts of the system (health and social care) work together effectively to provide holistic, seamless, care 	<ul style="list-style-type: none"> - national policy is drawn up that determines minimum requirements for national delivery of EOLC and can be used as a template to guide good practice and set aspirational targets -that policy is promoted and that staff are made aware of its existence - that necessary levers (incentives and penalties) are in place to provide the power and weight to implement policy -that staff have the skills and resources to allow them to effectively implement policy 	<ul style="list-style-type: none"> -that those responsible for implementing policy believe in its value (both service managers and clinicians) and therefore chose to refer to policy documents 	<ul style="list-style-type: none"> - more equitable national provision of EOLC
<p>Programme Theory</p> <p><i>That national end of life policy provides a framework and standards that can be applied locally to EOL care with a view to maximising its effectiveness both from a patient and systems perspective.</i></p>			

2. **Conjectured CMO mechanism for EOL commissioning**

Context Mechanisms	programme mechanism (resource)	Agency (reasoning)	Some possible outcomes
If this is already in place....	If this is provided as an 'intervention'...	Then this will happen	Leading to....
<ul style="list-style-type: none"> - professionals are provided with necessary resource in terms of staff time, finance, know-how to actively commission effective EOLC services - adequate evidence base on which to decisions are made - system level structures enable joined up working across seamless pathways. - an evidence base for outcomes based commissioning 	<ul style="list-style-type: none"> - professionals are educated in and enabled to use the policy framework to commission and implement effective services. 	<ul style="list-style-type: none"> - professionals recognise the value of working together and are motivated to do so - professionals recognise the value of seeking out evidence based models and pathways 	<ul style="list-style-type: none"> - improved patient experience - less aggressive interventions at EOL - less emergency acute admissions in last 3 months of life - greater percentage of people dying in UPR - system wide savings from reduced pressure on acute services

3. Conjectured CMO for Patient Choice at EOL

Context Mechanisms	programme mechanism (resource)	Agency (reasoning)	Some possible outcomes
If this is already in place....	If this is provided as an 'intervention'...	Then this will happen	Leading to....
<ul style="list-style-type: none"> - real patient choice around treatment options which are fully resourced - patients need to have sufficient information available to make the choice - patients need cognitive capacity to make choice - choices need to be available regardless of condition, ethnicity, socio-economic group, geographical region - relative/carers support patient choice - cultural/religious factors align with available choices - joined up services create seamless pathways between sectors and settings 	<ul style="list-style-type: none"> - patients are educated and supported to consider the potential impact/outcomes of the various choices available 	<ul style="list-style-type: none"> - patients choose the pathway that best supports their values and circumstances and preferences - patients are empowered to make choices best suited to their own circumstances - patients play an active part in care choices available 	<ul style="list-style-type: none"> - patients build trusting relations with professionals and are helped to make choices which are 'right for them' - improved patient experience - less aggressive interventions at EOL - less emergency acute admissions in last 3 months of life - greater percentage of people dying in UPR -system wide savings from more people at EOL treated in community

4. Conjectured CMO for metrics and measures

Table 1c. **Conjectured CMO mechanism for use of metrics and measures in EOL services**

Context Mechanisms	programme mechanism (resource)	Agency (reasoning)	Some possible outcomes
If this is already in place....	If this is provided as an 'intervention'...	Then this will happen	Leading to....
<ul style="list-style-type: none"> - recorded measures from across different localities provide a benchmark against which comparisons can be made - suitably sensitive/appropriate data is available for comparison - staff have adequate skills and resources to collect data - adequate resources are available to allow for system changes to be made - there is a culture of learning/improvement - data collected is credible 	<ul style="list-style-type: none"> - mechanisms and support are in place to encourage sharing of good practice across localities in order to improve performance of outliers - the data collection process may improve focus and attentiveness of those involved at system level 	<ul style="list-style-type: none"> -those with power to make changes will be motivated by the 'naming and shaming' process to improve outcomes and thus fall in line with best performers. 	<ul style="list-style-type: none"> - statutory recording of a number of identified measures, made available to the public will improve national consistency of End of Life Services - reduced inequalities in access to end of life services - it becomes easier to identify and asses the inherent value of the different EOL measures used.

5. Conjectured CMO mechanisms for role of education in EOL care services

Context Mechanisms	programme mechanism (resource)	Agency (reasoning)	Some possible outcomes
If this is already in place....	If this is provided as an 'intervention'...	Then this will happen	Leading to....
<p>A health and social care system which has begun to explore the long-term impact of the drive to extend life without reference to the quality of life.</p> <p>A recognition that we need to consider how spending on clinical/medical care impacts on the size of the resource left to invest in social/relational care.</p> <p>An understanding that the drive to keep people alive at all costs may be aggravated by a lack of knowledge and consequent fear associated with the process of dying</p>	<p>Education of staff and patients to:</p> <ul style="list-style-type: none"> - encourage more open communication with patients at EOL and early provision of ACPs - to help identify patients who may be EOL - improve the confidence of clinicians, patients and relatives/carers to plan for the EOL without unnecessary medical intervention. 	<p>That professionals choose to communicate openly and transparently with patients at the EOL.</p> <p>That professionals suffer less anxiety and improved confidence in registering patients onto palliative care and EOL registers.</p>	<p>Patients end their life in a manner that fits with personal choice, where: comfort; being in a familiar environment; being free of pain; being involved in choices around treatment options; being with family - are considered alongside life extending interventions.</p>

Annex 6.1 Forms of data commissioners reported referring to support commissioning

- Secondary Users Service (SUS) data records information from patient episodes of care, information is held by NHS Digital and used to inform healthcare planning, commissioning, public health, clinical audit and governance, benchmarking, performance improvement, medical research and national policy development.
- Payment by Results (PBR) data from the acute sector
- SLAM (service level agreement monitoring) datasets. SLAM data contains all activity data and is the primary source for detailed information regarding NHS Local Area Teams. total financial exposure.
- Those working at the broader STP level had access to data they believed to be 'richer' and more sensitive than SUS and SLAM. One such tool mentioned was the WSIC (Whole Systems Integrated Care) Dashboard – which provides data at STP level – collected across mental health, community and primary care to generate an integrated care record:

'The WSIC system – provides much richer data than standard health care data – it combines much broader metrics than would normally be available. It's better than standard SLAM and SUS data which is generally what most commissioners will be looking at.'
(C.ServiceManager10, CCG based)
- The CCG Business Intelligence Unit can provide specific facts and figures
- Direct contact – often through formal, regular network meetings, with key service providers and clinicians to glean inside knowledge from the front line of perceived gaps
- Co-ordinate my Care – the Royal Marsden led EOL care planning system now used across London

