

An implementation post-mortem: a study of coordinated care at the end of life

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Abstract

Background: Health policy in England has increasingly promoted coordinated and integrated health and social care services delivered through partnerships with public, private and voluntary sector organisations. End of life care would likely benefit from improved coordination as patients in the last few months of life with incurable, irreversible illness often require access to a range of services. A regional partnership project, which served as a case to study the implementation process, proposed to coordinate end of life care through establishing a Navigation Centre, shared electronic palliative care patient record (EPaCCS) and working groups to develop new patient pathways within the region. There is a gap in understanding how such complex, multi-innovative programmes are implemented by partnerships.

Aim: This study draws on implementation theory to explore the implementation process of a project delivered by a partnership, specifically the shape of the process, what influenced the shape and what implementation outcomes were achieved.

Design and Methods: The study adopted a pragmatic, pluralist design using primarily qualitative methods including: document review, observations, interviews, focus group and telephone interviews. A thematic analysis was conducted using the Framework approach which allows for the data to be reduced and sifted through to find linkages and patterns in the data by both source and theme as part of an inductive and deductive analytical process.

Findings: The implementation of the Project was characterised by an interactional, over-lapping process in which planning, development, implementation and adaptation of the various innovations proceeded simultaneously, though at the end of the two year project period many tasks were incomplete. Barriers to implementation included: the NHS reforms, lack of robust project management, interconnected project elements, and competition from similar innovations. Facilitating factors included: leadership by the Hospice as experts in end of life care, work benefit, individual motivation, and sole ownership and management over implementation. External threats to the Project had variable influence on the partners and suggests that project resiliency is particularly important for complex multi-organisational programmes which are implemented over time and by multiple stakeholders from different sectors. This study's contribution to knowledge is that resilience to unplanned events in a project appears to be the product of implementation strategies, innovation adaptiveness and implementer characteristics. Future research should look further at what contributes to project resiliency and how projects can develop resilient factors to ensure their success.

I Introduction

I.1 Introducing the focus of the study

There is a continual drive in health and care services to deliver better outcomes for patients with fewer resources. As budgets are tightened, new programmes must be delivered efficiently while achieving their desired impact, and increasingly services in the UK are expected to work together to improve patient care (DH, 2006 & 2010). These programmes can be complex targeting patient and professional behaviour and challenging existing working practices. Such changes can be difficult to implement successfully and unsatisfactory results may be blamed on a flawed intervention when in fact the problem may lie with implementation. Implementation is therefore an essential part of service delivery which all too often is overlooked (Demiris et al, 2013; Greenhalgh et al, 2004b). The implementation process of complex programmes can be lengthy and involve many people which leaves room for problems to compound and threaten programme sustainability; understanding the strategies and facilitators that influence the process can ensure that future programmes are implemented effectively.

This study is focused on exploring the implementation process of a new programme to understand what influences it. In particular, it seeks to explain the role of implementation strategies during the process and what shape it takes. It will also explore what implementation outcomes are produced from the process. The case for exploring this process is a programme aimed at improving end of life care through the coordinated delivery of health and social care services within a region of England. End of life or palliative care is characterised by patient and family centred care which often occurs over a relatively short length of time (WHO, 2012) and the unpredictable nature of terminal illness can be particularly challenging for professionals (Demiris et al, 2013). Palliative care represents a truly integrated approach to care through its whole-person focus which considers physical, mental, social, spiritual, and psychological well-being (WHO, 2012). Though the project took place at a regional rather than national level, it involved the entire health and social care system within the region and is a microcosm for exploring a systemic implementation process. The findings from this study have mainly service implications and will contribute to our knowledge of the implementation process of complex programmes and projects in health care and especially end of life care.

I.2 Policy context: coordination and choice in health and social care

This section sets the political and economic scene in which the case for the study was developed and implemented. Though the findings from this study are primarily service orientated, this policy context will help contextualise the findings for transferability (Guba and Lincoln, 1989).

In the last decade health and care services have developed within complementary policy themes of coordination and choice. There is an increasing demand for services to support greater patient choice and autonomy through a more coordinated and connected health and care system. This is in part a response to an increasing prevalence of a consumer healthcare theme in national health policy in recent decades (Greener, 2009). The message of patients as active participants in their care has been strengthened over time so that they are now even expected to participate in service planning (NHS England, 2013b) which was once only the remit of managers. Alongside the progression of the patient choice narrative is a relatively more recent shift in ideology away from top-down service planning towards patient-centred care and coordination between health and care services. 'Partnership', which mainly implied joint working and collaboration as a way to deliver services to patients, was introduced in 2000 in the NHS Plan (Lewis, 2001). While traditionally there has been tension between the health and social care sectors due to differences in financing, managing, and professional cultures, Lewis (2001) argues that it is in fact national policies which lacked clarity in care responsibilities which entrenched these differences. In the last decade, particularly with *Our Health, Our Care, Our Say* (DH, 2006), there has been a shift towards removing boundaries between health and social care so that patients and their needs and even wishes, might be more central in service planning and delivery. Thus rather than focusing on where responsibility lies, health and care services are expected to work together to jointly address needs.

The unification of health and social care continues in health policy with a series of policies beginning in 2010. The first of these policy documents, *Equity and Excellence: Liberating the NHS* (DH, 2010), anticipated that improvements in care would be made through coordination, partnership, and integration so that care is delivered where it is wanted. Subsequent policies have further reiterated a goal of integration (HM Government, 2012), with the primary aim to increase personalisation of services (Social Care Policy and DH, 2010). The theme of choice has shifted subtly to one of personalisation. Whereas choice implies agency in the selection between two or more options, personalisation indicates not just selection, but the moulding of services to suit individual needs. Whereas health and care professionals may have previously been

responsible for interpreting people's needs and offering services accordingly (Greener, 2009), within a personalisation agenda the public is viewed as being able to take control of meeting their own needs. It has been proposed within policy documents that this shift in how the population is conceptualised in terms of having greater agency requires a systematic change in how health and care services are delivered so that people can indeed be co-creators of their care (DH, 2010).

Liberating the NHS (DH, 2010) introduced a number of changes broadly in line with the ideological shift of the previous decade. Firstly, a fundamental change was introduced in the purchasing of services which has since received legal backing with the Health and Social Care Act 2012. The Act 2012 shifted the power to purchase services from Primary Care Trusts (PCTs) to general practitioners (GPs) working in consortia (Clinical Commissioning Groups) who are viewed as the "medical home" (DH, 2010, pp. 8) of patients, thus bringing service provision decision making closer to the public. It is assumed that those who interact with patients on a regular basis are better suited to understand the needs of the local population. This also echoes previous changes which have sought to put more emphasis on primary care and prevention. Secondly, provisions for the financial linking of health care providers to local authorities which provide social care were also introduced and which follows on from previous governments' efforts to integrate the health system with social care, such as through the introduction of the Care Quality Commission which is the single regulator for all health and social care services. Removing the barriers for sharing funding is meant to enable health and care services to innovate together as budgets can be pooled rather than cautiously guarded independently. However, while funding for the NHS has remained stable during the period of austerity from 2007, there have been large real cuts to local authorities (King's Fund, 2011). Under the new rules for budget sharing, the NHS has been able to transfer money to local authorities to cover their shortfall, but this has put increased pressure on NHS resources (King's Fund, 2013). In addition to resource sharing, information sharing is also seen as an essential means for integration. The Department of Health's information strategy (DH, 2012) put forth a number of aims: information will drive integration across all sectors, professionals should view information as a way to better understand their service users, information should be recorded once and shared securely, information in care records should be used for research and quality management and should be seen as a service in its own right, and that the easy flow of information around the system will improve care. The information strategy fundamentally requires a change in the way professionals approach information – that it is essentially an ongoing dialogue which requires professionals to both contribute to the discussion and listen to what others are saying. These three key systemic

changes of bringing service planning closer to patients and integrating funding and information systems represent both structural and cultural change within the health and social care system.

Underpinning these changes is a desire to reduce the top-down control in which national bodies govern the health and social care process and instead give responsibility back to the frontline providers. By freeing providers of top-down constraints, it is assumed that this will allow providers to innovate and develop new ways of working to deliver improvements in patient care and reduce costs. End of life care is one area which challenges the resources of the NHS and is felt to be lacking in coordination and choices available to patients (DH, 2008).

1.2.1 The position of end of life care in this policy context

Whereas end of life care encompasses a broad spectrum of activity in caring for people who are in the last days, weeks or even months of life, palliative care refers more specifically to a specialist approach to care which is patient focused. In practice these terms are sometimes used interchangeably, but in this thesis they will be used when it is useful to try to distinguish between these two slightly different yet overlapping areas. Palliative care as a specialism is a relative newcomer in the field of health care only being recognised as a specialty by the Royal College of Physicians in 1987 (APM, 2015). The origins of palliative care stem from the hospice movement of the 1960s led by Dame Cicely Saunders in the UK who sought to challenge the medical model that valued cure over the quality of life of those who were dying (Buckley, 2008). End of life care has received increased attention in health policy in the last decade with a call for an increase in funding (DH, 2006) which was then followed by the Department of Health's *End of Life Care Strategy* published in 2008. The strategy was to be implemented through the National End of life Care Programme which spawned a number of regional programmes like the one which will be explored as the case for this thesis. Additionally, NICE published a quality standard for end of life care for adults in 2011 which outlined a number of statements that characterise high quality care and which includes the provision of coordinated care. In line with policy for the wider health and care sector, two key changes have been under way. Firstly, a funding review of palliative care (Hughes-Hallet et al, 2011) was undertaken in 2011 to look at the way that palliative care is funded and to make recommendations for changes to the system. A key recommendation was made for a system to be developed to provide funding on a per-patient basis and which has been piloted since 2012 in order to be implemented widely by 2015/16. A second key change was the introduction of Electronic Palliative Care Co-ordination Systems (EPaCCS) which superseded Locality Registers in 2013 (NEoLCP, 2012). EPaCCS are a way for health and care providers to access care plans and advance statements of wishes for people who are identified as being in the last year of their life. The use of EPaCCS is recommended, but not mandatory, but for those

service providers who choose to use an EPaCCS, that system must meet minimum standards. These two changes reflect the wider policy agenda of personalisation and integration. Funding that follows the patient is meant to allow patients to choose their care provider(s) (and that these providers be remunerated according to their demand) which in end of life care is often a mix of voluntary, primary and tertiary care. EPaCCS should allow patients to move seamlessly through the system from provider to provider thus creating an integrated care package.

While policies and initiatives have helped to raise the profile of palliative and end of life care in the last ten years, focus and support might now be waning. Firstly, the End of Life Care Programme came to a close in March 2013. While some of the work of the programme continues through NHS Improving Quality, the loss of a dedicated programme has perhaps shifted focus away from end of life care. Secondly, negative media reports of the Liverpool Care Pathway (LCP), which was a tool developed in the late 1990s intended to improve the quality of care for those actively dying (Murphy et al, 2012), led to a review of the pathway which eventually resulted in it being withdrawn as a tool. However, the key problem with the LCP was not that the guidance was flawed, but that implementation by non-palliative care specialists was often poor because of a lack of knowledge and understanding in how it should be used (Neuberger et al, 2013). Despite the underlying causes for poor use, media reports labelled it a “road to death” (Liverpool Care Pathway: ‘They told my family I was dying’, 2013) and shone a negative spotlight on end of life care.

1.2.2 Critical issues for end of life in the health and care sector

This brief discussion of the key changes in health and care policy and ongoing developments in end of life and palliative care raise a number of issues about the relationship between end of life care and the wider health and care sector, particularly around boundaries and leadership. Firstly, palliative care was developed as a response to the medicalized management of patients who were dying at the expense of other personal needs, such as social, spiritual and psychological (Saunders, 2006). This implies a holistic approach to care, but health policy indicates an implied emphasis on the medical care of patients at the end of life as the NHS has responsibility for caring for people who have a “primary health need arising from a rapidly deteriorating condition that is entering a terminal phase” (DH, 2009, pp.5). This policy definition and funding responsibility sets the groundwork for the creation of funding boundaries in health and social care for end of life patients, as prior to pooled budgets it would have been very important to determine which sector is responsible for which patient (Lewis, 2001). But since restrictions on sharing budgets have been lifted, there is possibly now more opportunity to engage the social care sector in providing end of life care as not all end of life needs are medical in nature. However, end of life

care does not feature strongly in social care policy (e.g. Social Care Policy and DH, 2010), though end of life patients are expected to benefit from the integration of health and social care (Alltimes et al, 2012).

Palliative and end of life care has also been signalled out as separate in the health and care sector with the introduction of EPaCCS which highlights the need for up to date patient information for those near the end of their lives, but not for other groups of patients in a different phase of life. As of the end of 2013, all providers who use EPaCCS must conform to certain standards (NEoLCP, 2012) and while there is an expectation that all patient care records will become electronic for easy sharing (DH, 2013; Field, 2012), the same standardisation demand has not been mandated for all patients records. This suggests there is a high priority for information about those who are in their final year of life which is likely due to their high level of need and service use compared to other groups (Georghiou et al, 2012). However, ensuring that professionals modify their working practice to include the use of EPaCCS could introduce problems in the workforce especially as end of life patients can be difficult to define because of the unpredictability of disease progression (Gott et al, 2012).

Whether end of life care is the remit of health, social care or both also raises questions as to leadership in the care of people at the end of life. People with life-limiting illness have contact with numerous care providers, with most accessing hospital care and only about a quarter using social care services (Georghiou et al, 2012). In the UK, hospices (often with both inpatient and community outreach services) and hospital palliative care units are key providers of specialist palliative care to patients who are known to be in the last year of life. Not all end of life patients require specialist palliative care and many will receive end of life care through their primary care provider. Additionally, family members provide much of the informal care support for patients who remain at home. Family members are often labelled as ‘carers’ by care providers and this label might also help them to access social care support through carer entitlements (HM Government, 2012). Such a complex and variable landscape of formal and informal care raises questions about who leads the direction of care at the end of life which is often a difficult and vulnerable period for patients and their families.

1.3 “The Project”: an example of implementing end of life policy through a programme

The National End of Life Care Programme encouraged the development of regional programmes to meet the aims of the End of Life Care Strategy. One of these regional programmes forms the case for this thesis and will be described here. The Project is described here in detail in order to

address one of the key deficits in palliative care research which is the lack of published detail of interventions which prevents comparisons and transferability of practices (Higginson and Gysels, 2004). To preserve the anonymity of those involved, all names, locations and proprietary software systems involved have been anonymised and the project will simply be referred to as 'the Project'. The Project covered a region with a population of 630,000 and is characterised by average and high deprivation indices in coastal, urban and rural areas in England (Research & Intelligence, 2011). Approximately 1% (6,300) of the population dies each year with roughly 75% being predictable due to long-term and chronic illness (Blackmore et al, 2011). The Project was led by the Hospice which is a group of three voluntary sector facilities each operating an inpatient unit, day service, community nursing team, and hospice at home service all of which are supported by the multidisciplinary hospice team. Referrals to the Hospice are primarily older (median age 76 years) and with a cancer diagnosis (85%). The Hospice receives an average of 1600 referrals a year which means it provides care for approximately 25% of deaths within the area. The Hospice is a key provider for specialist palliative care within the area, but is not an NHS organisation. NHS providers in the area include one Hospital Trust with three acute treatment hospitals, a Community Health Trust which during the Project merged with another trust to cover a wider geographic area, and a Mental Health Trust. The area is also served by approximately 88 GP practices, social care services, and a variety of voluntary sector organisations such as Samaritans, Marie Curie Cancer Care and Admiral Nurses.

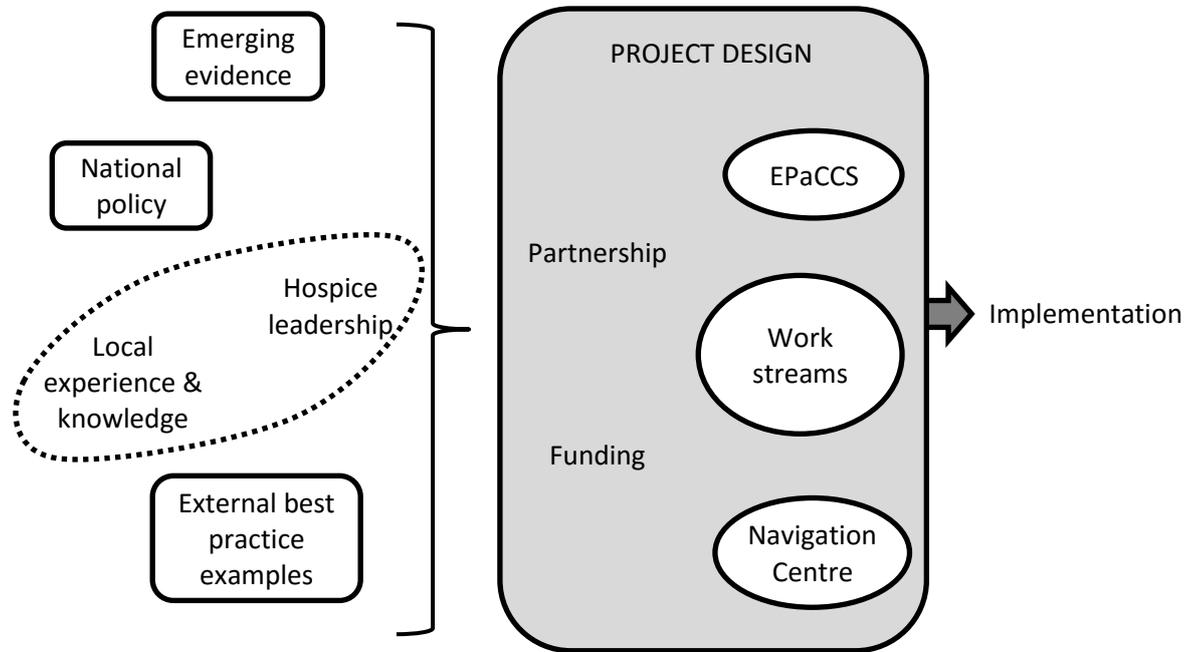
In 2011, the Hospice initiated a project to improve the end of life experience of patients, reduce inpatient admissions to hospital for dying patients and reduce service duplication, all of which would broadly meet the aims of the End of Life Care Strategy and was largely aimed at supporting more patients to die at home which is the choice of most people when given an option (Gomes et al, 2012). Indeed, implementing the End of Life Care Strategy was the primary driver for this project with funding allocated for that specific purpose. There may have been other policy drivers, such as the NICE Quality Standard for End of Life Care (2011), which were influential in the background such as in selecting quality metrics, but the emphasis among the Project documents and stakeholders was on delivering the End of Life Care Strategy. Under the Project, all end of life patients in the region would be targeted and not just those referred to the Hospice. It was proposed that such aims would be achieved through increased coordination and integration among services and therefore partners from across the region in NHS and voluntary health and social care organisations including providers and commissioners were approached to form a partnership to deliver the Project.

The Project involved a two year programme of work from March 2012 to March 2014 and fits the Medical Research Council's definition of a complex intervention (Craig et al, 2008) as it was composed of various interacting components targeted at a diverse population including both professionals and service users. The Project encompassed three main strands of work ongoing simultaneously. One strand in the Project was to select and implement an EPaCCS (as per best practice stated within national policy) in partner organisations to improve information sharing. The EPaCCS formed the core of the Project as it was the primary vehicle for regional system integration. Second, a Navigation Centre was established to direct patients and their family carers over the telephone to the most appropriate care provider for their needs or provide advice drawing on the information held in the EPaCCS. The challenging medical, social and emotional problems that often confront end of life patients can be difficult to navigate through usual services so it was believed that a more bespoke service understanding of these needs would result in better outcomes for patients. The Navigation Centre also took calls from health and social care professionals to provide palliative care advice to those caring for end of life patients and operated as a hub for transferring information. The third aspect of the Project was a number of work streams which would aim to identify and tackle some of the well-known problems within the region in order to coordinate care, such as problems with access to medicines in the community, and would also complete tasks to support the implementation process, such as facilitating communication and getting patient feedback. All of these tasks would be completed using a partnership approach as espoused in health policy (DH, 2010) and all partners would help manage the Project. The Project proposed that partner organisations adopt and implement the innovations developed and refined during the project. Access into these organisations was via a nominated stakeholder(s) who acted as gatekeeper to their respective organisation. The style of working in the Project was indicative of a shift in the NHS from new public management towards lateral and process-based forms of organising (McNulty and Ferlie, 2004).

Though the Project reflected national policy, it was an example of 'community' or regional level change rather than 'system' level change (Tabak et al, 2012). The Project was also based on multiple sources of evidence relying primarily on professional and organisational experiential knowledge, but also drawing inspiration from policy imperatives and scientifically derived evidence. This reflects a broad understanding of experience and by triangulating different sources of knowledge should lead to patient-centred care (Rycroft-Malone et al, 2004). The Project was more closely related to policy or managerial driven implementation for quality improvement rather than implementation of evidence-based practice (Nilsen et al, 2013) because the design of the Project stemmed more from tacit knowledge rather than research of

what is most effective. Figure 1.1 shows a visual depiction of the development of the Project and its relation to policy, evidence and implementation.

Figure 1.1 Illustration of Project development and design leading to implementation



1.4 Chapter summaries and structure

This thesis is presented in seven chapters. This introductory chapter has offered a brief summation of the national policy context which was a key driver for initiating the Project and which is essential background information for judging the transferability of the study's findings (Guba and Lincoln, 1989). The next two chapters review the literature on implementation. Identifying implementation literature is challenging because as a concept it is not well demarcated within the wider literature on putting innovations into practice (Greenhalgh et al, 2004b). Therefore the review of the empirical and theoretical literature was primarily guided by pragmatism in seeking out what was perceived to be relevant at the outset for understanding the implementation of the case under study. Chapter two presents a literature review of the empirical evidence on palliative care programme implementation and health services innovations. It begins with defining what is meant by implementation and explores the themes that emerge in the implementation process. Chapter three looks at the broader picture of

implementation in health services and theoretical positions on implementation in order to build a conceptual framework for the study.

Chapters four, five and six form the empirical study. Chapter four presents the study design which follows a pragmatic approach to research drawing on primarily qualitative methods. Chapter five is the first of two data chapters and describes the implementation process, strategies used for implementation and what shape the process took. This sets up the second data chapter (six) which looks more closely at what influenced the process and what implementation outcomes were achieved. The final chapter discusses this study's findings in relation to the empirical and theoretical literature reviewed, the study's contribution to knowledge, strengths and limitations, and presents an agenda for future research.

2 Literature review of palliative care programme and innovation implementation

Introduction

This chapter presents a review of the empirical literature on palliative care programme implementation and health services innovations related to the Project. The aim of the review is to begin to build a picture of the implementation process within the context of palliative care and consider appropriate methods for studying the process. It will start by defining what is meant by implementation and what the characteristics of palliative care are that might distinguish the implementation of palliative services from other types of health services implementation. It will then consider what the key empirical findings are regarding the characteristics of the process of palliative care programme implementation; this will also include discussion of the evidence base for the innovations proposed in the Project. Finally, the barriers and facilitators to palliative care programme implementation will be summarised. This chapter will also consider the conceptual and methodological strengths and weaknesses of the literature.

2.1 Definitions and background

This first section presents definitions and background information on key concepts which will contextualize and provide boundaries for the literature review.

2.1.1 Defining implementation

This section sets out a definition for implementation, including *what* is implemented and *who* is involved in implementation. Implementation has been variously defined, often times vaguely, in the literature. Rogers (2003) defines implementation as occurring “when an individual (or other decision-making unit) puts an innovation to use” (pp. 179). Implementation has also been succinctly summarised as “the act of carrying an intention into effect” (Peters et al, 2013, pp. 1), the study of change (Jenkins, 1978), and “efforts to mainstream an innovation” (Greenhalgh et al, 2004a, pp. 582). Implementation has been used to describe both the *process* of enacting a programme or innovation from idea to reality (Ripley and Franklin, 1982) as well as how something looks in practice (King et al, 1987). In the organisational literature, implementation is often referred to as planned change (Seo et al, 2004). A more specific definition of implementation for health care proposes that implementation involves the use of strategies for the purposes of enacting evidence into practice (Proctor et al, 2009). While this definition provides us with clear process information (i.e. using strategies), a definition from Linton (2002)

indicates a time frame for this process: “all activities that occur between making an adoption commitment and the time that an innovation either becomes part of the organisational routine, ceases to be new, or is abandoned” (pp. 66). This definition does not differentiate between planned activities and adaptive activities that may occur in response to unplanned events, but rather assumes that all activities whether planned or reactive are part of implementation. It also implies the decision to adopt an innovation is separate to the process of adoption which is part of becoming implemented (Denis et al, 2002). As process is the subject of interest here, the definition used in this thesis is that **implementation is a targeted use of planned strategies and adaptive activities to change and routinise new practices**. Thus implementation is differentiated from dissemination (targeted, active distribution of information) and diffusion (passive spread of innovations). Implementation is a process, not an event (Fixsen et al, 2005); it is not the adoption decision, but rather the adoption process (Scheirer, 1987).

While defining implementation it is also important to define what *it* is that is implemented. Policies, products, practices and processes can all be implemented (Peters et al, 2013; Scheirer, 1983). In health services, programmes are quite often the result of combining all four together, be they behavioural, material, technological or ideological and are often referred to as interventions (Peters et al, 2013). If implementation is located between an adoption decision and routinisation as suggested by Linton (2002), then this implies that the programme has some degree of newness or innovation; that it offers some different way of working which must be incorporated into routine working practice. However, May (2009) argues that implementation need not be about innovation, but can rather be about keeping existing practices in place. This perhaps reflects King and colleagues (1987) definition of implementation in which it is simply about how something appears in operation, what a programme looks like on the ground regardless of whether it is new or not. In applying Linton’s definition of implementation which gives consideration to time, this view is rejected as the period of implementation ceases when the programme is no longer new. But newness is subjective, and what is new to one person may be standard practice to another (Van de Ven and Rogers, 1988). Therefore the ‘things’ that are implemented here refer to programmes, products, practices or processes that are new or innovative (i.e. innovations) to the organisation, rather than the individual. Increasingly though, the study of implementation has been focussed on interventions which are ‘evidence-based’; that is to say their efficacy has been established (Proctor et al, 2009). However, this would preclude quality improvement initiatives which tend to develop at the local or organisational level. Such initiatives are not excluded here because both evidence-based interventions and quality improvement initiatives involve a change in working practices which require a shift in

cognitive and behavioural processes. Additionally, there is a distinction between ‘practices’ and ‘programmes’ (which are a collection of practices), however the literature indicates that there are commonalities in implementation for each and that they may be “two sides of the same coin” (Fixsen et al, 2005, pp. 27).

It is also necessary to consider *who* is involved in complex programme implementation. A general trend in health and public service delivery is for programmes to be delivered through multiple organisations, networks, and partnerships (Linton, 2002; McNulty and Ferlie, 2004). While one organisation might retain overall responsibility for a programme, it is not often able to implement the entirety of a programme itself. Implementation is therefore carried out by multiple professionals (actors) working from different organisations (Cline, 2000). This is particularly relevant in palliative care given that it is an interdisciplinary approach to care (van Staa et al, 2000) which often involves not just specialists, but primary care generalists, secondary care, and social care representing numerous organisations. One of the ways in which professionals from different organisations might work together is through the formation of a partnership or project group, as in the case of the Project. Project groups have similarities with networks and are formed of teams from different organisations who are brought together for specific short term projects or tasks (Morgan, G 1997) and may be particularly useful for integrating or coordinating care.

Thus combining the above definitions within a health service context, implementation research is concerned with the change process of how new practices or innovations come to be used in daily practice. The study of implementation fits within the wider context of social research as it is people who implement new practices and use innovations and it is their collective behaviour which leads to the success or failure of the process. The process itself has been characterised differentially; as either proceeding in stages following a rational approach of adoption decision making to use, or as an organic process with elements of trial and error more common to larger scale projects (Greenhalgh et al, 2004b). What determines the shape of this process will be further examined in chapter three, but the following sections will begin to consider characteristics of the process and what influences it, which is the primary focus of this thesis.

2.1.2 Key characteristics of the Project to guide the literature review: palliative care and collaborative approaches to service delivery

Having defined what is meant by implementation, this next section considers the characteristics of palliative care and collaborative approaches to service delivery which makes the implementation of such services distinct from other types of health services delivery. The Project

represents a complex intervention in that it has several interacting components and various degrees of complexity requiring different changes in behaviour by different groups of people (Craig et al, 2008). It might share common features with the implementation of other complex interventions in health care, but it is hypothesized that two distinct features of the Project may have particular influence on the implementation process. The first is the focus on palliative care, the second is the partnership structure.

Characteristics of palliative and end of life care service provision

Dame Cicely Saunders is often credited as the founder of the hospice and palliative care movement which took off in the latter half of the twentieth century. In the 1950s, the advancement of new drugs and understanding of pain in cancer care opened the door to better pain and symptom management – what has come to be known as palliative care (Council of Europe, 2003). Saunders, trained as a nurse, social worker and physician, understood pain to be beyond simply the physical manifestation, but also included mental, social and emotional distress to create ‘total pain’ (Clark, 1999). Therefore, she argued, the care of terminally ill patients must include physical, social, psychological, and spiritual care (Saunders, 2006). *Palliative care* aims to improve the quality of life of patients with life-limiting conditions and their families by providing relief from pain and symptoms, and through psychosocial and spiritual support from diagnosis through to bereavement (WHO, 2012). This holistic approach and acceptance of death as a natural part of life makes it distinct from other types of health care which are focused on the preservation of life. *End of life care* is often used synonymously with palliative care, though palliative care is generally associated with cancer whereas end of life care would be appropriate for anyone known to be dying, though they may not require palliative care (Radbruch et al, 2009). There are numerous other nuanced terms, such as hospice care, terminal care, and supportive care (see Radbruch et al, 2009 for a discussion), which have similar overlapping characteristics. Ultimately these services culminate in death and therefore they are often tasked with facilitating a ‘good death’. There is extensive literature examining the various factors that contribute to a good death (Granda-Cameron and Houldin, 2012; Miyashita et al, 2008), but in its most simplistic definition it is a death free from pain, surrounded by loved ones.

Palliative care in the United Kingdom, and increasingly in the United States, is often provided alongside other life enhancing or life prolonging treatment. This means it is usually coordinated with other health services and care disciplines. Palliative care can be coordinated by both generalists and specialists. Specialists in the UK are organised as part of hospital units or voluntary organisations, such as Marie Curie or local hospices. Specialist centres, in particular hospices, are usually umbrellas for a range of professions including: medical, nursing, spiritual,

psychological, social services, and allied health professions. They also provide advisory and outreach services and engage with other care providers in hospitals and the community. Though hospices are essentially self-contained examples of multidisciplinary, integrated care, they also coordinate with external services to fill gaps in patient care, such as advice for pain relief and day care service provision. As implied in the definition of palliative care, patients with complex needs at the end of life often require a multidisciplinary approach to care. Palliative care has clear parallels to other types of care, such as integrated care, long-term care, and shared care models which are utilized more commonly in the management of mental health and chronic diseases but are also found within palliative care (Marshall et al, 2008; Howell et al, 2011b). However, a unique aspect of palliative care is its finality; few second chances are afforded to professionals working with patients who are life-limited and often care packages must be organised quickly as patient deterioration can be sudden. Additionally, there is great emphasis on providing end of life care at home (Higginson et al, 2013), which presents operational challenges for providing equipment and strong opioid analgesics in an uncontrolled home environment. These issues are specific to palliative and end of life care, and may play an important role in implementation.

This discussion suggests that the implementation of palliative care services may be challenged by two issues. Firstly, the field of palliative care is a relatively young and niche area of care with an equally short research history, challenged by ethical concerns in carrying out research on the dying (Kaasa et al, 2006). While acceptance of evidence-based practice is increasing in palliative care, the translation of research evidence into practice is still in its infancy as is the corresponding implementation research. This means there is little information regarding what influences the implementation process in a palliative care setting. Secondly, while palliative care relies on a multidisciplinary approach, evidence suggests that health professionals outside of the palliative care speciality along with patients and families struggle to deal with the topic of death (Goepf et al, 2008). Death as a taboo subject imposes cultural challenges to professionals implementing palliative care services.

Collaborative care through partnership: integration, coordination, linkage

In addition to the focus on end of life care, the Project also represents an example of coordinated care, therefore it is worth defining what is meant by coordination and consider how it may impact on implementation. Lillrank (2012) makes a concise distinction between *integration* and *coordination*:

“integration is the combining of several specialized and differentiated resources and contributions to create an output that is a system consisting of several parts. The

essential difference between integration and coordination is that integration implies a fusion of components into something new, while coordination is the arrangement of roles and tasks into an organised whole” (pp. 8).

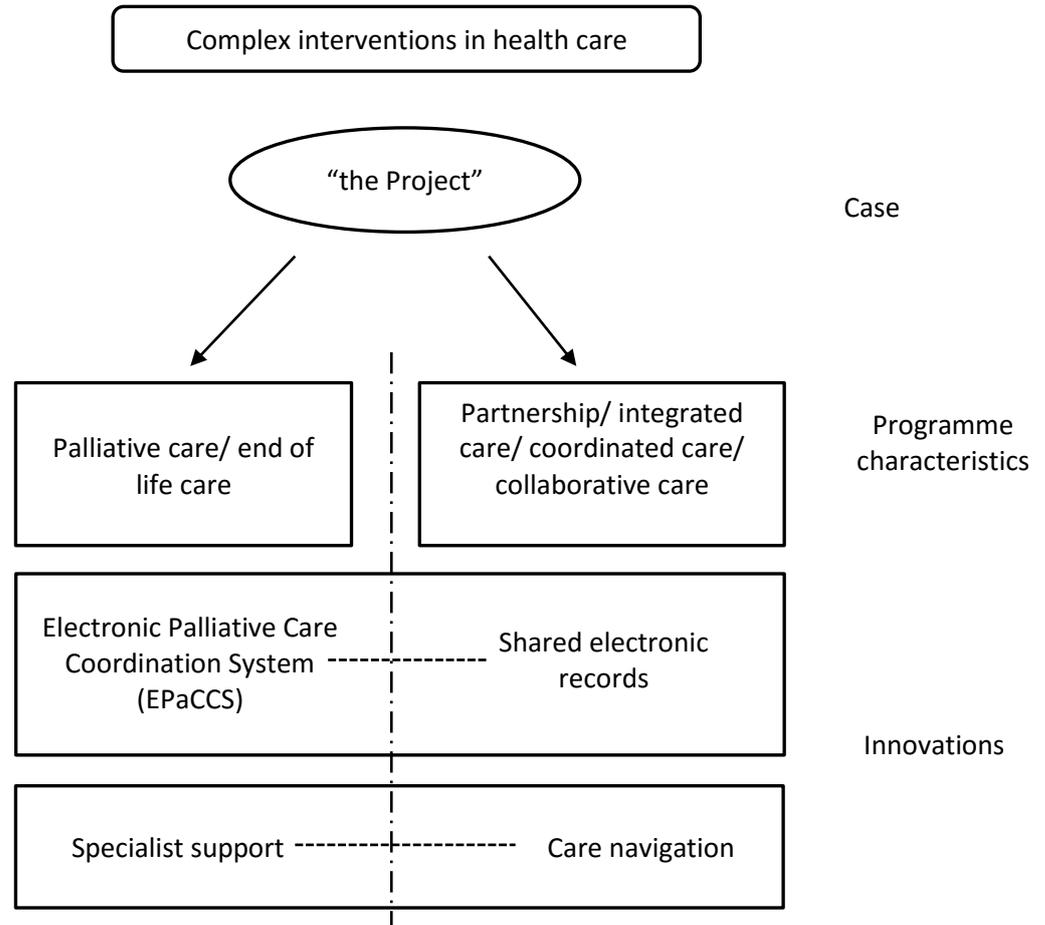
Thus in integration specialized roles are lost in the system, whereas they are maintained in coordination. Leutz (1999) makes a third distinction in describing service organisation with the term *linkage*, in which services maintain responsibility for a particular aspect of patient care, but on occasion link with other services as needed. A linked system likely characterises the relationship between most palliative care and generalist services with few working in a coordinated system, and even less integrated. The Project most closely resembles a coordinated system. A review of rural palliative care services found that the main avenue for integration of services was through establishing common clinical information systems (Masso and Owen, 2009). However, patients with palliative care needs represent a small number within the population and the authors found that there was limited success in achieving integration because it was difficult to integrate a system for one group of people within existing systems. One of the main challenges in the integration of services is that it often results in fragmentation for those working for the services as they try to expand their knowledge of the services with which they are integrating (Leutz, 1999). The various terms discussed here differentiate the way that health services work together, but irrespective of how the system is organised, care should still be experienced as ‘integrated’ by the patient as the “final integration takes place in the patient’s life-world” (Lillrank, 2012, pp. 9). Regardless of type of organisational working, success is defined at the micro-level; that is how the patient experiences his or her care.

2.2 A literature review of the implementation process in palliative care services

The previous sections have provided a definition of implementation and explored some of the specific characteristics of palliative care and coordinated care which may influence how such programmes are implemented. This next section discusses key empirical findings on programme and innovation implementation in palliative care services, and the specific innovations proposed in the Project described in the previous chapter. What is meant by *programme* in this case is a project of work which includes multiple innovative changes which are coordinated for a common purpose. The literature review is structured as a narrative review as its aim is to present an overview of relevant research in order to start developing a conceptual framework for the study rather than answer a specific question as would be the focus of a systematic review (Green et al, 2006; Harden, 2010). Figure 2.1 presents a thematic map for focussing the literature selection.

The Project is the selected case under the umbrella of complex health services interventions with the defining characteristics of palliative and coordinated care. Within those two streams of care typology (vertical columns) are the specific innovations of Electronic Palliative Care Coordination Systems and care navigation, though each has linkages to related concepts in the other typology as indicated by the dashed horizontal lines. The boxes below the arrows represent how concepts were grouped to create four search term topic areas.

Figure 2.1 Thematic map of literature search based on key features of the Project



The thematic map was used to produce the search strategy which is described in full in Appendix 1. Table 2.1 shows the search terms used in the Pubmed search as grouped by their thematic term and the number of papers returned using the search builder. The Pubmed search returned 210 papers and additional articles were identified through reference lists, suggested reading prompts from online databases, recommendations from colleagues, and serendipitous finds from web-browsing. Pubmed was selected as the database for searching because Medline is its primary component (USNLM, 2015) which holds the highest proportion of relevant papers (Tieman et al, 2009) and is free to access. The search builder included any of the terms from the implementation group and any of the terms from one of the other thematic groups. This resulted in four separate search groups: palliative care, shared electronic records, care navigation, and partnership. Papers were included if the authors analysed or described the implementation process or have provided a description of programme implementation from which lessons regarding the process can be extracted.

Table 2.1 Search terms used and search builder for Pubmed

Implementation group		Thematic group term	Search terms	Papers found
Search terms: “implementation process” “implementation research” Health plan implementation [MeSH]	+	Palliative care	End of life care	173
			Palliative care	
			Hospice and palliative care nursing [MeSH]	
	+	Care navigation	Patient navigators	15
		+	Shared electronic records	Electronic palliative care coordination system
	Electronic health records [MeSH]			
	+	Partnership	Partnership	7 ^b
			Coordinated care	
			Co-ordinated care	

^a Search returned 340 papers; implementation group limited to title/abstract to reduce return.

^b Search returned 382 papers; implementation group limited to title/abstract to reduce return.

The literature review is structured around these four themes: programme and complex intervention implementation in palliative care, implementation of the two innovations of shared electronic records and care navigation, and the partnership approach to service delivery. With respect to each term, the review will consider the experience of implementation and the characteristics of the process. While this chapter focuses specifically on the literature related to the case being studied, the next chapter will consider health service implementation research and implementation theory more widely.

2.2.1 Programme or innovation implementation in palliative care

The following section presents an overview of the key empirical findings from studies which have presented information regarding the implementation process of a programme or innovation in palliative care. The findings from the studies have been synthesized thematically to build a picture of the key influences and characteristics of the implementation process. Firstly though, the methodologies used in the studies will be briefly considered as this relates to the synthesis; a more considered review of methods will be given in section 2.4 in assessing the literature.

Methodological considerations

The majority of the studies that have examined the implementation process have used qualitative approaches either exclusively or to supplement audits and evaluations of the programme against service delivery aims. This seems appropriate given that implementation is a complex process which is more easily described with words than numbers. While some authors have explicitly aimed to examine the implementation process (Della Penna et al, 2009; Vahedi Nikbakht-Van de Sande et al, 2014; Davis et al, 2006; Tolson et al, 2007; Dudgeon et al, 2009),

others have only included a description of the implementation process as anecdote whilst describing programme outcomes (Santa-Emma et al, 2002; Fainsinger et al, 2007; Howell, et al 2011b). More emphasis is given in this review to studies of the former.

Studies appear to lack two criteria which confounds their contribution to understanding the implementation process. Firstly, most studies have not been explicit about what they mean by implementation. Some mean the process of enacting a new programme in the sense of the definition used in this thesis, whereas others are concerned with describing how a service or innovation looks in practice and what outcomes it achieved. This leads to the second deficit in the literature which was highlighted by McConnell et al (2013) in that much of the literature is focused on “reporting outcomes rather than the factors leading to those outcomes” (pp. 219). The literature seems to be dominated by the reporting of outcomes of interventions and retrospectively considering the process that led to the outcomes; there is less research explaining the mechanisms of the implementation process.

Introducing palliative care in non-palliative care environments

Most of the studies have looked at the implementation of palliative care programmes or innovations into non-palliative care settings. This includes introducing a new palliative care pathway or unit in a hospital or clinic (Della Penna et al, 2009; Mirando et al, 2005; Santa-Emma et al, 2002; Vahedi Nikbakht-Van de Sande et al, 2014), or new home-based programme to deliver palliative care with community primary care services (Davis et al, 2006). The introduction of a palliative care approach within a generalist or acute environment appears to be limited or enhanced by the ‘push/pull’ fit of the new service to the environment (Della Penna et al, 2009). For example, an environment which embraced the palliative care approach was described by Della Penna et al (2009) in which an initiative to establish an inpatient palliative care model took place at the same time that other quality improvement activities in palliative care were taking place. Thus health professionals seemed primed to accept and adapt to the new model. Likewise, Davis et al (2006) describes an attempt to replicate an in-home palliative care programme in two medical centres representing a top-down push. Early-adopting physicians were those who had already made attempts to adopt a palliative care approach and were therefore ready to ‘pull’ the programme in, whereas laggard physicians were those who wanted to keep control over patient care rather than utilise the programme.

Introducing a new approach to care requires health professionals to make changes to their working practices. If health professionals feel the need to change, as represented by a ‘pull’, then these changes may be easier to make. However, if the need for such changes is not perceived,

then the introduction of a new practice can lead health professionals to perceive that their work is being fragmented and potentially lead to a slower rate of adoption (Leutz, 1999). For example, Mirando et al (2005) observed that some hospital staff needed to be continually reminded to use an integrated care pathway. This is likely because the introduction of the pathway was not easily integrated into daily working practice.

Stimulus for change

The stimulus for implementing a palliative care approach appears to be driven by either the existence of an innovation which has evidence of effectiveness or is based on best practice (Della Penna et al, 2009; Di Leo et al, 2014; Mirando et al, 2005; Davis et al, 2006; Tolson et al, 2007), or there is an identified need and subsequently a change in practice is proposed (Santa Emma et al, 2002; Vahedi Nikbakht-Van de Sande et al, 2014). In the former case, implementation appears to be highly planned and structured with particular strategies for introducing and sustaining the new practice. A study reporting the implementation of the Liverpool Care Pathway into Italian inpatient hospices presents a 10-step planned process for implementation (Di Leo et al, 2014). The Liverpool Care Pathway was based on the hospice model of care and has been used in the UK since the late 1990s (Broadbent, 2013). This is not to say that innovations with careful planning have all been successful, as in this case three of the seven hospices decided to discontinue use of the Liverpool Care Pathway at the end of the study because they perceived a lack of benefit. These studies have generally reported moderate implementation success with a number of barriers and facilitators identified as part of the process. Most of the studies which aimed to explicitly investigate the implementation process, as opposed to outcomes, have focused on the application of innovations with established efficacy into new settings. This perhaps reflects the planned approach with professionals who plan implementation being more likely to prospectively consider the need for evaluation of the process.

At the other end, palliative care programmes have also been developed from a bottom-up approach with the identification of a problem at the practice level and then a change in practice proposed to address the problem. In this case, the innovation proposed has been something developed within the organisation (Santa-Emma et al, 2002; Vahedi Nikbakht-Van de Sande et al, 2014), or existing services have been expanded or optimised (Dudgeon et al, 2009; Fainsinger et al, 2007). This is a more grass-roots approach to creating change and while strategies for implementation are identified in these studies, they are not necessarily more successful at sustaining change. Vahedi Nikbakht-Van de Sande et al (2014) report a failed attempt to implement a palliative radiotherapy programme for outpatients. Despite the involvement of frontline radiographers, radiologists and nurses in identifying the problem and developing the

programme, a lack of ownership in the programme at an organisational level contributed to its failure to take root. The programme relied heavily on one nurse practitioner to disseminate and implement the programme, potentially indicating that the programme relied mainly on frontline desire to change without considering the rest of the organisational environment, such as policies or workforce, to sustain changes.

Each of the studies describe some purpose driving change, which broadly fall into two camps: changes in funding or governance arrangements which *force* service change, or a desire to *improve* patient care as the stimulus for change. These might be conceptualised as either *external* or *internal* drivers of change. The Edmonton Regional Care Programme described by Fainsinger et al (2007) is an example where governmental changes in healthcare funding created an environment to force change, and it may be because there was a lack of alternative options that the programme was successful. A parallel example in England might be the *End of Life Care Strategy* (DH, 2008). On the other hand there are interventions which are driven by the desire to improve patient care at the end of life. The implementation of these interventions is more mixed, perhaps reflecting that these interventions must rely more on professional motivation rather than some external force.

Strategies to create change

Each of the studies described one or more strategies to implement the programmes or innovations. Key strategies used for creating change have focused on raising awareness through communication and marketing activities, and persuading health professionals to change practice through education and training packages (Davis et al, 2006; Della Penna et al, 2009; Di Leo et al, 2014; Dudgeon et al, 2009; Tolson et al, 2007). These strategies largely address cognitive and behavioural components of change (Grol, 1997). The process described by Della Penna et al (2009) had particular success which they attribute to the strategies creating “something akin to a social movement” (pp. 8). The programme and strategies seemed to target the emotions and mind-set of health professionals to drive change. This is in contrast to educational and training approaches which focus more on functional, behavioural tasks. Palliative care’s relative obscurity in the health profession means many programmes must include an educational component for professionals who may see few dying patients a year. These educational components seemed to rely on participants agreeing with the programmes’ content (i.e. that it is a good thing to do) and then do it. In the study described by Di Leo et al (2014) on implementing the Liverpool Care Pathway, health professionals were left to self-educate themselves on the programme and therefore any changes in cognitive approaches to work would have to come from within each individual rather than through a collective movement as described by Della Penna et al (2009).

The ‘facilitator’ role – someone whose primary focus is on ensuring programme implementation – is a key strategy for overseeing the implementation process as part of formalized project management. (McConnell et al, 2013; Mirando et al, 2005; Vahedi Nikbakht-Van de Sande et al, 2014). A systematic review of the implementation of the Liverpool Care Pathway (LCP) found that a dedicated facilitator role was essential in explaining the success or failure of implementation. They stated that:

“facilitation appears to work by making staff aware of the goals of the LCP, providing reassurance in terms of their skills and decision-making in early implementation, and demonstrating the benefits of using the LCP. This leads to increased motivation to use the LCP and a self-perception of competency and capacity” (McConnell et al, 2013, pp. 230).

Essentially facilitation appears to tap into the cognitive processing that is essential for the internalisation of work, likened to the sense-making and relationship activities in normalisation process theory (Gallacher et al, 2011). It seems clear from the literature that implementation of complex programmes requires full time facilitation.

Strategies also include capitalising on the influence of key people, who are usually physicians (Davis et al, 2006; Della Penna et al, 2009; Dudgeon et al, 2009; Mirando et al 2005).

Professionals with a positive attitude towards the project or who are opinion leaders are often targeted to be champions for the project in an attempt to influence others. However, regardless of whether a project has a champion, physicians appear to hold a greater sway in enacting or preventing change. In the study by Davis et al (2006), sites which had leadership from physicians who were well-established and respected by their peers had more success in implementing the in-home palliative care programme.

Characterizing success

Whether the implementation process had been determined successful largely depended on whether the service achieved its stated aims and if it continued to be sustained at the end of the study or project period (Dudgeon et al, 2009; Marshall et al, 2008; Mirando et al, 2005; Vahedi Nikbakht-Van de Sande et al, 2014). This means that the programmes have to be both effective in producing patient and service outcomes, and routinizing working practices which achieved those improvements. Thus, Vahedi Nikbakht-Van de Sande et al (2014) concluded that whilst professionals and patients were positive about the programmes effects, the fact that it was not sustained over time led the authors to conclude that implementation failed. It is not always clearly reported whether implementation has been successful or not as barriers to

implementation are commonly identified and not all programmes achieve all of their goals (Davis et al, 2006; Di Leo et al, 2014). There is no clear criteria for determining whether the implementation process in these cases has been successful or not, particularly where the innovation has been developed to meet a particular need rather than taken 'off the shelf' and applied in a new setting.

2.2.2 Innovations in the Project: Electronic health records and care navigation

The previous sections considered the implementation of palliative care programmes as complex interventions in order to start identifying barriers and facilitators to implementation. This section considers the individual innovations proposed in the Project to determine whether they have particular characteristics which are relevant for understanding strategies for implementation and what evidence there is to support their use, as this is related to the stimulus for change. This section discusses the two material innovations proposed in the Project: the Electronic Palliative Care Coordination System (EPaCCS) which has similarities to the more ubiquitous shared electronic health record, and the Navigation Centre.

Shared electronic records

Electronic Palliative Care Coordination Systems (EPaCCS) are a relatively new concept within health care and there is little research regarding their use. However, it is closely related to electronic health records which hold a patient's health and care history and are accessible electronically to facilitate sharing of data across the care continuum (McGinn et al, 2011). They also share similarities with patient summary care records used routinely in the NHS, but which contain a minimum amount of clinical information used primarily to treat patients in emergencies or out-of-hours (HSCIC, 2014). Like the summary care record, EPaCCS contain essential patient information for use in emergencies and not the entirety of the patient's clinical history, but like electronic patient records, it is available to the wider care community with the primary purpose of providing continuity of care.

The most similar configuration to that in the Project is the Coordinate My Care (CMC) service recently developed in London, which is an example of an EPaCCS. Coordinate My Care is a web-based care record accessible to the whole health and social care economy and contains information regarding patients at the end of life. A paper by Smith et al (2012) describes the rationale for the service, how it was implemented and reports on how it has been used by reviewing patient records added to the system. One of the key issues that this paper highlights is a lower than expected usage of the EPaCCS, even though the system includes the Scottish Supportive and Palliative Care Indicator Tool (SPICT) which aids the identification of patients

suitable for palliative care. Roughly 1% of the population dies each year, of which approximately 25% of deaths could be considered unexpected meaning that 75% or (0.75% of the population) could be predicted due to the impact of long-term and chronic illnesses (Blackmore et al, 2011). Thus, 0.75% of a GPs caseload could be expected to have a Coordinate My Care record, but the study shows that Coordinate My Care only held records for 0.15% of the Primary Care Trust's population. There is clearly a gap between expectations and practice. The authors surmise that more education and training is required for professionals so that more patients can be identified and professionals feel comfortable having difficult end of life discussions with their patients. The authors recognise that the Coordinate My Care system is disruptive to normal working practices and that integrating it into routine practice requires a culture shift. This conclusion mirrors that of the review by Masso and Owen (2009) which concluded that there is "difficulty in integrating an information system for one group of people (i.e. those requiring palliative care) within existing primary care information systems" (pp. 265). EPaCCS are no different to other electronic health record implementations in that they are all 'disruptive technologies' and such workflow disruption can be barrier to implementation (Nguyen et al, 2014), but there is the added complexity that the EPaCCS is targeted at a much smaller proportion (0.75%) of the total patient population.

A second study looking at an electronic palliative care summary system in Scotland focused on the experiences of those implementing the system to identify barriers and facilitators to its use (Hall et al, 2012). Whereas Coordinate My Care is a web-based tool used separately to existing patient record systems in primary care, the Scottish system used an "electronic template embedded within existing primary care electronic patient record systems" (Hall et al, 2012, pp. 577). The information in the template is then automatically updated in a central computerized store for access by out-of-hours, acute and emergency services. Despite the fact that the system was designed to work with the existing record system, health professionals felt that not enough patients had a record, as was also found with Coordinate My Care. The authors suggested that underutilization was perhaps linked to a lack of widespread buy-in among GP practice staff. Despite this, professionals perceived there to be an improvement to out-of-hours care and out-of-hours staff were highly supportive of the system because they had more information at their disposal and could be more confident in the care given; essentially they found the greatest benefit to their work. Like Coordinate My Care, the GPs in the Scottish study also found it difficult to know when to approach patients about end of life issues and when to create a record for them on the system. Both of these studies seem to demonstrate that while such shared electronic records fill a need for information among secondary and emergency care providers (out-of-hours,

acute, ambulance etc), the needs of primary care providers are possibly not being addressed even though primary care is the origin for these records. Neither study has demonstrated conclusively that electronic palliative care records are effective in improving patient outcomes across the targeted patient population because both have faced issues in implementation at the professional user level.

While these two studies on electronic records demonstrate the difficulty of mainstreaming palliative care within the wider health care economy and specifically highlight issues pertaining to implementation in primary care, a number of systematic reviews have considered the implementation of the more general concept of electronic health records (McGinn et al, 2011, Nguyen et al, 2014, Mair et al, 2012). A review by McGinn et al (2011) identified ten implementation factors affecting use: design or technical concerns, perceived ease of use, interoperability, privacy and security concerns, costs, productivity, familiarity and ability, motivation, patient and health professional interaction, and lack of time and workload. Interestingly, these factors could be either barriers or facilitators to implementation, though some appeared more often as a barrier, such as costs, interoperability and design issues. The two chief facilitators were perceived usefulness and motivation to use which suggests that successful implementation seems to be grounded at the individual level rather than the organisation or system level. Indeed McGinn et al (2011) found that top-down managerial approaches to implementation were less effective than bottom-up approaches which created enthusiasm and commitment. This is not to say that top-down strategies like education are not beneficial in generating the desire to change, but simply that the required culture shift that is needed for implementation (Nguyen et al, 2014) must come from the frontline. Electronic health records are often seen as a way to automate work, but Nguyen et al (2014) argues that they require a change in the way work is done, which is perhaps why they are seen as a barrier to workflow when professionals try to continue their existing work practices.

Care navigation via telephone

'Care navigation' in the Project refers to a 24 hour telephone advisory service which directs callers to the appropriate service to meet their needs. Users of the service include patients, family carers and health and social care professionals. Callers might be given advice by the care navigator or the call might be forward onto the Hospice nurses or doctors for clinical advice over the phone, or they might be directed to another service for advice or help. In many cases, the care navigators take on some of the administrative tasks in phoning other services to arrange support, especially if the caller is a patient or carer, and will often follow-up with the patient or carer to ensure the problem was resolved. This type of service is facilitative and personal, and

also comprehensive in providing support to both service users and professionals; this dual role is uncommon among navigating services which are generally targeted at either service users or professionals, but not both.

The type of navigation offered in the Project differs to the types of navigation services described in the literature. 'Patient navigation' is a relatively new concept and stems largely from a US context in which patients are helped to navigate the health system and make treatment decisions, particularly in oncology settings (Hauser et al, 2011; Fillion et al, 2012). Services use either peer navigators or professional navigators (Fillion et al, 2009). Hauser and colleagues (2011) have argued that there is a natural role for navigators to help oncology patients to transition seamlessly from curative treatment to palliative care, but as yet few papers describe the role of navigation in palliative care. In the UK, many palliative care services tend to focus on support given in person rather than over the telephone, making care navigation in palliative care an innovative approach to coordinating care for which there is no evidence of impact on patient or service outcomes.

Looking beyond the palliative care patient group and focusing on the assessment, triaging and referral activities of the Navigation Centre for service user callers, Miake-Lye et al (2011) describes a service with similar functions aimed at identifying risk factors for falls among older people on the phone and triaging them to appropriate services. The qualitative study focused specifically on how the service was implemented, the barriers and facilitators to implementation, and patient outcomes. The study interviewed both the staff delivering the service and patients who used it, therefore was able to provide a rounded picture of service delivery and receipt of service. The facilitators to implementation described included: perceived patient benefit, a strong basis for the model which presumably refers to the fact that it was an expansion of the existing telecare service, and a clinical champion and project manager. Barriers to implementation included: the dispersed nature of the patient group which made follow-up by services in person difficult, and limited resources and staffing to handle the caseload. They also noted that the service was discontinued at the end of the pilot period when the clinical champion retired and thus this study serves as an example of implementation failure. The authors concluded that the locally initiated or bottom-up nature of the project was a barrier to gaining traction when it had to compete against top-down initiatives which had greater support from higher levels of leadership.

While the above study describes a service targeted at patients, the other element of the Navigation Centre in the Project is the support provided to care professionals. A descriptive study

by Teunissen et al (2007) looked at telephone consultations in the Netherlands in which professionals could call a 24 hour telephone advisory service to get palliative care advice. The advisory team was composed of a range of generalist and specialist clinicians each with several years of palliative care experience. The study looked at calls received over a five year period, who called and for what reason. The number of calls received each year increased from 319 to 452, which at its peak amounted to 1.2 calls per day on average with 25% taking place out-of-hours. The study did not assess any outcomes of advice given, but it might be concluded that professionals found some benefit in calling the telephone service as calls increased over time though this was not evaluated. Most phone calls came from GPs providing care at home and were of a medical nature rather than for psychosocial or spiritual issues. The authors concluded that there was a clear need among GPs for support in palliative care, though the aim of creating an integrated system of palliative care was not achieved because the service did not reach all professionals providing palliative care in the region. However, the assumption that all professionals need or even want palliative care advice might be questioned.

A similar service in the UK of providing specialist advice 24 hours to professionals was described by Carr et al (2008). Their study looked more explicitly at the knowledge transfer process over the telephone and addresses some of the cognitive process questions raised by the Teunissen et al (2007) study. Carr and colleagues (2008) broke the process into three parts: advice seeking, assessment of advice required and providing advice. The majority of callers sought advice for a solution to a specific clinical problem, so the decision to seek advice was based on the need for expert knowledge. Assessing the caller's advice needs was determined to be a complex skill in unpicking the case and listening for any subtle cues which might give more information than was being offered by the caller. In terms of giving advice, four out of five scenarios involved the call being forwarded on to a more senior advisor, and advisors who were more experienced often had less clear-cut interpretations of the advice needed. Giving advice was also complicated by the fact that the advisory service had no other information available to them about the patient other than what the caller gave them; this is similar to the operation of emergency services, but different to that in the Navigation Centre which was assisted by access to the EPaCCS. The authors concluded that a telephone advice line is a useful way to transfer knowledge between generalists and specialists.

Joining the evidence for service user and professional navigation together, a service which aims to provide both types of support would need to have the following: care navigators with good knowledge of the care system, ability to assess the callers' expressed and unexpressed needs through listening only, access to patient records to fill in gaps, and buy-in from health and social

care professionals who both use the service and respond to referrals for support. These requirements cover personal characteristics of care navigators and users, and system infrastructure to embed the service. The literature search revealed that there is scanty evidence of similarly designed services and the efficacy of such services are questionable.

2.2.3 Partnership approach

The Project is structured around a partnership and assumes a collaborative working process to deliver the project aims. A partnership is defined as a local, voluntary coalition of independent health care and social care providers that focus on improving care within the context of limited resources and coordinating an integrated provision of care (Plochg et al, 2006). This section considers what the relevant factors are in partnership working in health care for implementation. The studies discussed in this section are those which consider collaborative schemes which most closely resemble the partnership and collaborative approach in the Project and discuss how they were implemented.

Jackson (2000) describes the implementation of a shared leadership model in a multi-site health care organisation in Canada and the drivers and barriers in the operation of the model. It is based on the principle that “those who are doing the job are in the best position to improve it” (pp. 166). In the model relationships are central and the four concepts that are the foundation of the model are: accountability, partnership, equity and ownership. The model is sustained through a number of drivers: internalisation of the model’s concepts by staff, effective communication, tangible outcomes, continuous education, organisational support, physician involvement, and staff motivation and attitude. Essentially a common vision and desire to improve is what drives implementation, but is only sustained through visible improvements in outcomes and where it is supported by an organisational structure which values the shared decision making intrinsic in the model. Change is achieved through engagement from the bottom rather than through diktats from management above. However, implementation of the model is sensitive to external forces, such as historical drivers, the culture of the environment and organisational changes. What Jackson (2000) describes is a high maintenance and delicate system which needs careful attention and management to sustain and guard against a range of deleterious influences.

Whereas Jackson (2000) describes an approach to decision making in one organisation, Connor and Kissen (2010) describe the process for designing a whole-system integrated care strategy for Trafford in the UK. Their stance is that integration is the product of an iterative, whole-system change process involving clinicians, patients, and institutions in which consensus building and relationships, particularly between clinicians, are more important than structures, which is a

similar argument to Jackson (2000). A number of principles form a framework for developing infrastructure: the patient voice should be at the centre of change; integration should be based in general practice; consultants should be incorporated as they provide specialist expertise; delivery of integrated care is primarily through nursing and allied health professions; and social care and the full range of primary care services must be incorporated. Their strategy for change includes the following work streams: live data streaming from GP records as the foundation of the integrated care record, multi-professional panels to set standards, constant monitoring of the patient experience, medical service redesign, surgical redesign, leadership and quality improvement, patient coordination, and vertical integration (Connor and Kissen, 2010). The paper demonstrates the importance of planning for complex change, as two years were spent developing the strategy for implementation. Changes proposed are based on assessed local needs akin to quality improvement, rather than the application of evidence into practice. This paper essentially represents a first step in the implementation process which is setting out goals and how outcomes are meant to be achieved.

What these studies demonstrate is the centrality of the relationship between actors in multi-disciplinary and cross-organisational initiatives to join up care. However, such relationships can be difficult to maintain when professionals are subject to different organisational demands which reflect different political or economic influences. The substantial body of literature on collaborative working has led Williams and Sullivan (2010) to conclude that there are four areas where collaborative working goes wrong: motivation and meaning (why people and organisations choose to collaborate and their interpretation of the collaboration, aims etc), capacity and capability (collaboration is seen as a bolt on activity; people are attached to collaborations because of seniority rather than as partners seeking change), learning (learning takes place because of proximity and is ad hoc, rather than planned), and conceptualising and measuring success (difficulties in defining success for a process). As indicated in the fourth issue (measuring success), collaborative working is process based rather than outcome orientated. This has led to conclusions that both the process and outcome of coordinated care should be evaluated; how it works and whether it delivers improvements for service users (Dickinson et al, 2009; Walshe et al, 2007). These studies also demonstrate one of the problems with evaluating programmes of integration or coordination which is that the strategy of implementation (e.g. a nurse coordinator, multidisciplinary meetings, shared policies) is often the innovation itself (Masso and Owen, 2009).

2.3 Barriers and facilitators in the implementation process

While the previous sections synthesized the experience of implementation with palliative care programmes, electronic health records, care navigation and partnership working, this next section considers the specific barriers and facilitators to implementation described in these studies. Table 2.2 summarises the studies included in the literature review and the barriers and facilitators identified in each study. Barriers and facilitators seemed to fall into five categories which are described here: the role of individuals, the perception of the programme by intended users, change interventions, environment, and funding. Most of these issues are apparent at the micro or meso level which seems to indicate that implementation largely takes place on an individual or group level. Only environment seems to reflect macro level influences.

Individual actors are quite clearly important in shaping how a programme is introduced and received. Individuals are not blank slates; they have attitudes, preferences, existing knowledge, and different professional traditions which shape how they will respond to a programme. Some of these factors might be mitigated by preparing professionals, as was the case in the study described by Della Penna et al (2009) in which the focus of the programme was on changing the mind-set of professionals and creating a vision for change. Tolson et al (2007) also observed the importance of spending time in reconciling the values between professionals when they come from different backgrounds with differing views on care.

Tied to individual characteristics is the perception of the programme. There may be aspects of the programme which professionals perceive to benefit them, whereas other programmes are perceived to add to the health professional's workload. Clearly it is important for the programme to demonstrate its utility to the professional implementer, which importantly for palliative care, might be tied to its opportunity for use. Palliative care patients make up a small proportion of the overall patient population (approximately 0.75%), and therefore the perception of need for palliative care support is comparatively small.

Some of the studies demonstrated that specific activities or strategies for producing change were particularly facilitative in implementation. In particular, project coordinators or facilitators were influential in driving programmes and ensuring engagement from key health professionals. This role had different terms in the literature, but largely referred to someone who had the role of organising project activities and encouraging professionals to participate. This role is likely crucial because facilitation itself encompasses three central tenets: knowledge and data management, project management, and administrative and project-specific support (Doghererty et al, 2012), all of which appeared fundamental in the implementation process. Champions, especially physicians

or high level managers, were also effective in creating buy-in among professional groups. Educational and training strategies were also commonly employed, most likely because the innovations were introduced in non-palliative care environments which required informing professionals on how to give care using a palliative approach. Palliative care is not universally understood and professionals each interpret it differently (Dudgeon et al, 2009).

Only a few studies discussed the impact of the wider political, social, economic and organisational environment on the implementation process. The impact of the environment would likely mediate the success of the implementation process. This was particularly evident in the study by Dudgeon et al (2009) which observed that the outbreak of the highly contagious SARS disease resulted in health providers shifting priorities to activities to secure public health, away from the Palliative Care Integration Project. This implies that the palliative care project was not an essential service, but rather a project to engage with so long as there were no other priorities.

Finally, funding was a barrier in studies which cited a lack of it. Where funding was adequate it was not cited as a facilitator, except in the study by Mirando et al (2005) which stated that funding for the project allowed for a dedicated study team. This seems to suggest that resources of funding and time appear to be taken for granted when they are available, but criticised when they are not.

Table 2.2 Summary of programmes and innovations included in the literature review and facilitators and barriers in their implementation

Programme/ innovation & description	Study & design; Country of origin	Implementation strategies	Factors in implementation	Factor description/evidence	Enabling characteri-stic
Palliative Care Programmes and Interventions					
In-home Palliative Care Programme: Interdisciplinary home-based model of care designed to provide treatment with the primary goals of enhancing comfort and improving quality of care in a patient's last year of life	Davis et al 2006: retrospective study using focus groups and interviews, draws on diffusion of innovations theory; USA	Education and training involving visits to original implementation site by replication team; marketing strategy to emphasize positive aspects of the programme	Increasing awareness	Marketing strategy to demonstrate value, spread use, and increase positive feelings about innovation; aimed to affect individual preferences and beliefs	Facilitator
			Ensuring clarity	Education programme to communicate programme requirements, goals, and objectives	Facilitator
			Leadership	Successful sites had physician leaders who were well established and respected by staff and peers	Facilitator
			Training/mentorship	Critical to learning process and provides motivational/ emotional support	Facilitator
			Attitudes	Preferences of adopters had an impact on how they engaged with the intervention; physician referral rates dependent on their personal interest in the programme	Facilitator / Barrier
			Inadequate funding	Programme required more: funding, administrative support, allocated time for programme activities, and staffing	Barrier

Inpatient-based Palliative Care: Interdisciplinary team to help patients identify and communication health care preferences at the end of life; efficacy for the model established through randomised controlled study	Della Penna et al, 2009: quality improvement project using case study design, interviews; USA	Led by national leadership, core team established, model specification, kick-of meeting, training, visits to original site by replicating teams, standardised tools, 'dashboard' for monitoring	Evidence for model	Promoted spread, compelled professionals to use the model	Facilitator
			Leadership	National directive from top leadership provided clear message	Facilitator
			Knowledge transfer	Facilitated through social networking	Facilitator
			Observability	Able to see model in action at original site	Facilitator
			Resources	Not enough money to cover needs of model	Barrier
			Existing service model	Sites with a strong palliative care service model in place were slow to implement	Barrier
Italian Liverpool Care Pathway (LCP-I): LCP for care of dying translated to Italian inpatient hospice setting, created through literature review	Di Leo et al, 2014: assessment of achievement of objectives through questionnaire and audit after pilot period; Italy	10-step continuous quality improvement programme; hospice sites 'self-implementation': preparation of hospice site, self-education programme, audits	Attitudes	Scepticism by professionals	Barrier
			Internal oversight	Each hospice could decide how to offer education and whether to do the audits	Barrier
			Self-education	Education led by hospice, lacked structured training programme	Barrier
			Increased workload	Potential benefits not seen to justify the added workload	Barrier
Palliative Care Integration Project: optimising existing clinical services, resources and funding	Dudgeon et al, 2009: formative evaluation using surveys, focus groups;	Yearlong planning stage to establish governing body of stakeholders, expert working groups of champions to	Varied working practices	Multiple organisations involved with different perspectives	Barrier
			System changes	One agency involved stopped providing palliative care	Barrier

	Canada	develop changes; project coordinator, champions for each site, organisational impact analysis, train the trainer, resource manual, pilot of tools, evaluation	SARS outbreak	Impacted on all health providers, public health took precedence	Barrier
			Leadership	Upper level administrative leadership from key organisations, clinical leadership	Facilitator
			Project coordinator	Was member of all groups, provided continuity and drive	Facilitator
			Unclear terminology	Lack of common understanding of the definition of 'palliative'	Barrier
Edmonton Regional Care: Programme composed of: hospital based teams and palliative units, hospices, a home care programme, palliative care consulting service, and a registry of family physicians willing to provide palliative care	Fainsinger et al, 2007: descriptive study; Bruera et al, 1999: retrospective analysis; Canada	None described	Funding as driver	Changes in funding arrangements; funding follows the patient	Facilitator
			Low opportunity for use	Family physicians see relatively few palliative patients per year	Barrier
			Professional interest	Uncertain level of interest from family care physicians in engaging with palliative care specialists	Barrier
Hospice Palliative Care Network (HPCNet): Integrated service delivery model involving hospices, palliative medicine consultation, and home care programme; incorporates	Howell et al, 2011a: analysis of secondary data; 2011b: pilot project Marshall et al, 2008: mixed methods; Canada	None described	Building on established relationships	Drawing on existing resources and professionals relationships	Facilitator
			Working benefit	Programme users perceived benefit to current working practices	Facilitator

the Enhanced Palliative Care Team which has access to a clinical database accessible by PalmPilots updated in real time					
Integrated Care Pathway: for use in hospital setting to improve treatment of care of dying, modelled on LCP	Mirando et al, 2005: description of model of care, audit; UK	Used PROjects IN a Controlled Environment (PRINCE) method, rolled out in 4 stages, training, monitoring/evaluation, project nurse	Project nurse	Reminded staff to use the pathway, motivational, enthusiastic	Facilitator
			Systematic project management	Project nurse and project manager employed to manage project	Facilitator
			Resources	Funds for dedicated project team	Facilitator
			Leadership	Better success where leadership from ward manager	Facilitator / Barrier
			Time	Some wards were resistant, enough time for project nurse to encourage change	Facilitator
Acute Palliative Care Service: consultation service and in-patient acute palliative care unit	Santa-Emma et al, 2002: descriptive study; USA	Physician Advisory Board proposed development of service based on assessment of local need	Perceived need	Service was developed to meet perceived need	Facilitator
			Project advocate	Administrator acted as advocate for the project	Facilitator
Managed care network (MCN): development of new MCN which is a	Tolson et al, 2007: realist evaluation,	Network meetings including executive group, patient-held	Evaluation	Evaluation itself was assessed as critical as it helped to adapt and change strategies over time	Facilitator

coordinated approach to interdisciplinary care	prospective assessment; UK	records, education programme, coordinator role	Practitioner knowledge	Identified as prerequisite for success	Facilitator / barrier
			Lack of experience	Executive group employed a process of trial and error which was felt to be inefficient	Barrier
			Lack of reconciliation of values	May have contributed to delay in professional buy-in	Barrier
Care Programme for Palliative Radiotherapy: four elements: responsibilities for care chain, checklist of tasks, guidelines for nursing, transfer of care form; supplemented by nurse practitioner	Vahedi Nikbakht-Van de Sande et al, 2014: participatory action research; qualitative descriptive design: participatory observations, semi-structured interviews, focus groups, document analysis; Netherlands	Four stages: problem choice and diagnosis, planning and intervention development, implementation, evaluation; nurse practitioner responsible for dissemination, gaining support and carrying out activities	Nurse practitioner	Responsible for most programme activities	Facilitator
			Task allocation	Tasks for nurse practitioner too broad, solely responsible for most tasks, unequal distribution	Barrier
			Prioritisation	Department expected to refer to programme did not prioritise implementation	Barrier
			Professional-led	Professionals had developed programme using participatory approach, driven by professionals and quality concerns	Facilitator
			Lack of engagement	Senior managers did not attend meetings	Barrier

Electronic Health Records					
Electronic Palliative Care Summary: electronic template embedded into existing primary care electronic patient record systems	Hall et al, 2012: descriptive qualitative study using interviews; UK	Template as standard in upgraded version of patient record systems	Technical design, interface	New and unfamiliar, not intuitive design	Barrier
			Patient benefit	Patient anxiety relieved because out-of-hours holds their information	Facilitator
			Working benefit	Out-of-hours staff have access to information giving greater confidence in their work	Facilitator
			Lack of buy-in, awareness	Not part of collective consciousness, only being used when prompted	Barrier
Coordinate My Care: central component is EPaCCS; includes education and training components; clinical governance arrangements are embedded	Smith et al, 2012: descriptive study, analysis of record completion; UK	Training package to form basis of future implementation	Embedded clinical governance	Local organisations required to use system	Facilitator
			Education and training	Comprehensive package available to users, limited evidence of impact	Facilitator (low)
Care Navigation					
24 hour specialist advice line for health and social care professionals	Carr et al, 2008: action research, pluralistic design; UK	None described	Expertise	Dedicated expert advice line created confidence and comfort in those calling	Facilitator
			Team culture	Teams encouraged staff to use line if knowledge not available in team; fear of exposing knowledge deficit to team	Facilitator / Barrier

Telephone advice line for falls prevention: scripted assessment by nurse who makes referral decisions based on predetermined algorithm; service was part of a larger quality improvement programme	Miake-Lye et al, 2011: mixed methods formative evaluation including interviews, electronic health record review, cost estimation; USA	Prevention service added on to existing telecare system	Clinical champion	When champion retired, service was ended	Facilitator
			Patient benefit	Patients expressed benefit in using the service; staff able to reach more patients	Facilitator
			Access to patients	Telephone service allowed greater access to remote patients, but this also made it difficult to do an in person follow-up	Facilitator / Barrier
			Resources	Large caseload for number of employees	Barrier
			Awareness of service	Service needed better recognition (awareness) among health providers; patients unable to distinguish between service and other care services offered by phone	Barrier
Telephone helpdesk for professionals: 24/7 helpline for professionals to call for palliative care advice	Teunissen et al, 2007: descriptive analysis of phone calls; Netherlands	None described	None described		
Partnership					
Trafford framework for integrated services: whole-systems change within one area	Connor and Kissen, 2010: description of process of programme development;	Leadership by Nuffield Trust, seminars/ meetings/ events to create dialogue, focus on redesign rather than	Executive support	Support from Board level within organisations	Facilitator
			Clinical involvement	Input from clinicians through vote, clinical leadership group	Facilitator

	UK	procurement, create common vision	Project management	Clear project management required to deliver complex change	Facilitator
			Commitment	Good attendance at events, especially by senior clinicians	Facilitator
Shared leadership: model encompasses: decentralised organisational structure, balance between the individual and collaborative decision making, supportive environment, and shared vision	Jackson, 2000: qualitative study using focus groups and interviews; Canada	Proposed changes made by nursing staff, internal organisational restructuring	Model acceptance	Concepts from the model internalised by staff, common mental model	Facilitator
			Communication	Communicating council decisions to the rest of the unit	Facilitator / Barrier
			Education	Continuous education to improve internalisation of concepts	Facilitator
			Physician support	Support and commitment from physicians	Facilitator / Barrier
			Organisational change	Changes threatened staff job security	Barrier

2.4 An assessment of the literature

This section discusses the strengths and weaknesses of the literature discussed and highlight gaps which the following empirical study may hope to address.

Firstly, with regards to terminology, much of the literature has been vague about what is meant by implementation; it is not often distinguished from related activities of diffusion or dissemination. At times, implementation as a term has been used narrowly, but the process of enacting change encompasses a broad spectrum of activities beginning with planning which then effects implementation. This is illustrated in the study by Vahedi Nikbakht-Van de Sande et al (2014) which described overlapping stages. It is quite often overlooked in studies of effectiveness and becomes the scapegoat when interventions do not produce expected results, or is taken to mean 'how something looks in practice.' However, what is of interest here is implementation as a planned activity, where strategies are employed to effect a change in practice and these strategies are evaluated for efficiency in creating the desired change. In this respect, there is little research to date in palliative care specifically. The inconsistent use of the term 'implementation' and what was presented in reference to the 'implementation process' was often obscured in the literature, so judgements had to be made on what was actually described in abstracts and full text. Many papers indicated that they were studies of implementation, but in fact focused on the impact of newly implemented programmes.

Additionally, the literature is rife with an abundance of terms used to explain similar concepts. For example, 'nurse practitioner' (Vahedi Nikbakht-Van de Sande et al, 2014), 'project nurse' (Mirando et al, 2005), and 'project coordinator' (Dudgeon et al, 2009) were all terms used to describe a role to facilitate the implementation process. Also, 'mind-set' (Della Penna et al, 2009) and 'mindlines' (Tolson et al, 2007) were terms used to describe the cognitive state of preparedness for change. The variety of terms used seemed to indicate a general lack of awareness of implementation as a field of study, with authors instead reflecting on the topic area of palliative care, electronic records, care navigation or partnership. This makes the accumulation of knowledge more difficult, particularly when terms are used inconsistently.

Absent from many studies was a discussion of the role of context in the implementation process. It seems somewhat absurd to describe the process without reference to the wider context, as though implementation is occurring in a vacuum. Yet context was often only described in situations where it was a barrier or facilitator (Dudgeon et al, 2009), and elsewhere treated as a neutral entity by its conspicuous lack of description.

Evaluations of palliative care programmes, like much of the health care literature, are usually focussed on outcomes rather than implementation. Palliative care programmes often have mixed results, but what is less clear is whether a lack of efficacy is because of deficits in the programme design or deficits in implementation. Some studies focused on evaluating the intervention and assumed implementation was successful or not based on the outcomes of study, rather than evaluating the process and whether it was implemented as intended. Implementation seems to be given greater consideration in the case of an innovation being adopted in a new setting and sustained, or where an intervention has failed to deliver its expected results (Vahedi Nikbakht-Van de Sande et al, 2014).

2.4.1 Methodological assessment

While this chapter has so far largely considered the contribution of these studies to the understanding of implementation in palliative care, it is also worth considering the various methodologies which underpin this understanding. Firstly, how implementation is conceptualised in each of the studies varies slightly and is reflected in the lack of consistency in the structured reporting of findings. The majority of the studies have presented the development and planning of the programme or innovation as the background to the study of the implementation process (Davis et al, 2006; Della Penna et al, 2009; Jackson, 2000; Miake-Lye, et al 2011). This seems to represent a narrower view in that implementation is a stage after planning and development. Other studies have taken a broader view incorporating the planning and development stages into data collection and analysis as part of understanding implementation as a whole (Dudgeon et al, 2009; Di Leo et al, 2014; Vahedi Nikbakht-Van de Sande et al, 2014). While these may present two distinct understandings of implementation, it might also be that programmes which were designed in-house view the development process as part of implementation, whereas those implementing an off the shelf innovation exclude the decision-making and development processes that led to adoption. As a caveat, the distinction might also reflect the role of the evaluator and when they became involved in evaluating the implementation process. Often evaluators are drawn into the process after an intervention has been defined so data might only be collected retrospectively through document analysis or interviews. Lack of clarity in how implementation was conceptualised meant it was difficult to assess in each case whether the selection of methods and data collected truly reflected the process that the author intended to study, or whether the data simply presents an opportunistic snapshot of a particular part of the process.

Many of the studies included in this review have been largely descriptive rather than explanatory in design. While they may describe how various implementation strategies were used, they are

not able to explain how or why they achieved the results observed. Additionally, a number of papers which described the implementation process appear to be drawing largely on anecdotal experience as no data appears to have been collected which captures process information or indeed other contextual information which may have influenced the process. For example, the study by Miranda et al (2005) describes the project and how it worked in practice and data collection focuses primarily on describing the outcome of that process. The conclusions that implementation was successful because of systematic project management presupposes that management was responsible for training and adherence to the pathway without any other evidence to explain the role of management.

Studies are also divided in terms of whether they were designed to reflect back on what occurred during the process or capture it as it unfolds. Retrospective studies occurred after implementation and reflected back on the barriers and facilitators to implementation from the point of view of the implementers (Davis et al, 2006; Della Penna et al, 2009; Hall et al, 2012; Jackson, 2000) or assessed the quality of the process (Di Leo et al, 2014). Prospectively designed studies captured the process as it happened in addition to considering barriers and facilitators (Dudgeon et al, 2009; Miake-Lye et al, 2011; Vahedi Nikbakht-Van de Sande et al, 2014). Prospective studies still relied on retrospective data collection, like interviews after implementation, but the difference is that the decision to assess implementation seems to have been made prospectively. For example, the study by Tolson et al (2007) incorporated a realistic evaluation into a three-stage implementation process and therefore unpicked the mechanisms for change as they unfolded. While even prospective studies consist of some retrospective reflection through interviews, a retrospective design means that people are reflecting on their experience in the light of either successful or unsuccessful implementation. This might colour their view of the process.

Studies have drawn primarily on qualitative methods and/or audit or a quantitative evaluation of outcomes. While different sources of data have been used to understand the process, authors do not seem to state whether or how data was triangulated, which perhaps reflects the more descriptive nature of these studies. Rather, different data has been collected to answer different questions rather than multiple data sources to answer one question (e.g. Miake-Lye et al, 2011). Data was often presented separately (e.g. Dudgeon et al, 2009) rather than organised thematically (e.g. Davis et al, 2006). Triangulation and thematic organisation of findings seems to give a better sense of the whole process rather than pieces of it.

Thus the key gaps in the literature with regards to palliative care programme implementation appear to be: few prospective studies of the process of programmes as implementation is often considered as an afterthought; lack of in-depth understanding of the role of context in shaping the process and what challenges are specific to palliative care; little clear, conceptual differentiation between implementation outcomes versus patient or service outcomes; inconsistent use of implementation terminology and concepts; and little discussion of effective implementation strategies for palliative care.

Summary

This chapter has defined implementation as planned strategies and adaptive activities used to change and routinise new clinical practices. It is necessary to view implementation in palliative care as distinct from health services more generally because it has unique characteristics, including relatively low patient numbers yet high service usage across the care continuum which often needs to be coordinated and dealing with the cultural taboo of death. The literature review considered a range of studies examining the implementation process in various guises and concluded that: interventions most commonly focus on implementing palliative care into primary or acute care settings; implementation is driven by the desire to address a specific need or to apply an existing innovation in a new setting which gives shape to the process; strategies for implementation address cognitive and behavioural changes; and success in implementation is difficult to characterise. The innovations of shared electronic records and care navigation were considered and it was concluded that there is little research to conclusively demonstrate their efficacy in practice or effective approaches to implementation. Lastly, barriers and facilitators that shape the implementation process were also examined which revealed in particular the key role of facilitation, the necessity of support from influential champions particularly physicians, and the role of education strategies to spread understanding of palliative care.

3 Theoretical and empirical perspectives on implementation

Introduction

The aim of this chapter is to set out the conceptual framework which will inform the questions for the empirical study. The literature will focus on implementation theory with particular reference to health services research, which is aimed at developing and applying new knowledge to improve service delivery for patient care (Fulop *et al*, 2001). This implies a practical focus for the framework with which to interpret and translate the findings into practice by health service managers and frontline professionals. Implementation theory provides the perspective for the study and will be used to guide the research questions, data collection and analysis (Cresswell, 2014). Theories, frameworks, and models, though all having separate definitions (Tabak *et al*, 2012), will be used collectively here as there are overlapping concepts and ideas which can be used to establish a conceptual map from which to begin. This chapter draws particularly on theoretical works and syntheses of empirical studies, particularly works by Damschroder and colleagues (2009) and Greenhalgh and colleagues (2004b). These works draw on a wide range of implementation research spanning various fields from health, education, policy, agriculture and beyond. Whereas the previous chapter focussed specifically on the literature in palliative care, this chapter takes a wider view of implementation in both theory and empirical work.

The chapter is divided into four sections. The first section draws primarily on the theoretical literature for discussing different conceptualisations of the shape of the implementation process focussing on linear and non-linear models and the role of power in shaping the implementation process. The second section discusses both theoretical literature and seminal works which have developed models based on empirical studies in order to identify key factors in the implementation of innovations and programmes. The third section considers how successful implementation might be defined in a health service context drawing on theory and empirical studies. Finally, these three sections will be drawn together along with barriers and facilitators discussed in the previous chapter to present a conceptual framework for the study. The aim of the framework is to guide the exploration of what shapes implementation and how the process can be characterised, which will feed into interpretations about the success of the case studied in this thesis.

This thesis draws primarily on implementation and innovations literature, and is focussed at the project group level which largely involves organisations, or more specifically individual

stakeholders working on behalf of organisations. There are alternative perspectives which could have been taken, for example a systems approach (macro level) (Walt, 1994) or theories of behaviour focussed on the interactions between care professionals and patients (micro level). There are clearly important aspects to be considered at each of these levels and they cannot be ignored as they invariably impact directly or indirectly on implementation. However, the Project is primarily focused on the coordination of patient care through organisational collaboration, thus this is the focus of the study.

3.1 Theoretical perspectives on the shape of implementation

Implementation has been defined as a targeted effort through planned strategies and adaptive activities to change and routinise new clinical practices. In exploring the implementation of a new programme, a primary question might be how these strategies are designed and what is driving them, and how this affects the shape that implementation takes. Implementation theory has its roots in a number of different areas of research including policy, agriculture, education and health (Greenhalgh et al, 2004b), and this discussion reflects an accumulation of that knowledge. The literature presented draws on syntheses of empirical research with theory and is therefore a somewhat nebulous amalgamation of normative models of implementation based on expectations and descriptive or explanatory models derived from observation of individual cases. This discussion therefore simply aims to explicate the current state of thinking in implementation. There are generally considered to be two differing views regarding the shape of implementation: those who view it as a linear, staged or top-down process, and those who see it as a nonlinear, negotiated or bottom-up process.

3.1.1 Linear, top-down models

Rogers' (2003) theory on how innovations spread or diffuse developed over the latter half of the twentieth century is foundational for conceptualising the innovation process as happening linearly in stages. For individuals implementing an innovation, Rogers depicts five stages: knowledge, persuasion, decision, implementation, and confirmation. The first three stages, and possibly the last, are largely cognitive processes affected by contextual factors, personal characteristics, and features of the innovation. The knowledge, persuasion, and decision stages must take place before implementation which requires behaviour change. Rogers argues that organisations also go through a similar five stage process involving agenda-setting, matching, redefining/restructuring, clarifying, and routinizing. In this type of model, implementation might be conceptualised as one of the last phases in a much larger development and transfer process which involves phases of: research, development and testing, diffusion, adoption,

implementation, and routinisation or abandonment (Table 3.1). This process starts with developers of an innovation and describes the transition from development through to adoption and use. Each phase is characterised by its own processes, and each phase is predicated on the success of the previous phase (Scheirer, 1983).

Table 3.1 Phases of innovation development and transfer process

Phase	Characteristics of the phase (actors involved)
1 Research	Basic and applied research; establishing effectiveness (developers)
2 Development and testing	Assessment and evaluation; cost efficiency (developers)
3 Diffusion	Awareness of innovations to meet identified needs; knowledge; persuasion (adopters)
4 Adoption	Decision making; commitment to the innovation (adopters)
5 Implementation	Orientation, initiation, integration (adopters)
6 Routinisation/ abandonment	Normalisation/ routinisation/ embedding / confirmation or abandonment (adopters)

Adapted from: Linton (2002); McKinlay (1981); Roberts-Gray and Gray (1983); Rogers (2003); Scheirer (1983)

Roberts-Gray and Gray (1983) go one step further to break implementation as a phase into three sub-stages, drawing on Lewin's (1947) theory of planned change in which there are periods of orientation, initiation, and integration, likened to Lewin's "unfreezing", "moving", and "refreezing", respectively. In the orientation stage, the programme is planned and introduced operationally to the organisation; in the initiation stage the programme is put to use by the intended users to determine how best it can be integrated into standard practice; and integration is when the programme has become a part of routine practice and implementation is at an end. Thus the behaviour change required during the implementation stage is conceptualised as having its own linear process nested within a longer adoption process.

The above describes the process that individuals and organisations go through in adopting and using an innovation. The question then turns to how quickly people go through this process as we know the rates must be different because if they were not then every care professional and organisation would be doing the same thing. Rogers (2003) proposed that there are five types of adopters: innovators who like to break the mould, early adopters who are largely the opinion leaders in their field, early majority who are cautious in their decision making but still act faster than average, late majority who engage with an innovation only when the majority are using it,

and laggards who prefer the traditional ways of doing things though they may be aware of new innovations. Rogers argues that this rate of adoption is dependent both on characteristics of the innovation and the adopter, both of which will be covered in the next section on determinants in programme implementation. The rate of adoption is also linked to the number of people involved in making the decision to adopt – the more people, the slower the rate of adoption (Rogers, 2003). While this concept may have stemmed from an organisational setting, how this plays out in a partnership is perhaps unknown, particularly whether there may in fact be a sixth category of non-adopters within the partnership and what impact this will have on the efficacy of programmes to coordinate care.

Underpinning these linear models are normative ideals about a rational or logical process whereby implementation can be controlled through a top-down planning process prospectively. This top-down process has been conceptualised by Elmore (1980) as a ‘forward map’ in which one can specify a sequence of events to lead to the desired outcome. In this approach it is believed that the path towards successful implementation can be conceived logically, as though one can specify actions and predict the outcomes of those actions. Thus implementation begins with a hypothesis, if X is done then Y will result (Pressman and Wildavsky, 1984). There is an assumption here that X is executed as intended without deviation and that settings for implementation are equivalent.

The top-down conception of implementation has led to a number of prescriptions for how to achieve ‘perfect’ programme implementation (Gendreau et al, 1999; Hogwood and Gunn, 1984; Sabatier and Mazmanian, 1979). The idea being that if such prescriptions can be met, then the actions of frontline workers can be constrained to achieve the desired programme results (Sabatier and Mazmanian, 1979). Such preconditions are outlined by Hogwood and Gunn (1984):

1. External circumstances do not impose crippling constraints;
2. There is sufficient time and resources available;
3. The programme to be implemented is based on a valid theory of cause and effect with the fewest possible intervening links;
4. The programme is minimally dependent on other agencies for implementation;
5. There are clear and agreed objectives;
6. Programme tasks are planned in the correct sequence;
7. There is perfect communication and coordination; and
8. Those in authority can demand compliance with the programme.

These preconditions naturally form a framework for preliminary evaluation as to how well a programme is likely to be implemented, for if some of the preconditions cannot be met then it is unlikely that the programme will be successfully implemented.

Linear, top-down models emphasize authority and hierarchy; where policies and programmes are conceived of at the top and implemented as planned by dispersed health care managers and professionals (Barrett, 2004). Performance is therefore judged on adherence to policy or programme specification, and the focus of implementation studies is on the failures that arise because of gaps between the programme plan and its implementation. However, Greenhalgh and colleagues (2004b) argue that while this model might be applicable to independent individuals, it does not easily transfer to more complex interventions such as in an organisational setting. This is because organisations involve groups of individuals who each require different amounts of knowledge or persuasion in order to make the necessary change in behaviour.

3.1.2 Non-linear, negotiated model

As suggested by Greenhalgh et al's (2004b) criticism, other theorists have observed that the innovation adoption and change process is less structured and more erratic (Ferlie et al, 2005). Rather than progressing linearly, implementation may be interrupted by events external or internal to the process. This is evidenced by the early studies of implementation which are focused around failures (e.g. Pressman and Wildavsky, 1984) which indicates some force competing with a planned approach. Actors then have to respond to these changes which may involve repeating previous 'steps', therefore creating feedback loops which implies a non-linear process (Van de Ven and Poole, 1995). Additionally, implementation of complex innovations takes place at multiple organisational levels and it is unlikely that this transformation process takes place at the same rate at each level (McNulty and Ferlie, 2004; Mendel et al, 2008). McNulty and Ferlie (2004) argue that it is the complexity of organisational transformation which means that implementation is a non-linear process.

Transforming clinical practice may be even more challenging in palliative care which is multidisciplinary. Social boundaries likely exist between professional groups who each have their own traditions, roles, and identities which may be threatened in different ways by a new innovation (Ferlie et al, 2005). Ferlie and colleagues (2005) suggest that in such instances, it is professionals rather than managers that undermine and slow the innovation process because of social and cognitive boundaries between professionals. Based on their empirical findings, McNulty and Ferlie (2004) argue that actors do not simply resist change, but rather they seek to shape it on their own terms. Likewise, Lipsky (1976) has argued that those responsible for

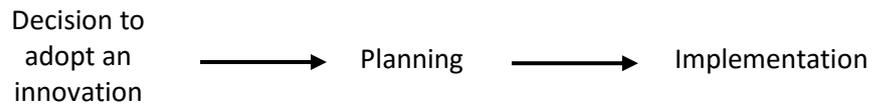
frontline implementation of policies within an organisation wield extensive power in the implementation process due to the discretion they use that influences daily practice. For Lipsky, the constraints of the workplace force frontline workers to adapt their behaviour to fit their circumstances. These constraints stem from a lack of resources, threats to physical or mental well-being, and conflicting or ambiguous role expectations. While these frontline workers may lack influence at a system level, they have highly influential roles in affecting health service delivery and service user experience. This is particularly true of the medical and nursing professions where clinicians are also involved in management and planning, particularly in the Clinical Commissioning Group configuration of the NHS post Health and Social Care Act 2012.

Buchanan and colleagues (2007) have suggested that particularly in healthcare, change agency may be distributed among professionals, rather than led by someone from the top. In their analysis of change in a cancer service, they state that “the change process in some contexts may benefit from being dispersed, fluid, migratory, and influence-based, rather than well-defined, planned, and stable in definition and location” (pp. 1081). What this may indicate is that ownership of the innovation at the frontline is essential for successful implementation so that the change process can respond to the setting and actor characteristics rather than being imposed by the top with little concern for what is happening on the ground (Ferlie and Pettigrew, 1996). The focus of implementation is thus on *performance*, rather than *compliance* with stages in the implementation process. A non-linear or bottom-up process assumes that adaptation is likely to occur because of variable working environments, which cannot or are not necessarily predicted or controlled from the top.

3.1.3 Characterising the shape of the implementation process of palliative care services

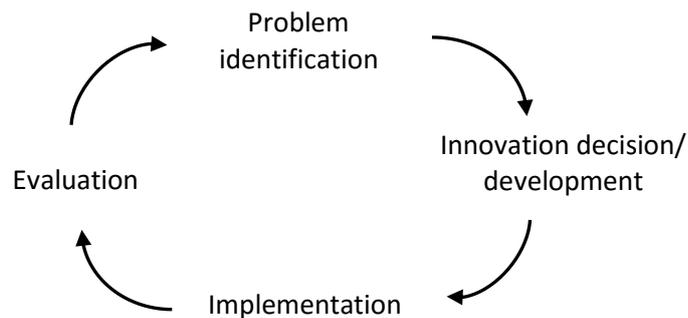
These two distinct shape patterns were also reflected in the empirical studies in palliative care presented in the previous chapter. The top-down characterisation accords with the planned, structured or managerial approach which appears to be common to the implementation of innovations which have established efficacy (e.g. Davis et al, 2006; Della Penna et al, 2009; Di Leo et al, 2014; Dudgeon et al, 2009; Mirando et al, 2005). This process seems to be characterised by a decision to adopt an innovation, planning and then implementation, depicted in Figure 3.1. These studies then described what happened during implementation, the strategies to effect change, the barriers and facilitators identified, and in some cases the outcomes produced.

Figure 3.1 Linear, top-down, or managerial implementation process



In comparison, innovations which were developed following the identification of a problem in practice or in response to changes in policy appear to have non-linear characteristics. These studies described the problem being addressed, the development of the innovation, the implementation process and how the innovation addressed the problem. This process accords with a bottom-up, practitioner-led approach (e.g. Santa-Emma et al, 2002; Tolson et al, 2007; Vahedi Nikbakht-Van de Sande et al, 2014) and is represented in Figure 3.2.

Figure 3.2 Non-linear, bottom-up, or practitioner-led implementation process



3.1.4 A critique of linear and non-linear models: towards an integrated approach for programme implementation

One of the strengths of the linear or top-down approach is the notion of cause and effect in which one stage logically leads to the next. However, as noted previously, external events can interrupt any one stage reducing the predictability of planned subsequent stages. To some degree the conditions for implementation can be programmed from the top through legal frameworks so that actors are provided with a favourable environment to lead to expected actions. Indeed the influence of governance structures was noted as a facilitator to implementation in the previous chapter (Smith et al, 2012). However, Langstrup (2008) argues that “the concept of implementation tends to regard the organisational setting and its actors as given” (pp. 119), but in reality actors, organisations and innovations interact and shape each other. This is reiterated by May (2009) who says the focus of implementation needs to be on what the “work is, how it is interactionally shaped and institutionally framed” (pp. 157). Thus the

focus of enquiry should shift to social processes occurring during implementation, which are greater unknowns.

These social processes likely lead to adaptation which may be an inevitable part of implementation. Rogers (2003) states that mutual adaptation occurs when programmes evolve in response to changing environmental conditions, just as organisations change in response to new programmes. Indeed it has been argued that adaptation of an innovation is a sign of sustainability in that an organisation which modifies the innovation to suit its needs is more likely to continue using it (Scheirer, 2005). However, if adaptations are continually made so that a programme is only a shadow of its original form, does that not compromise the effectiveness of the programme (Proctor et al, 2009)?

In addition to adapting an innovation to suit a new context, adaptations may also occur in response to external events which may at times be random. Cheng and Van de Ven (1996) suggest that the innovation process is neither predictable nor random, but is defined more by chaos where the beginning of the process is chaotic and the end is more linear, though external events remain a random factor. Essentially, implementation may be planned and is expected to progress linearly, but as random external events disrupt the learning process, implementation must be adapted to cope thus linear progression is lost and the process becomes chaotic. However, towards the end of implementation, external events may be dealt with more efficiently or become more predictable through learning, so the process can be better planned and takes a more linear shape. This conception of the implementation coherently blends together three key elements of planning, unplanned events, and adaptation.

3.1.5 Conceptualising power

An important element which has been hinted at in the discretion of frontline actors is the role of power relationships in health care. Power can be defined as the “ability to bring about significant effects specifically by furthering the agents own interests or by affecting the interests of others” (Williamson, 2008, pp. 512). Power represents a relationship between one or more actors in which one actor uses their influence to bring about change (Dahl, 1957; Foucault, 1982). Power has been thought to be related to conflict in the sense that where there is no conflict, power is not exercised and therefore does not exist (O’Farrell, 2005). Thus Clegg (1979) states that “power, when it is exercised, is exercised over issues” (pp. 146), essentially that there is a conflict which thus defines the relationship between two actors. When implementation requires interprofessional or interorganisational collaboration as might be the case in palliative care, it

involves various actors from different backgrounds bringing competing professional and organisational priorities which has potential for conflict.

Much of the theoretical literature on power within organisational contexts focuses on the relationships between individuals within single organisations. Within one organisation, power is generally conceived of being tied to the organisational structure and indeed there is an implicit understanding that power is hierarchical within organisations (Hardy and Clegg, 1996). However, the Project is not an 'organisation' with such an established structure, but rather a partnership of organisations represented through a number of individuals. Conceptualising power through this hierarchy is not particularly helpful since, though there is some structure within the Project, the structure has no established history which would legitimate a hierarchical basis of power (Hardy and Clegg, 1996). Instead, it is perhaps more useful to conceptualise power in an interorganisational context. There is less literature reflecting on interorganisational working and networks (Addicott and Ferlie, 2007) despite this becoming a more common form of working particularly in the health and social care sector (Ferlie and Pettigrew, 1996). The organisational motivation for working in a network is often based on mutual benefit in which the workload can be spread across organisations while still affecting a high level of performance (Hjern and Porter, 1981; Palfrey, 2000; Parsons, 1995). This suggests that organisations that work in a coordinated way have common goals and a relationship that might be based on compromise rather than competition. A fundamental part of the implementation process is decision making, which because of the potential for competing organisational priorities will necessarily include compromise, and then the enacting of these decisions within respective partner's institutions. Mutual benefit, coordination, and goal sharing provide clues to how power might be conceptualised pluralistically within the case of the Project.

Pluralism

Dahl's (1957; 1958) conceptualisation provides the framework for exploring a pluralist view of power. Dahls' (1958) concept of power stems primarily from his criticism of elitism which postulates that power structures are constant, such that those in power will always have power. Instead of power always being held within a minority group, he argues that power is spread within the system and is dependent on the specific issue at hand. For pluralists power is fluid and context specific. Power in pluralism is apparent in behaviour, specifically in decision making and how conflicts are resolved. The idea that power is used to generate conflict resolution, or consensus, implies interdependence between actors who have shared goals. Having shared goals is essential in collaborative and partnership working (as indicated in section 2.2.3), thus the focus on decision making and conflict resolution may explain the processes involved in implementation

within interorganisational projects. The idea of consensus as the aim of power relationships reflects a non-linear concept of implementation in which negotiation rather than top-down dominance is a central feature.

Pluralism is not without its critics (Bachrach and Baratz, 1962; Lukes, 1974). Firstly, Bachrach and Baratz (1962) argue that power is not just limited to when decisions are made, but also in the control of what decisions are *allowed* to be made:

“Of course power is exercised when A participates in the making of decisions that affect B. But power is also exercised when A devotes his energies to creating or reinforcing social and political values and institutional practices that limit the scope of the political process to public consideration of only those issues which are comparatively innocuous to A.” (pp. 918)

They argue that the exercise of power is more subtle than simple decision making, but also includes the process in which decisions are made. This implies that the issue of conflict is minimised as powerful actors who perceive potential conflict act so as to reduce actual conflict. Lukes (1974) takes this criticism one step further by arguing that actual conflict is not necessary for power to exist, but rather that powerful actors can shape the preferences and interests of those excluded from power without them knowing it. This of course is a very insidious view of power, that we might be manipulated by someone else’s agenda without being aware of it – an idea which Dahl (1958) acknowledges as a possibility, but then does not address with his theory.

These criticisms of pluralism raise important points which must be considered within the context of implementation of interorganisational and interprofessional programmes. Implementation is fundamentally about action, and though while Lukes is critical of conceptualisations of power which focus narrowly on behaviour, it seems an important feature within the context of implementation. Interorganisational partners have made an agreement for joint working in order to realise mutual benefit and so it might be expected that power relations reflect a reciprocal relationship that comes from sharing an agenda. In order to achieve mutual goals within the Project we would expect partners to negotiate and share in decision making. Expressions of power might then be manifest when there is conflict within the process. The partners working in coordination in the Project have entered into the partnership knowingly, though their motivation for participating may have come from pressure stemming from the wider political and legal context – ultimately this may affect their participation and effectiveness in the Project which may impact on implementation. Therefore, are all partners expected to participate equally in power sharing as pluralism suggests? Or might “doctor power” (Goodwin, 2000) overwhelm other

members of the group? An adapted view of pluralism which additionally addresses the role of structure postulated by Addicott and Ferlie (2007) offers an alternative view which suggests that within such project networks there exist strong coalitions of actors which dominate within the group.

Bounded pluralism

Addicott and Ferlie (2007) explored the distribution of power within managed care networks, which share similar characteristics to the Project in that they involve health professionals and organisations from primary, secondary, and tertiary care working in a coordinated manner across boundaries. However, and perhaps crucially, because of differences in funding arrangements, the Project also includes non-NHS organisations including voluntary sector and social care so is more organisationally complex than a managed care network. Addicott and Ferlie (2007) found that rather than actors bargaining with the whole network, there were dominant groups who bargained and battled amongst themselves for resources at the expense of weaker stakeholders. Within the dominant group there was a pluralistic shifting of power, but within the larger network power did not transfer to other members and the dominant group was not interested in achieving consensus. This view takes into account the issue of competing priorities – while there may be one shared goal, members may prioritise differently the way that goals are achieved. The formation of coalitions is a strategy to gain power in a situation where power is perhaps equally shared or exchanged (Cook, 1977). But along what lines might these coalitions form? There are likely at least two factors relevant to how coalitions might form within a palliative care context: professional roles and clinical specialties. There is much evidence regarding the power of doctors in health care which is attributed to the dominance of the medical profession (Goodwin, 2000; Ham, 1992; McNulty and Ferlie, 2004;). McNulty and Ferlie (2004) observed that doctors in a hospital context not only resisted change, but actively sought to alter change programmes to suit their needs. They found that doctors could be influenced by hospital administrators, but not controlled. Within the medical profession, power relationships might also be influenced by clinical specialism. Addicott and Ferlie's (2007) work looking at managed care networks demonstrated that there were divisions between medical professionals with those in cancer centres exerting dominance over other medical professionals. Do specialists wield more power than generalists or vice versa? Do coalitions form along professional tribal lines? Does professional power depend on the locus of care, i.e. the patient's ailment? If so, then we might expect the power of palliative care professionals to be fluid and case dependent as some patients may require intense specialist input and others very little.

Bases of power and leadership

The above discussion of shared power arrangements seems suggestive of a dispersed leadership structure more common to team-based forms of organising rather than the traditional leader-follower model (Gordon, 2002). In a dispersed leadership model, the roles of leader and follower become blurred. However, Gordon (2002) suggests that there are deep structural levels of power which challenge a true dispersal of leadership and power, such as inequities in control of knowledge, thus suggesting that even in a shared model there still exists a base of power from which leaders emerge. Therefore, from what base might professionals draw their power in different situations to influence others? French and Raven (1959) posit five bases of power depicted in Table 3.2: reward, coercion, legitimacy, referent, and expert.

Table 3.2 French and Raven's (1959) five bases of power illustrated with hypothetical examples relevant to the Project

Power type	Description	Hypothetical example within health service context
Reward	Ability of A to reward B	GP consortia (A) commissioning service (B)
Coercive	Ability of A to punish B	GP consortia (A) withdrawal of service contract (B)
Legitimate	Right of A to rule over B (authority)	GP End of Life lead (A) in relation to GP practices (B)
Referent	B desiring to be associated with A	Generalist services (B) working with hospice (A) to show commitment to end of life care
Expert	A having special knowledge which B does not have	Hospice doctor (A) knowledge of pain medication compared to GP (B)

Within the health and social care system, reward and coercive power bases are most obviously related to resource allocation, with either the award of a service contract or the withdrawal of one. This is particularly relevant within the new legislative and political context in which GP consortia have been given commissioning powers and social care funding has been cut. Expert power also seems relevant in this context because palliative care is a speciality which is why patients with complex problems are referred from generalist services to hospice or specialist palliative care units. Perhaps of less relevance are legitimate and referent power bases within a partnership which implies equality, though as we see in the referent example, benefits may be conferred unequally between partner organisations. However, those who can allocate funding

might be seen as the ones with the legitimate power since they can ultimately decide the fate of a service.

It is possible to see how these power bases may factor into relationships within the Project and how the relevance of each base may shift by issue. For example, community nurses may have a better understanding of access to medication within a home environment so might have authoritative power when it comes to pharmacy issues. These bases of power have been used as a basis for increasing leadership potential (Northouse, 2013). But do powerful professionals seek to lead others or do they simply dominate them? Within the conceptualizations of power for partnership working which have so far been discussed, negotiation and bargaining feature quite strongly. This implies that in the resolution of conflict there will be both leaders and followers in the sense that conflict resolution requires concessions. Leadership has been defined as “a process whereby an individual influences a group of individuals to achieve a common goal” (Northouse, 2013, pp.5). Thus power is a feature of leadership (Hollander and Offerman, 1990). Where there are indeed competing interests, leadership might come from those who can be most persuasive – this might come from their status, expertise, or charisma (Kudisch et al, 1995). In order to have leaders, one must have followers. Followers have often been conceived of as passive, dominated by those more powerful (Hollander and Offerman, 1990). But leadership is more inclusive of agency as it implies an active process of internalizing change and the interests of the organisation within followers rather than just forcing their compliance (Braynion, 2004). This is perhaps why leadership is often a strong feature in implementation strategies and the sustainability of change programmes.

3.2 Determinants in programme implementation

It has been established that programme implementation involves the purposeful enacting of an innovation(s) by actors and organisations and that the process begins with a plan, but is ultimately subject to adaptation by users and external events. In a partnership approach, it is also suggested that how this process unfolds will be determined by the interaction of the stakeholders which will be influenced by the exercise of power in decision making within the group. It is also suggested that leadership in the group may come from those with expertise in a given topic area as the goal of the partnership is to improve patient care. While the previous sections outlined the shape of the implementation process and the anticipated role that power may play in how the partnership will facilitate this process, this next section considers other factors that may influence the process. The sections will outline the factors involved in programme implementation, which draws primarily on Damschroder and colleagues (2009) Consolidated Framework for Implementation Research (CFIR) as an overarching structure. The

CFIR uses Greenhalgh and colleagues' (2004b) synthesis and conceptual model of the determinants of diffusion, dissemination and implementation as its starting point. The CFIR is meta-theoretical in that it is a synthesis of existing theories, but does not depict the relationships between the constructs. The aim of the framework and other such models is both to describe implementation and work towards generalisability, which has historically been lacking in the field. Damschroder et al (2009) argues that the salience of the framework constructs will depend on the individual case and it is therefore important to adapt it to suit the study at hand. Therefore the framework for this study draws on additional theoretical and empirical work specific to palliative care and the case of the Project to increase its specificity. The framework for the study is guided by a simple principle put forward by Greenhalgh et al (2004a) that the implementation of new interventions into working practice is contingent on attributes of the innovation itself, people using the innovation, and the context in which it is used. The aim of this section is to describe concepts which are relevant to implementation so that they may be explored empirically. These determinants are grouped under four domains: context, innovation characteristics, implementation strategies, and individual and group behaviour.

3.2.1 Context

Context is a broad term encompassing "the social, cultural, economic, political, legal, and physical environment, as well as the institutional setting, comprising various stakeholders and their interactions, and the demographic and epidemiological conditions" (Peters et al, 2013, pp. 1). As stated by Greenhalgh and colleagues (2004a), the context in which an innovation is to be used is related to its implementation. Context is important as it affects the capacity of organisations to change and the agency of individuals (McNulty and Ferlie, 2004). Context includes the external environmental conditions within which organisations exist and the organisational structures in which professionals operate. Damschroder and colleagues (2009) differentiates between two settings which make up the context: "the outer setting includes the economic, political, and social context within which an organisation resides, and the inner setting includes features of structural, political, and cultural contexts through which the implementation process will proceed" (pp. 5). They also state that boundaries between external and internal setting are not always clear, which is why they have been included here under the general domain of 'context' which refers to how the programme is situated politically, socially, culturally, economically and physically, but the conditions of each will be described separately.

External conditions

External conditions describe the plethora of determinants outside of the organisational setting which directly or indirectly affect the people and operations within an organisation. This includes

legal frameworks and national policy which gives direction to how organisations should operate and indicates the allocation of funding for publicly funded health services. This draws on the top-down model of implementation in which the conditions for implementation are to some degree set by policy-makers. External conditions, such as policies, that are congruous with the aims of a health care intervention can help facilitate implementation (Greenhalgh et al, 2009). These conditions might be seen as incentives to implement, such as when funding is allocated for a programme of work that accompanies a new policy. Such political and financial incentives likely increase the chance of implementation (Schmid, 1996), which likely means that opposite conditions may pose obstacles for implementation.

The external setting also includes the relationships that exist between organisations and the influence that they exert on each other. Relationships between organisations which are based on mutual trust, a history of collaboration and compatibility of values are more likely to facilitate change than those which are characterised by mutual suspicion, competition, and have mismatched values (Greenhalgh et al, 2009). Kanter (1988) argues that organisations that are dependent on other organisations are more likely to be constrained internally with regards to innovation development, but equally this arrangement can also lead to a greater spread of innovative activity. Essentially this is a statement about collective capacity; where dependent organisations are only innovatively enabled as far as the organisations on which they are dependent.

The configuration of a project group may play a part in influencing the willingness of partner organisations to implement innovations. Though control over a joint project may be shared in a partnership, there still must exist some type of control configuration, perhaps mutually agreed, that keeps the project group moving as a unit in a complementary direction. Lehman (1975) discusses different control configurations for coordination in health care. He argues that there are three broad patterns of control configuration: laterally linked organisations, mediated interorganisational relations and guided interorganisational relations. The most basic configuration is a feudal system whereby the organisational units are largely independent and joint decision making is sporadic. Innovation in this model is perhaps less likely to spread as a result of dependency relationships. The most integrated configuration is one which acts like a corporation; where decisions are made from above by an administrative unit external to the system. Which control configuration is apparent largely depends on what level in the system is investigated. Within a locality, service providers may have different coordination arrangements for condition-specific projects. The type of coordination arrangement is linked to the network's ability to affect change. Those that have given more control for decision making and resource

allocation to a guiding unit may be able to affect greater change because the unit is able to draw on more informational and material resources which are contributed by each member unit. Organisations that are innovative are perhaps more likely to spread innovation if they are higher up in the decision-making process than if they are dependent on organisations that are not. External conditions are clearly important in terms of enabling or constraining implementation activities that take place internally in an organisation.

Internal capacity

Internal capacity refers to the characteristics of organisations and the individuals working within that facilitate implementation. Greenhalgh et al (2004a) refers to these characteristics as “system antecedents” which includes the organisational structure, its ability to take on new knowledge, and enable change. Structures which allow organisations to work flexibly, respond rapidly to needs, and form collaborations inside and outside the project group are more likely to engage with innovations (Kanter, 1988). Indeed rigidity, particularly associated with funding arrangements and reporting regimes which is common in the NHS, reduces an organisation’s ability to adapt to fast-paced change (Greenhalgh et al, 2009; Weick and Quinn, 1999).

Organisations which are able to adapt in response to innovations or even create new structures within the organisation to handle the innovation are more likely to be successful at implementation (Rogers, 2003). Much of this internal capacity is determined by the amount of resource the organisation has at its disposal. Linton (2002) argues that slack resources enable organisations to spend more time on identifying, evaluating and implementing innovations and that slack resources are more common in large organisations.

Greenhalgh et al (2004b) concludes that external factors affect the predisposition of the organisation to implement, whereas internal conditions influence the process. The external and internal conditions which form the context for implementation are generally presented as immutable. But as previously discussed, implementation often results in mutual adaptation of the innovation and organisation which implies that the context may shift in response to an innovation as organisational characteristics are part of the context. How the context shifts and to what degree is likely dependent on the innovation and how professionals respond to it.

3.2.2 Innovation characteristics

While context refers to the conditions in which the innovation will be received, the characteristics of the innovation itself are also important in influencing how it is received and adopted. The relevance of innovation characteristics to the implementation process have been widely discussed (Damschroder et al, 2009; Gendreau et al, 1999; Greenhalgh et al, 2004a;

Linton, 2002; Rogers, 2003; Scheirer, 1983) and will be briefly summarised here. The innovation must address a perceived need or have some advantage over current working practices. Innovations which are less complex, less radical or do not involve money are easier to implement. The risk of implementing complex innovations can be minimised if it can be divided into smaller parts, widely referred to as divisibility (Greenhalgh et al, 2004b). Additionally, being able to trial the innovation or observing it in practice can help make clear the benefits to intended users. Innovations are more likely to be implemented if they are congruent or compatible with the existing organisational structure or where individuals already have some knowledge of the innovation. In health care, the quality of the evidence supporting the efficacy of the intervention may increase uptake (Grol and Grimshaw, 2003), though it has also been argued that evidence alone is not enough to galvanise change at the frontline (Ferlie et al, 2005; McKinlay, 1981; Rycroft-Malone, 2004). Even where acceptability may be high, organisations may need to adapt the innovation or organisational structure to improve compatibility with the context. As discussed previously, adaption or reinvention occurs because innovations developed in one setting or region may not transfer easily to other settings which may have different contextual components (Durlak and DuPre, 2008). Innovations which are adaptable are more likely to be implemented (Rogers, 2003). Identifying what characteristics an innovation has can then inform what processes are needed during implementation.

3.2.3 Implementation strategies

If context describes the conditions for how an innovation is received, then implementation strategies are how the innovation, actors and context are manipulated to achieve desired performance. Implementation strategies are “deliberate and purposeful efforts to improve the uptake and sustainability of treatment interventions” (Proctor et al, 2009, pp.27). They pertain to the efforts to mobilise human and material resources to effect professional behaviour change congruent to the demands of the innovation. The definition of implementation strategies is somewhat vague and can reflect individual interventions to affect change, or an overall ‘package’ of interventions which are combined to form a strategy (Proctor et al, 2009). In this thesis, ‘strategies’ are used to represent individual methods or interventions for effecting change. These techniques for implementation should be context sensitive and match the operating practices of the organisation (Calciolari and Ilinca, 2011; Kimberley and Cook, 2008). Leonard-Barton (1988) argues that the implementation strategies used are dependent on the characteristics of the innovation. Numerous strategies have been identified in the literature including: the use of champions, sponsors or opinion leaders to lead innovation use and persuade others to use the innovation (Rogers, 2003; Flodgren et al, 2011); user involvement for developing the innovation

in practice (Greenhalgh et al, 2009; Leonard-Barton, 1988); boundary spanners who are able to link the innovation to the outside world (Greenhalgh et al, 2004a); educational strategies; and audit and feedback (Grol and Grimshaw, 2003). Facilitation in making the innovation easy to use by professionals seems to be key (Rycroft-Malone, 2004). These strategies are used to help improve the receptiveness of professionals to new innovations.

The aim of implementation strategies is to normalise the new practice or innovation. Normalization Process Theory (NPT) “explains how new technologies, ways of acting, and ways of working become routinely embedded in everyday practice” (May et al, 2009, pp. 1) and is particularly relevant within health and social care contexts (May and Finch, 2009). It is a way to help conceptualise the processes that take place at the personal and operational level to enact a programme: “NPT is concerned with the social organisation of the *work* (implementation), of making practices routine elements of everyday life (embedding), and of sustaining embedded practices in their social contexts (integration)” (May and Finch, 2009, pp. 538). The process of normalization is largely concerned with issues of ‘workability’, that is individual level factors and interactions, and ‘integration’, how work fits into existing or new configurations of health services (May, 2006).

Implementation strategies encompass not just activities aimed at the individual, but also the steps taken to assimilate an innovation into the organisation’s operation. If an innovation allows, it can be divided into smaller component parts, each of which can be individually implemented. Hjern and Porter (1981) argue that the role of the hierarchy within organisations is to ensure the completion of complex tasks by subdividing them into smaller tasks which can then be assigned to different units in the organisation. Of course the hierarchy must manage the task completion and ensure that tasks assigned to the units are straightforward. The importance of information processing in organisations has been described by Galbraith (1997). The greater the uncertainty in a task, the more information must be processed in order to make it workable, which puts pressure on organisational structures, particularly the management structure which is called upon to make decisions. Task uncertainty can result in management becoming overburdened with decision making, thus leading to a slip in performance. Divisibility is therefore both an innovation characteristic as well as a management strategy, but must be overseen by the management hierarchy. However, as has been discussed previously, programme innovations are rarely carried out by isolated organisations, and therefore a task or decision made in one organisation can likely impact the whole partnership. It is perhaps appropriate to consider the affect of implementation strategies on the project group as a whole as well as to ensure the best fit between context, innovation and implementers.

3.2.4 Individual and group characteristics and behaviour

Each of the previous factors involved in the implementation process are dependent and shaped by the responses of the innovation users who are implementers (i.e. healthcare professionals) and indeed their actions are shaped by these organisational and social factors (Schmid, 1996). May (2009) argues that there is an interdependent relationship between innovations and their users. Innovations are characterized not just by their shape and form, but by the knowledge and practice that they require for implementation which in turn shapes the user. Users' behavioural responses to an innovation may depend on their existing knowledge and relationships (May, 2009) rather than on the basis of evidence, or else there would not be a gap between evidence and practice (McKinlay, 1981). Early adopters have greater awareness of the system in which they exist because they are better connected to others in their network and communicate more freely, and therefore are more exposed to new ideas making them seem less risky for adoption (Rogers, 2003). Above all, users have agency and the way they choose to act, evidence-based or not, will shape implementation (Damschroder et al, 2009). As Greenhalgh et al (2004a) states:

“people are not passive recipients of innovations ... they seek innovations, experiment with them, evaluate them, find (or fail to find) meaning in them, develop feelings (positive or negative) about them, challenge them, worry about them, complain about them, ‘work around’ them, gain experience with them, modify them to fit particular tasks, and try to improve or redesign them – often through dialogue with other users” (pp. 598).

The people involved in providing holistic palliative care is wide ranging; it requires a multidisciplinary approach (WHO, 2012), which in the UK is usually coordinated across professional groups working within and between organisations. A diverse group of professionals can prove challenging for implementation because the innovation must meet a need for a wide range of health care professions and specialisms (Ferlie et al, 2005). What appears to be missing from the CFIR (Damschroder et al, 2009) is an explicit discussion of the role of power and how this plays in the relationship between actors. This is possibly because the CFIR reflects the effectiveness of implementation within a single organisation and not across organisations where power relationships may be more overt and influence how the partnership as a whole functions.

Not only is professional behaviour important in health service implementation, but also the behaviour of the patients and their family carers. However, service users are an overlooked group within the CFIR and in implementation frameworks generally which tend to focus on professionals implementing an innovation (Wandersman et al, 2008) and not those who are the

intended beneficiaries of the innovation. Coordinating care relies on professionals and family carers who are integral in determining the care options for patients at the end of life and are an instrumental part of the ‘workforce’. Their role must be considered because while they are unlikely to improve the success of implementation, they can prohibit implementation by not altering their behaviour in congruence with the innovation being implemented. Individual behaviour is just one part of the implementation process. Innovations are implemented by networks of individuals and groups and therefore there are complex group processes taking place (May, 2009; May and Finch, 2009) which are diffused in each of the determinants discussed.

3.3 Identifying successful implementation

Implementation is one aspect of the innovation development and transfer process. It is generally accepted that routinisation signals the end of implementation (Rogers, 2003). As has been discussed, innovations and organisations undergo mutual adaptation during implementation, in which case innovations after implementation may be different to the original innovation. This raises the question of what is most important in judging the success of the implementation process: is it conformance with the intended innovation plan or performance for the intended recipient (Barrett, 2004)? Should success be judged from the viewpoint of the innovator or the innovation recipient (Kanter, 1988)? Judging success is highly subjective (Leithwood and Montgomery, 1980) and likely depends on where a person sits in the implementation process – whether developer, professional, or service user recipient. Additionally, it is also likely dependent on what type of innovation is being implemented: technology, policy, programme, or practice. Defining an end point for implementation may be easier in material innovations or practices, such as new surgical procedures or computer systems, but less so when the desired outcomes are changes in frontline clinical thinking and practice. These outcomes are less tangible and do not readily lend themselves to quantifiable measurement. Increasingly it is recognised that there are different levels of outcomes including: patient outcomes, service outcomes and implementation outcomes (Proctor et al, 2009). In health services, these outcomes are distinct, but interrelated and are considered in the following two sections.

3.3.1 Patient and service outcomes – assessment of impact

From a health service point of view, perhaps the most obvious way to view implementation success is in terms of whether it achieves its desired performance or impact. Ripley and Franklin (1982) state:

“a successful program is, centrally, that which achieves both short-run performance in accord with its objectives and longer-run impacts in accord with objectives ... It is also

one that does not have deleterious unintended consequences, although it may have beneficial unintended consequences.” (pp. 202-203)

This version of success may be difficult to evaluate as some impacts may only be detected after years, which given constant changes in healthcare innovations and professional roles, can make the establishment of reliable cause and effect difficult. Indeed in a study by McNulty and Ferlie (2004) the impact of organisational changes in a hospital were not felt by the majority of patients. Additionally, an innovation may perform well, but if it has not been implemented as planned or even fully utilized then performance should not be considered an optimal outcome (Linton, 2002). Lack of implementation which results in non-significant findings in evaluations has been referred to as a Type III error (Goodman, 2000; Durlak, 1998). A patient or service outcome assumes implementation, so while desirable from a health service point of view, does not necessarily reflect the implementation process.

3.3.2 Implementation outcomes – assessment of process

An alternative view, and increasingly preferred among implementation researchers (e.g. Proctor et al, 2009), is to identify *implementation outcomes* which are indicative of the process, but do not indicate patient or service effects. Proctor and colleagues (2009) argue that implementation research should have “outcomes that are conceptually and empirically distinct from those of service and treatment effectiveness” (pp.30). Essentially, these outcomes reflect the *degree* of implementation. They are reflective of the implementation process in that “implementation processes are the sequences of organisational changes and support mechanisms that account for the degree of implementation found at a given time” (Scheirer and Rezmovic, 1983, pp. 601). Proctor and colleagues (2011) propose eight outcomes on which to assess implementation which are described in Table 3.3: acceptability, adoption, appropriateness, costs, feasibility, fidelity, penetration and sustainability.

Table 3.3 Proctor et al (2011) implementation outcomes and definitions

Outcome	Definition
Acceptability	Perception that the innovation is agreeable, palatable or satisfactory
Adoption	Intention, initial decision or action to try and employ the innovation
Appropriateness	Perceived fit, relevance or compatibility of the innovation for the setting or individual
Feasibility	Extent to which an innovation can be successfully used or carried out
Fidelity	Degree to which an innovation was implemented as prescribed or intended
Cost	Cost impact of an implementation effort
Penetration	Integration of an innovation within a setting, similar to 'reach' or 'coverage'
Sustainability	Extent to which an innovation is maintained or institutionalised

Such an assessment is necessary to ensure any patient or service outcomes achieved by the innovation or intervention can be attributed to the implementation of the programme (Scheirer and Rezmovic, 1983). Some of the outcomes, such as acceptability or appropriateness, seem more like characteristics of the innovation rather than an outcome, but Proctor and colleagues (2011) argue that implementation strategies could be used to increase acceptability of the innovation and therefore would be used as an outcome measure of that strategy.

3.4 Conclusions and conceptual framework

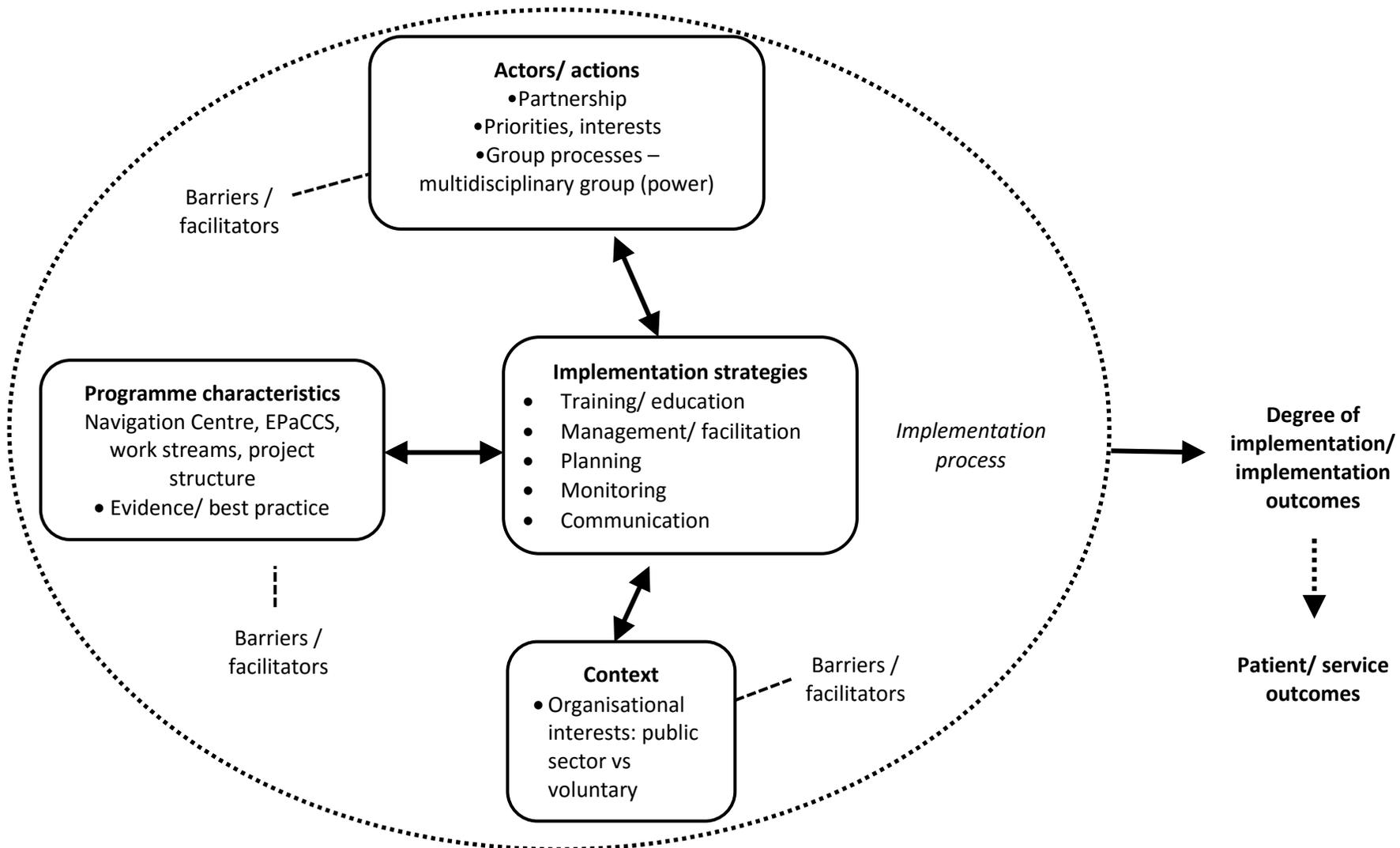
The previous chapter argued that implementation in palliative care is distinct because such services are by their nature multidisciplinary and deal with death which itself can present a number of unique challenges. Change in palliative care services seems to be brought about either by a desire to implement a new innovation which has established efficacy or is based on best practice, or because a need is identified for which an innovation is developed. There was found to be a lack of evidence regarding the impact of care navigation and likewise evidence of Electronic Palliative Care Coordination Systems (EPaCCS) is only emerging, but in electronic health records more widely, such change is seen to require a culture shift. To embed these innovations implementation strategies are thus used to initiate and sustain practice. There was found to be a lack of exploration of how this process unfolds and what implementation outcomes are forthcoming.

This chapter has looked more widely at implementation from the theoretical literature and empirical syntheses which have modelled implementation. The implementation process has been seen to take two distinct shapes: linear, staged models, and non-linear, negotiated models. It was argued that a balanced view of implementation might incorporate aspects of both in a largely non-linear process that may become more linear as learning occurs and changes are made dealing with unanticipated events. It was also argued that innovations in health services are often implemented by multiple actors or organisations, although the way they work together could range from formal hierarchies of control to informal configurations based on mutual benefit. A number of factors at play during implementation were then discussed, grouped under four domains of context, innovation characteristics, implementation strategies, and individual and group behaviour. These factors were judged to be interdependent, and ultimately subject to the behaviour of actors. While routinisation might be viewed as the end of implementation, it was contested that determining success in the health service context would be viewed in two ways. First, it was suggested that patient or service outcomes for determining programme success is essential in health services as ultimately the impact on service users should be evaluated. However, it was also argued that such outcomes do not necessarily reflect the implementation process and thus there are a separate set of intermediate outcomes which focus on implementation. However, a successful process that leads to implementation outcomes, but not change in patient or service outcomes is unlikely to be viewed positively by the NHS and therefore it seems reasonable that both criteria are considered when determining implementation success because there seems little point in implementing something successfully if it has no meaningful impact on service users.

The conceptual framework for the study aims to reflect the specifics of the programme being implemented (Parsons, 1995). The Project which serves as the case for the study involved the coordination of care through a number of innovations employed by a project group made of professionals representing various organisations. The framework aims to capture the implementation process at the project level even though there are likely to be processes happening at macro, meso and micro levels (Morgan G, 1997). The conceptual framework (Figure 3.3) shows how each of the concepts are expected to link to each other and produce implementation outcomes. The implementation process is captured within the large dotted sphere. Reflecting the concept of implementation as a planned process, the focal point here is the implementation strategies which are expected to create the change that will lead to outcomes. For example, if the framework is able to explain implementation then training and education (strategy) of the benefits of the EPaCCS (innovation) will lead to higher numbers of

patients being added to the system (implementation outcome). However, the effectiveness of these strategies will be mediated by actors and their actions who may engage differentially with the strategies based on their priorities or interests and power relationships may influence the way the group as a whole interact. Likewise, strategies are determined by the characteristics of the project; for example the opening of the Navigation Centre will likely require a communication strategy to encourage patients and professionals to call (implementation outcome). Context will also influence how and what strategies are used; for example some organisations, such as the Hospice, may be very experienced in end of life care planning and therefore require little facilitated training. Each of these elements are also expected to be mediated by different barriers and facilitators.

Figure 3.3 Conceptual framework of the implementation process for the Project



Using this framework, this study will address three broad questions:

1. What is the shape of the implementation process?
2. What influences the implementation process?
3. How and to what effect are strategies used to produce implementation outcomes?

4 Methods

Introduction

The previous chapters have discussed the state of implementation research and theory with particular focus on palliative care and health services. The implementation process has been characterised as having linear beginnings due to planning, but that the process becomes non-linear as it becomes influenced by unexpected events and actions which lead to negotiation. At the core of implementation are social processes in which people act on information and events, though conditions can be somewhat manipulated to affect these processes. Studying implementation thus involves developing a rich picture of actor, organisation, context and process.

This chapter will describe the methods that will be used to explore programme implementation. The aim of this thesis is to identify how a complex health service programme is introduced, implemented, and what outcomes are produced. A number of research questions will be used to guide the study:

1. What is the shape of the implementation process?
2. What influences the implementation process?
3. How and to what effect are implementation strategies used to produce implementation outcomes?

Implementation will be explored using the Project, which was described in chapter 1, as its case. There are three important characteristics about the programme and the researcher's relationship to it which had an impact on feasible, robust research designs. Firstly, as demonstrated in the literature review in chapter two, not all elements of the programme were evidence-based, and certainly there were no known examples of the programme configuration with which to draw comparisons. Therefore, this is not a study of the translation of evidence into practice, but rather a practical example of how well-intentioned programmes might achieve their aims. Second, the programme and its implementation were not open to manipulation by the researcher; instead implementation was studied as an independent observer in a form of natural experiment. Lastly, the programme itself is complex as it has multiple components targeted at various organisational levels which are likely to have different effects based on different settings and groups.

4.1 Research design and method

This section will describe the methods and underpinning rationale for the study. It will begin by summarising and critiquing the methods of studies discussed in the previous chapters to determine an appropriate method for this study.

4.1.1 An 'ideal' design and review of implementation research methods

Considering the discussion from chapters two and three, an ideal design for studying implementation would have a number of defining features. Firstly, it would be prospective to capture challenges, decision making and actions as they happen thus eliminating the potential bias that comes from reflecting on either a successful or failed programme. Observation would begin at the planning stage and continue through to full implementation and sustainment, thus indicating a longitudinal design. Second, the design should use qualitative methods to capture the views of both professionals and managers implementing the programme to understand how they make sense of it and integrate changes into their work, and the views of service users to understand how they engage with the changes being implemented to have a rounded view to how service changes become embedded. It should use quantitative and qualitative measures of implementation and service user outcomes to understand the impact of the process. Lastly, it should observe how strategies are used in real life, particularly in light of any contextual changes that are likely to arise and therefore how the programme adapts. Programmes should not be viewed in isolation (Schmid, 1996) particularly as it might be the interaction between the innovation and context which determines outcomes (Datta and Petticrew, 2013). These features suggest an explanatory, mixed methods design.

How does this 'ideal' design fit with the designs of studies identified in the literature? Chapter two briefly highlighted some of the methodological issues with the study of implementation in palliative care; namely that it is dominated by qualitative approaches and that a lack of clarity of the definition of implementation has resulted in studies not clearly distinguishing one concept of interest from others. The studies considered in chapter two can be broadly categorised based on the core aim of the study. As such, four categories emerge: assessment of the process (e.g. Della Penna et al, 2009; Di Leo et al, 2014; Vahedi Nikbakht-Van de Sande et al, 2014), examination of the barriers and facilitators to implementation (e.g. Hall et al, 2012; Davis et al, 2006; Jackson, 2000), a formative evaluation to influence the process (e.g. Dudgeon et al, 2009; Miake-Lye et al, 2011; Tolson et al, 2007), and an assessment of implementation outcomes and/or patient or service outcomes (e.g. Mirando et al, 2005; Teunnison et al, 2007; Smith et al, 2012). This is not to say that a study of process does not also consider barriers and facilitators or what outcomes

are achieved, but rather these categories indicate the primary purpose of the study. Only the formative evaluations and one evaluation of process assessed implementation prospectively, the remainder of the studies were retrospective in that the process was studied after the innovation or programme had been implemented. However, even in prospective studies there is still an element of retrospection in that actions are the result of past events, but they also capture action in preparation for future expectations, whereas retrospective studies would only capture the former. Analysing the implementation process would be enhanced by a prospective design so that an assessment of outcomes can be linked to the process and to capture predictive decision making and not just rationalised decision making *post hoc*.

Studies on process and barriers and facilitators have been dominated by qualitative methods, namely interviews in the case of retrospective designs. The rationale for this is that implementation is seen as a process led by people and therefore their perceptions of what happened and why is of interest. Studies of outcomes have been dominated by quantitative designs such as counting the number of new records on an electronic system (Smith et al, 2012) or the number of instances that a 'Do not resuscitate' order has been recorded in patient notes (Mirando et al, 2005). Rarely do the two seem to be combined in the sense of asking professionals what led them (qualitative) to increase the number of times they recorded resuscitation orders (quantitative).

As suggested in chapter two, the literature specific to implementation in palliative care is somewhat limited, but there are examples of more advanced study designs in health care more widely and indeed other fields of study from education to agriculture (Greenhalgh et al, 2004b). Table 4.1 shows that the concept of 'implementation' as a focus of study is drawn from a range of fields each developed independently over time, though more recently cross-fertilization of concepts has occurred (e.g. Greenhalgh et al, 2004b). Likewise, methodologies for studying implementation have expanded from process evaluations, to implementation research and more recently implementation science which aims to standardise implementation and develop evidence-based strategies (Demiris et al, 2013; NIH, 2013). The studies considered thus far fall under the top two categories of process evaluation and implementation research. They are characterised largely by a naturalistic approach in which the process or influences are observed and explored as they unfold. Implementation science is more concerned with experimenting with implementation strategies to see which produce the greatest effect for the implementation of evidence-based innovations (NIH, 2013). This implies some kind of involvement or manipulation of the implementation process and is only feasible if evaluators are integral to the

implementation team. This is a different focus to studying implementation to what is proposed in this thesis and is therefore not a particularly relevant design for this study.

Table 4.1 Overview of implementation research, how different areas of study are conceptually linked

Paradigm / tradition	Concept	Methodology <i>Characteristics</i>	Focus of study
Cognitive psychology Social networks Diffusion of innovations Organisational studies	Implementation	Process evaluation <i>Descriptive, explanatory</i>	Explore process to understand patient outcomes
		Implementation research <i>Naturalistic, case study</i>	Explore process to identify implementation outcomes
		Implementation science <i>Positivist, hypothesis testing, frameworks</i>	Implementation strategy effect

Studying the implementation process has been equated with process evaluation as implementing is fundamentally about processes (McGraw et al, 1989). McGraw and colleagues (1989) also argue that the aim of process evaluation is to identify the causal mechanisms that explain success or failure, assess generalizability and enhance the design of outcome evaluations by identifying intervening variables. More recently, realistic evaluation (Pawson and Tilley, 1997) has been used as an approach for studying the process and identifying the mechanisms that lead to change (e.g. Greenhalgh et al, 2009; Tolson et al, 2007). Realistic evaluation is a theory-driven approach to explain what mechanisms lead to which outcomes in different contexts. It is an attractive approach to the study of implementation because one might conceptualise implementation strategies as mechanisms and therefore look at what outcomes they produce. However, a number of authors provide a cautionary tale in its use (Tolson et al, 2007; Greenhalgh et al, 2009; Byng et al, 2008). Previous studies which have adopted a realist approach have indicated that it can be difficult and even artificial to differentiate between context and mechanism (Greenhalgh et al, 2009; Byng et al, 2008). Byng et al (2008) state that “realistic evaluation is a useful tool but the principles should be flexibly not slavishly adhered to” (pp. 8). Additionally, realistic evaluation is often combined with case study methodology (Harris et al, 2013; Rycroft-Malone et al, 2010), likely because realistic evaluation does not guide the user towards any analytical strategy and is at best vague about how to refine theories. Realistic evaluation as a methodology for uncovering process may be ideal, but is perhaps not pragmatic for a researcher working by herself. Additionally, the programme under investigation in this thesis is broad, encompassing development and implementation and therefore a less restrictive approach is perhaps necessary.

4.1.2 Research method

The design and methods for the study were driven by the research questions (Snape and Spencer, 2003). To that end it is worth considering some of the key features of these questions and what this indicates in terms of method. The key focus of this study is on the characterisation of the implementation process, what shapes it and what outcomes it produces. This emphasis on process, which is inherently complex as the previous chapters discussed, indicates a need for a primarily qualitative approach to inquiry to describe and explain what is happening and how the process is influenced (Ritchie, 2003). The implementation process of complex programmes has been characterised as changing and non-linear, and therefore research designs need to be able to observe these changes indicating an iterative, longitudinal element to the design (Peters et al, 2013). Thus this study adopted a naturalistic and pragmatic approach to understand and interpret the implementation process as it unfolded (Hammersley and Atkinson, 2007).

This study followed the pragmatic approach to research espoused by Snape and Spencer (2003) who advocate a 'researcher's toolkit' in which methods are drawn on for their applicability to the researcher's question rather than their epistemological stance. This reflects an applied approach which produces "qualitative evidence that has been rigorously collected and analysed, is valid, able to support wider inference, as neutral and unbiased as possible and clearly defensible in terms of how interpretations have been reached" (Snape and Spencer, 2003, pp. 19). Their approach stems from the ontological position of 'subtle realism' (Hammersley, 1992) in which they argue that while there is an independent reality, it can only be accessed through respondent interpretations and that differing perspectives do not deny the existence of an external reality, but rather that reality is itself diverse and multifaceted. This diversity is seen to add to our ability to understand the complexity of reality. Such a view lends itself a pluralistic approach to methods to gather evidence relevant to the conceptual framework to ensure that data collection was focused around the questions of interest. Data was collected using largely ethnographic methods (e.g. observation, interview, document analysis) to capture the flow of the process (Hammersley and Atkinson, 2007). Multiple qualitative and quantitative methods (described in subsequent sections) were used to exploit the strengths of each method and to minimise inherent weaknesses (Miller, 2003). The study also employed inductive and deductive approaches as part of an iterative analysis process (Ritchie and Spencer, 1994). A deductive approach is relevant because the study starts with preconceived notions of what implementation involves, which was outlined in the conceptual framework while at the same time inductively looking for any new phenomena, concepts or explanations not represented in the conceptual framework (Ritchie and Spencer, 1994). In line with Snape and Spencer's (2003) pragmatic approach, findings are reported at an abstracted level (rather than using participant language verbatim), so that it is understood by readers and contribute towards our understanding of implementation using existing terminology rather than adding to the already expansive implementation thesaurus.

The design of this study is described as a prospective longitudinal and primarily qualitative mixed methods study using a pragmatic approach to inquiry. The previous section exploring an ideal study described a design with many of the same features as the one used in this study, namely that it is primarily qualitative, collects data at multiple time points and emphasises explanation of a natural process. The pragmatic, pluralist approach in this study has clear similarities to case study research (Keen, 2006; Yin, 2009) and indeed at first glance this study might be classed as a case study. However, 'case study' as a method is often perceived by the reader as suggesting a number of assumptions which were not applicable here (Yin, 2009; Lewis, 2003; Flyvbjerg, 2006) and therefore it was decided to focus on describing the rationale and methods of the study

rather than label it with a particular term which is often misconstrued. Case study research, and the methods in this study, both focus in depth on a contemporary phenomenon (implementation process) within a specific context using multiple perspectives (Yin, 2009; Lewis, 2003). However, case studies have been criticised for lacking distinction (Lewis, 2003) which perhaps stems from the fact that descriptions of case study are often seemingly devoid of a theory of method (Keen, 2006; Yin, 2009). In contrast, Snape and Spencer are explicit with the epistemic foundations of their pragmatic research approach and therefore conceptually it can be easier to make the link from ontological foundation through to method which for some researchers may make carrying out the research easier. This study was strongly driven by *a priori* notions of implementation described in the conceptual framework indicating a more deductive approach which is suited to a pragmatic, applied methodology than the more exploratory nature of case study research (Keen, 2006). For case studies, many decisions need to be made up front, such as the boundaries of the case, who to interview and a clear understanding of context prior to the start (Lewis, 2003), which was not entirely achievable in this case and could be seen to be incompatible with a longitudinal design in which context and key actors change over time. For this study it seemed appropriate to adopt a more ethnographic approach to follow the process which would reveal actors who could provide the most insight to avoid collecting unnecessary data. There are also perceived differences in terms of the conduct of case studies versus more ethnographic approaches; case studies are associated with shorter, more focused studies whereas ethnographies are associated with longer research studies with broader questions (Hays, 2004). There are many similarities and subtle differences between case study research and the methods in this study, but case study is associated with some assumptions regarding the conduct of research which would be misleading here.

The previous section also suggested that realistic evaluation might provide insight in terms of exploring 'mechanisms' of the social processes at play (Pawson and Tilley, 1997). This depth of understanding is not proposed in the method described here because of the practical issues present in the current case; specifically that this study is to be carried out by a single researcher and therefore the discussion and consensus process which forms a part of realist evaluation is impractical. Additionally, the vagaries of the programme which involves development, adoption and implementation processes hint that the process will not be straightforward and therefore a more fluid design which can respond to the process, as suggested by Peters et al (2013), may be more practical than one which is focused on seeking out causal mechanisms.

4.1.3 Data collection methods

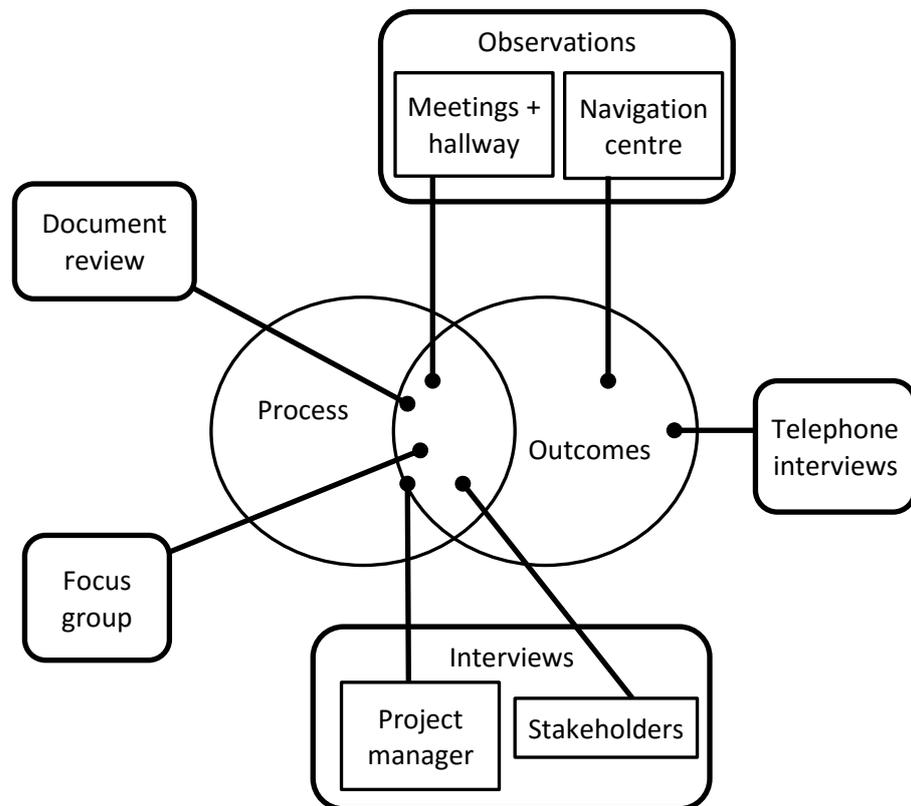
This next section describes in detail the data collection methods which were used in the study. The methods were aimed at collecting data from multiple sources at the programme level which encompassed individuals at different organisational levels. Capturing data at different levels reflects the concept of implementation structures which is to say that implementation takes place at various organisational and individual levels (Hjern and Porter, 1981). To that end five data collection methods were selected: participant observation, interviews, semi-structured telephone interviews, focus group, and document review.

A scoping exercise was undertaken at the start of the study to determine appropriate data sources, arrange access and refine tools for collection (Hammersley and Atkinson, 2007). The scoping process and key ways that it informed data collection are summarised here. The scoping period began with an informal interview with the project manager which indicated that attendance at the Executive Project Board and Project Delivery Group meetings would provide the best overview of the implementation process and its management. Subsequently, the researcher attended one meeting for each of the groups to determine what data could be captured via observation. This exercise indicated that little action was to be observed, but rather elements of the conversation (e.g. topics, tone, body language, contributors, group dynamic etc) and decision making would be of interest. Thus the tool for observing the project meetings was designed to capture the flow of the conversation, reactions of attendees and researcher reflections. The researcher also observed the Navigation Centre operation once it had opened. The activity here indicated that the flow of calls, how they were handled and how advice was given would be of interest, as well as that these actions would vary at different times of the day and week. It was also clear from the interview with the project manager that regular interviews with the project manager would be the most pragmatic way to stay abreast of all project activity and would help with arranging access to project documents, the Navigation Centre and any other project activity.

Data collection was thus guided by the implementation process which is reflective of an ethnographic approach, rather than be rigidly prescribed at the outset (Hammersley and Atkinson, 2007). Data collected longitudinally can also be used to identify patterns as they emerge over time (Spyridonidis, 2010); in this case data was collected repeatedly over time from the same groups of people. The following types of data were collected and are mapped out in relation to relevance to the implementation process and outcomes in Figure 4.1: documents, observation notes, structured data and notes from interviews, and transcripts from interviews and a focus group. Data was collected continuously over two years rather than at set

predetermined time points (e.g. six monthly) as these would have been arbitrary time points in the programme and may not have captured nuanced key decisions or contextual factors that occurred throughout the implementation process. Each data type and the methods for collection are summarised in the following sections following guidance by Mays and Pope (2006) on quality in qualitative research. Each section describes how data was handled in the pathway to analysis and the full analysis process is described in section 4.1.5.

Figure 4.1 Data collection in relation to implementation process and outcomes



Ethnographic observation

Observational methods are useful when the aim is to capture social interactions in a naturally occurring setting (Bowling, 2005) as would be the case in a study of implementation. Observation enabled discussion, decision-making processes and group interaction to be studied naturally (Lee, 2000). What should be clear through observation is how implementers respond to issues as they arise over time. The fact that the observer's role was participatory rather than non-participatory was for both practical reasons and data quality control. An evaluation of the implementation process was a part of the Project funding and therefore was accepted by those involved in the Project. At times the researcher was asked to report on study progress and while this was usually

just a description of work to date, some feedback might have been influential to the implementation process. For example, the researcher commented that identifying the impact of the Navigation Centre was difficult because callers to the service were greeted as though they had called the Hospice and not the Navigation Centre. Where the researcher's participation may have influenced the implementation process is reflected in the data presentation in subsequent chapters. Responding to questions and engaging as a natural, though largely silent, group member helped to minimise the reactive effect of the observer (Bowling, 2005). Additionally, many of those observed were acquainted with the researcher which enhanced acceptability among the group. The researcher's presence was explained at the start of each meeting or observational visit and those present were asked for verbal consent for observation. Being explicit about the purpose of the researcher's presence also allowed the researcher to ask those being observed to clarify any confusing observations, which was particularly important given that the researcher is not trained in nursing or medicine, nor entirely conversant in the plethora of regulatory jargon associated with commissioning and service delivery. It is likely that attendees would have become habituated to the researcher's presence over time (Lee, 2000).

Observation has some obvious benefits to which have already been alluded, particularly for the study of implementation (King et al, 1987). In a health service setting, to carry out observations only requires the approval of a gatekeeper, in this case the Hospice where the programme was based rather than consenting numerous individuals as in interviews (Liamputtong and Ezzy, 2005). Observation also allows data to be collected on a range of behaviours and activities (Morgan DL, 1997). However, observation is a highly interpretive activity with the researcher placing meaning on actions and thus observations may reflect the researcher's perspective rather than those being observed (Liamputtong and Ezzy, 2005). To reduce the bias that this might introduce, observations and understanding of discussions were summarised and fed back at the end of meetings to participants so they could confirm or contest the accuracy of the observations; Navigation Centre call handlers (care navigators) were asked to explain any confusing observations (Hammersley and Atkinson, 2007).

Sample and access

Observations were carried out in a variety of environments. First, Project Delivery Group and Executive Project Board meetings were selected for observation to capture discussions, decision-making processes and actions of those responsible for managing implementation at a cross-organisational level. The membership of both groups included all partners and specifically senior members of the organisations involved in service delivery which were affected by the programme. The Project Delivery Group planned to meet monthly and the Executive Project

Board had planned quarterly meetings. Observations continued as long as the groups met. Access to both groups was arranged through a senior Project member. Work stream meetings were not observed because it would not have been feasible for the researcher to attend all of the meetings simultaneously and it was decided in consultation with the project manager that a good overview of work stream activity could be achieved through attending the Project Delivery Group meetings. A second set of observations came from the Navigation Centre (NC). The aim of these observations was to understand the day to day running and activities of a key component of the Project, in order to get an 'on the ground' view of programme implementation. After the first scoping visit, it was decided that the NC would be observed on one occasion with follow-up observation visits as necessary until the point of data saturation. In total there were four visits (including one scoping visit) carried out at different times and days of the week. Access to the NC was arranged through the NC manager. The third set of observations is of training sessions, such as software training at GP surgeries and the Hospice. These were not originally part of the planned dataset determined after the scoping exercise, but were identified as relevant to the study as implementation unfolded as these were opportunities to meeting observations.

Tools and data representation for analysis

Preliminary tools for data collection for the project meetings and Navigation Centre (NC) site visits were refined after the scoping observations in order to consistently record actions and dialogue of interest in each setting bearing in mind the limitations of a single researcher working alone (Hammersley and Atkinson, 2007; Bowling, 2005). This constitutes the first stage of analysis, data reduction, in that only selected observations were to be recorded (Miles and Huberman, 1994). A form was created to ensure each observational visit recorded a minimum amount of information regarding time and date, people present and room characteristics (Appendix 2). Short field notes were written up either by hand or typed into a Microsoft Word document using a laptop during observation. Notes distinguished between value-free observations and the researcher's interpretations, thoughts, questions and feelings. The notes were then expanded to full sentences with additional reflections added for analysis the same day or the day after while the memory was fresh (Miles and Huberman, 1994; Hammersley and Atkinson, 2007). Observations became more focussed over time as it became apparent that certain topics or actors were particularly influential in the implementation process, a common feature of ethnographic research known as 'funneling' (Hammersley and Atkinson, 2007). Familiarity with the researcher and the engrossing nature of meetings and Navigation Centre activity were thought to minimise any reactive effect that the researcher's presence may have had on normal behaviour and therefore no data was discarded (Lee, 2000).

Data collected during the meetings aimed to understand how decisions were made and general feelings among the group and therefore included: who was present, discussion, flow of dialogue, body language and tone of speech. Additional contextual details for the meeting included length, location, agenda items and papers presented for discussion. Discussion notes were written as they occurred with direct quotes indicated with double quotation marks (e.g. says it has been “fraught with disaster”); observed body language or notable actions were indicated with < > within the flow of discussion (e.g. they are unlikely to want to put patients on [the ambulance system] too <she laughed at the thought>). Occasions where unsolicited ‘hallway’ interviews took place were documented at the end of the planned observation notes. Upon returning to the office after such encounters, notes and thoughts were typed up as a narrative.

Data collected for the Navigation Centre (NC) aimed to build a picture of functional activities. Notes were recorded by hand or using a laptop on the set up of the room, staff present, frequency of calls, how calls were handled and general operations, and interaction between call centre staff or other hospice staff. Because activity was computer and phone based, not all activity could be readily observed; e.g. a phone call resulting in the care navigator sending an email to someone using the computer based phone system. Therefore, the researcher asked questions of the care navigators during quieter periods to understand what they were doing and why. Impressions of activity were also recorded in the notes. Notes were analysed in terms of activity, particularly barriers and enablers to work.

Any additional notable events that happened over the course of the Project were journaled in a Microsoft Excel spreadsheet which was used to provide a timeline of events for context to be used during analysis. The analysis process for all methods will be described in section 4.1.5.

Interviews

In keeping with a pragmatic, ethnographic approach to research (Snape and Spencer, 2003), interviews were used as a direct means of understanding the meaning that actors attribute to actions within the implementation process (Legard et al, 2003). Interviews are useful when the aim is to capture people’s understandings of their own experiences and their interpretation of events, and it is likely for this reason that they are commonly used in implementation research (e.g. Vahedi Nikbakht-Van de Sande et al, 2014; Della Penna et al, 2009; Hall et al, 2012; Tolson et al, 2007; Greenhalgh et al, 2009). However, interviews also suffer from some potential weaknesses. Participants may try to represent themselves in a socially desirable way to the researcher by over-reporting what they perceive to be favourable behaviours (Lee, 2000). Another bias common to interviews is that the interviewer is a co-participant who is involved in

shaping the participant's responses (Liamputtong and Ezzy, 2005). However, interviews complimented the ethnographic observations because whereas observations can reflect the researcher's interpretations of events, interviews allow people to explain their own interpretations of those events and observations informed the interview questions. Interviews followed a semi-structured, conversational approach in which the conceptual framework gave structure to the conversation, but discussions were fluid and flexible to adapt to the participant's ideas as it is assumed that not all relevant questions can be known prior to the research (Liamputtong and Ezzy, 2005).

Sample and access

Sample selection was purposive with the aim of identifying critical informants who would have key insights about the implementation process specific to their organisation or role in the project (Ritchie et al, 2003a). Thus interviews were a practical approach to gaining insights from a variety of individuals whose senior position within their respective organisations would have made other forms of data collection difficult (Mason, 2002). Interviews were carried out with stakeholders involved in implementing the programme, including Project Delivery Group and Executive Project Board members. The project manager, who was later replaced by a director at the Hospice, was a key source of information and provided more of an 'informant' role than participant (Yin, 2009). Access to participants was assisted by a senior project leader, as with the observations above.

Tools and data representation for analysis

Prior to each interview a topic guide and specific questions (Appendix 3) were produced based on insights from previously collected data. Thus interview tools were iteratively developed so that each interview could enhance understanding, interpretation and validation of other sources of data (Miles and Huberman, 1994). The topic guide was used to ensure coverage of the concepts identified in the conceptual framework while at the same time allowing for a conversational interview approach. Recorded interviews were transcribed in smooth verbatim (i.e. all dialogue but excluding pauses, ums, ahs, etc) (Franklin Square, n.d.) by a transcriber for analysis. Any additional thoughts or notes were typed up immediately following the interview and added to the transcript once prepared. Each transcript was read through a first time whilst listening to the audio to check for transcribing accuracy prior to coding. Transcripts were coded (described in 4.2.5) whilst listening to the audio as the richness of the data is in as much as what people say as how they say it.

Focus group

A focus group was conducted with the Navigation Centre care navigators in order to understand the day to day operation of running the service. The focus group was conducted after all observation visits had taken place and following a review of documentation on call records so that this information could provide the basis for discussion with the care navigators. The use of the focus group method was to supplement data from the observations and document review to verify or refute the researcher's interpretations of events and to understand the care navigators' experiences of observed events (Morgan DL, 1997). The focus group provided clarity about how situations were generally handled by staff and where practices differed which was easier to capture as a result of the group interaction rather than probing each person's experience in-depth as group processes help members to interpret and clarify their own views (Liamputtong and Ezzy, 2005). Focus groups are also useful when trying to elicit information about routine or habitual activity (Morgan DL, 1997), as individually the care navigators may have had little to say about their routine, but a group environment may provoke people to think differently about what they do and why. Focus groups are also more efficient than numerous one to one interviews and allow the researcher to collect a large amount of data in a limited amount of time (Morgan DL, 1997). However, group interaction requires control from the researcher to keep the group on topic, which can create a somewhat artificial environment as compared to observation (Morgan DL, 1997). Focus groups tend not to be used with a diverse group of informants in order to elicit their shared experiences (Kitzinger, 2006).

Sample and access

The focus group consisted of a homogenous group of only care navigators, though it aimed to include people who worked different shift patterns as the observations indicated that Navigation Centre activity differed from day to night, weekday to weekend. The focus group took place towards the end of the two year project period after a sustained period of implementation to ensure that care navigators had sufficient experience to comment on the Centre's operation. Access to the care navigators and a suitable location for the focus group was arranged via the Navigation Centre manager.

Tools and data representation for analysis

Preparation of the topic guide (Appendix 3) and transcript was similar to that of the interviews. The topic guide was developed following an analysis of call records and after the observation visits to the Navigation Centre previously described so that care navigators could respond to and potentially explain any unclear observations or findings from the call records. The focus group was transcribed in smooth verbatim by a transcriber and alternated by speaker. Any additional

thoughts or notes were written up immediately following the focus group and added to the transcript once prepared. The transcript was read through whilst listening to the audio to check for transcribing accuracy which was particularly important given that there were multiple speakers to distinguish between. Transcripts were coded whilst listening to the audio as with the interviews.

Content Analysis of Documents

Document reviews are a commonly used unobtrusive method when evaluating implementation because written project documents often indicate what was meant to happen, expected milestones and service data (Greenhalgh et al, 2009; Willis et al, 2012). It has been argued that implementation usually begins with a plan which is written down, and thus it seems reasonable that to understand the implementation process the researcher must first be familiar with these plans. The benefit of document reviews is that they are relatively easy to access as only permission from project management needs to be granted to access files. Compared to interviews, document reviews rely on researcher interpretation to ascribe meaning and construct data (Denzin and Lincoln, 2003), whereas interviews allow participants to interpret of their own actions. However, it could also be argued that the information contained in texts has been selected and edited by the writer for a particular purpose and so contains the writer's interpretation, thus the researcher must read between the lines (Yin, 2009.) Documents were used in conjunction with interviews and observations which provides balance to interpretation.

Sample and access

All of the project documents were downloaded from project computer files at the start of the study (August 2012) and again at the end (March 2014). Additional documents (e.g. meeting minutes, audits, communications) were collected as they were disseminated throughout the project period. All documents were collected and archived because it was not clear which documents would be of value until they could be assessed for relevance (Hammersley and Atkinson, 2007).

Data representation for analysis

The format and quality of the documents for coding varied. Some documents had a narrative structure and could be coded like a transcript. Others were heavily numeric, such as audits, or were shorthand notes which were difficult to interpret without context and therefore not suitable for coding. These documents were first analysed for their content and summary notes were produced to facilitate coding (Miles and Huberman, 1994). The summary notes reflected not just the content of the document, but also any notable features which might provide insight

into implementation. For example, meeting minutes appeared to be a poor record of the meeting when compared to observations; salient points were usually recorded as well as any actions, but they did not include much detail. Previously completed actions often appeared on meeting minutes as though they were keeping track of tasks completed rather than an account of the meeting. Additionally, they were sometimes inaccurate with names misspelled or an incorrect list of attendees. Therefore while the meeting minutes did not provide much insight into project progress because of their lack of detail, their quality was interpreted as an indication of the value that the project manager placed on meeting minutes, specifically that they were not viewed as a priority among other project tasks which is why little consideration was given to them.

Of the set of documents included in analysis, the monitoring documents served two purposes. Firstly, the data contained in them contributed to the data on implementation outcomes and project outcomes. The Project employed a data manager whose role was to collect and analyse patient data. Pragmatically it made sense to incorporate this data in this study of implementation rather than attempt to seek out the same data separately. To that end, the researcher consulted with the data manager on what data should be collected and how. Secondly, the monitoring documents were also analysed in terms of what their existence and general content indicated about the implementation process. For example, the Navigation Centre call records audit was analysed to understand implementation outcomes, but also was considered for its implications in whether or not it influenced the actions of individuals in the implementation process.

Telephone interviews

The above methods captured the implementation process from the implementer point of view, but as described in the previous chapter and represented in the conceptual framework, the implementation process is also influenced by the actions of service users. This is particularly true with regards to the Navigation Centre as it is their use which will largely determine how it is implemented in practice. Fortnightly telephone interviews comprised of structured and open-ended questions were carried out with family carers to understand how service users engaged with the Navigation Centre and health and social care services. It was also considered whether service users could contribute to understanding the influence of the EPaCCS on helping to coordinate care. A study by Hall and colleagues (2012) similarly attempted to interview patients regarding their views of an electronic palliative summary system. However, they found that patients and carers were “largely unfamiliar with the technicalities of the [electronic Palliative Care Summaries]” (Hall et al, 2012, pp. 578) which limited the usefulness of the data collected. Therefore, it was decided to only ask service users to reflect on what services they used and their

experience as a whole, rather than asking them to try to comment on something that would be happening ‘behind the scenes’.

This sequential interviewing process was selected for methodological and practical reasons. Firstly, the interviews aimed at understanding patient service utilisation, but the poor health of this patient group means that it is impractical to interview patients and therefore interviews were conducted with family carers. Carrying out the telephone interviews fortnightly allowed for a relatively short recall period, but not so frequent as to overburden the carer (Guerriere et al, 2010). Additionally, the researcher’s prior experience of conducting interviews several months post bereavement suggested that bereaved carers have the benefit of retrospection; they have had time to reflect on their experience as a whole and may rationalise their experiences or views which might not accurately represent their immediate reactions. Therefore conducting sequential telephone interviews whilst the patient was alive, but with minimum burden on carer recall appeared the best way to understand patient use of services in ‘real time’.

Sample and access

Potential participant carers were identified by the hospice data manager or GP practice manager who had permission to view patient identifiable data from the EPaCCS as they were newly added to the system between August 2012 and February 2014. Where no carer was listed in the records, a letter was sent to the patient asking to identify a carer. Telephone interviews were carried out at the convenience of the participant and were at all times guided by sensitivity to the carer’s needs, which often meant that interviews had to be rescheduled and some carers withdrew from the study. Interviews were carried out until: the patient died, the end of the study period, or six interviews (approximately 10 weeks) had been completed with the carer as it was advised by the hospice director that more than this would present an undue burden on the carer.

Tools and data representation for analysis

The telephone interviews had structured questions to capture specific service utilization activity as well as having open-ended questions which allowed respondents to add their thoughts and feelings. For the structured section of the telephone interview an adapted version of the Ambulatory and Home Care Record (AHCR) was used because it systematically gathers information on health system and informal caring input which can subsequently be used for cost analysis which will be carried out in a separate evaluation (Guerriere and Coyte, 2011) (Appendix 4). The AHCR is a structured questionnaire used to collect data on service utilization and informal costs of caring, such as the number of home visits by care professionals or the costs of over-the-counter medicine purchases. Though the questions are structured, responses frequently took on

unstructured characteristics as participants volunteered unsolicited information about their experiences. When this happened, participants were given the opportunity to express their views in full and the interviews had a conversational style to encourage participants to give full details. The researcher would then interpret and agree with the participant a structured response whilst noting their open-ended response. The telephone interview was recorded with participant permission for reference. Telephone interviews were conducted approximately every two weeks with carers, in keeping with previous examples of AHCR use, to gather 'real-time' data to reduce the recall bias that can occur in retrospective interviews (Guerriere et al, 2010).

Structured responses which were recorded by hand in a blank questionnaire during the interview were transferred into a Microsoft Excel spreadsheet following each interview. A summary of the phone call, additional notes and reflections (similar to observational field notes) were also recorded in the spreadsheet which was reviewed prior to each telephone interview to refresh the researcher's memory of the carer's individual case to help build rapport with the participant (Erickson, 1986). Following the data collection period, the summaries of the phone calls were aggregated into a Microsoft Word document for each participant to present a chronological picture of patient service use and carer involvement. In some cases, particularly after death interviews when carers were asked more open-ended questions about their experience, sections of the recorded interviews were transcribed and added to the summaries. The summaries were created to facilitate a thematic analysis to be described in section 4.1.5.

4.1.4 Data management and quality assurance

In attending to the quality of the research, Hammersley (1992) argues that 'validity' and 'relevance' are the criteria for judging quality in ethnographic research which stems from a subtle realist perspective, and that criteria espoused by others, such as Guba and Lincoln (1989), are in fact means to assess these criteria rather than criteria themselves. Validity, in simple terms, is a statement of whether phenomena are accurately presented as perceived by the study population (Lewis and Ritchie, 2003). For Guba and Lincoln (1989), there are a number of techniques for enhancing the study's validity or 'credibility'. This includes establishing trust and rapport through 'prolonged engagement', in this case attending meetings regularly or carrying out multiple site visits to the Navigation Centre, so that the researcher can get behind any artificial behaviour that people might initially present. Accurate presentation of phenomena is also enhanced by 'persistent observation' in identifying and focusing on those elements of interest. The conceptual framework and scoping period at the start of the study was used to focus on the elements of interest that could be captured.

Whilst Guba and Lincoln (1989) argue that ‘triangulation’ has positivist implications and therefore prefer ‘member-checking’ for constructivist validation, method and source triangulation can be useful technique for establishing the credibility of evidence (Lewis and Ritchie, 2003). One of the strengths of this study design is the use of different methods to collect data on the same phenomena and which do not share the same weaknesses (Craig et al, 2008). Multiple sources and methods allows for the development of what Yin (2009) terms “converging lines of inquiry” which is a process of triangulation and corroboration between types and sources of data. In this case, concepts were viewed as stronger if there was evidence for their existence within datasets (e.g. a theme identified in multiple stakeholder interviews) and across datasets (e.g. a theme identified within interviews and observations). Triangulating sources was also used for checking factual content to assess the quality of documents, for example comparing meeting attendees as recorded in observational field notes to those reported in documented meeting minutes.

Explicit description and auditability of data handling and analysis procedures (discussed in the next section) give the study ‘dependability’, that is stability over time, and ‘confirmability’, or objectivity (Guba and Lincoln, 1989). This is primarily achieved through having a clear audit trail to demonstrate progression from raw data through levels of analysis and abstraction. The Framework approach to analysis (to be described in next section) along with the use of computer based analysis tools is ideally suited to provide such an audit trail (Pope et al, 2006). Firstly, a journal for the project was created using Microsoft Excel to record data collection points, implementation activity and any thoughts or reflections which could then be referred to during analysis as a record of the study (Bazeley, 2013; Liamputtong and Ezzy, 2005). This was also a useful tool for the researcher to reflect on her position in data collection, such as whether all relevant data sources were accessible. All raw data (e.g. handwritten notes, audio recording etc) were typed up or transcribed into a Microsoft Office, Excel or pdf document which could be organised into folders and stored on a computer. Secondly, a database was constructed using QSR International’s NVivo version 10 as per Yin’s (2009) guidance. NVivo helps facilitate data storage, organisation, coding and retrieval. Data which was stored on the computer but not suitable for importing into NVivo were altered; for example telephone interviews were turned into summaries and interviews were transcribed and checked for accuracy. Within NVivo, different folders were used for different types of data and documents were organised by type. Documents were reviewed once imported into NVivo and those that were excluded from analysis were moved to an ‘excluded’ folder, but kept within the study file, thus the NVivo database was used as a complete record of data collected for the study. As chronology is important to the implementation process, i.e. one event precedes another, codes (nodes) were created to

categorise data by date. In keeping with a largely ethnographic and iterative approach (Hammersley and Atkinson, 2007), all data was reviewed and reflected on as it was collected so that the next round of data collection could be used to confirm or refute initial ideas. Questions or ideas stemming from initial stages of analysis were recorded in the next version of a topic guide or framework for observations.

The role and position of the researcher in the research process was alluded to in describing the management of data. Qualitative researchers are not blank canvases; they bring to the research their biographical history which will impact on their interpretive position (Denzin and Lincoln, 2003). It is therefore important that the researcher is reflexive of her role in the research process and be explicit about how this background may have an impact on the research. In this case the researcher had worked with the Hospice on previous research projects and was therefore familiar with the services provided and operation of the Hospice, but was less familiar with the other organisations involved. This prior relationship was useful as rapport was already established with a number of the professionals involved in the Project and trust was established for access to project documentation (Hammersley and Atkinson, 2007). However, it may have also meant that the researcher was given more privileged information from those with whom she had an established relationship than those who she did not and may have viewed her as an ally to the Hospice. The researcher was also mindful that organisational viewpoints were not equally distributed as the Hospice led the programme and had more people involved and therefore had more opportunity to voice their views. With regards to observations, interviews and the telephone interview, the researcher treated each person as an informant or knowledgeable expert. The researcher's aim was to understand their views as they are seen as experts in their own experiences.

Thus far this section has focused on the techniques to ensure study validity within a qualitative paradigm, but Hammersley's (1992) second criteria for good quality research is that it must be relevant in that the study question must address a question of public concern and must contribute to wider knowledge. The former concern is somewhat a subjective claim, but the preceding chapters have argued the case for why this research is needed. The latter point is likened to generalisability, which is a contentious issue within health services research, and even within qualitative inquiry more widely. Guba and Lincoln (1989), from a constructivist viewpoint, argue the notion of 'transferability' instead of generalisability; that the outcome of an intervention might be transferred to another setting if the contexts are similar. Therefore constructivists rely on 'thick description' so that the 'receiver' can judge whether the findings are applicable to their setting. An alternative, realist view argued by Lewis and Ritchie (2003), is that

inferential, theoretical and representational generalisations can be drawn from qualitative data, but that there are strict limits based on the foregoing factors of data use, design and conduct, and validity. Implementation is context specific and therefore generalisability will depend on full description of the case. However, using the conceptual framework to drive data collection should mean that concepts identified in this study should have some theoretical generalisation.

4.1.5 Analysis

The analytic process was drawn from guidance by Miles and Huberman (1994) and the Framework approach to analysis described by Ritchie and Spencer (1994), both of whom argue for a pragmatic approach to analysis and are orientated towards realist traditions in research. The Framework approach involves five steps of familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. The steps in the analysis process are described in detail below and examples of the steps are provided in Appendix 5.

- 1) The first step in qualitative analysis is to reduce the quantity of data down (Cresswell, 2014; Miles and Huberman, 1994), particularly in ethnographic research where there is the temptation to record everything (Bazeley, 2013). As described in the previous section, all data collected was checked through for relevance which was particularly important for the documents and led to approximately a third of the documents being excluded from further analysis. This process also formed a familiarisation stage which was necessary as some data had been gathered nearly two years previously (Ritchie and Spencer, 1994). Key events in the Project identified through this process and also by referring to the study journal were mapped into chronological order in a matrix. Data sources were then organised within the matrix and colour coded by date and relevance so that analysis could proceed in time order and so a visual representation of data sources could be referred to at any point during analysis.
- 2) Deductive, *a priori* codes were determined from the conceptual framework and from first impressions formed during step one of familiarisation (identifying a thematic framework). The *a priori* codes for describing the content were colour coded in Nvivo so that they could be distinguished from the emergent, thematic codes. The final coding structure which was created in NVivo contained up to three levels of nested codes and included both descriptive (content) and thematic codes.
- 3) All data sources were sifted through and chunks of data sorted into the coding framework (indexing) whilst at the same time inductively looking for any salient themes not identified in the framework. Data collected via the different methods were treated to the same process of descriptive and thematic coding.

- 4) Coded data was then displayed in a matrix using the 'autosummarize' function in NVivo which automatically imports coded data into the matrix (charting). Larger chunks of data were then reduced into summaries and different coloured text was used to differentiate between interpretations and ideas added to the matrix (Ritchie and Spencer, 1994). In total eight matrices were created from natural groupings: Executive Project Board observations and documents, Project Delivery Group observations and documents, Navigation Centre and related training meetings observations, project manager and hospice director interviews, stakeholder and professional interviews, care navigator focus group, documents, and telephone interview vignettes. A matrix display allows data to be analysed by source (horizontal row) and theme (vertical column). Because of the quantity of documents (112), which for many had little coding because of their brevity, documents were grouped by quarter so that each case or row represented a period of time in order to reflect implementation as a process. NVivo permits easy movement between coded data and the original source so that individual documents can be identified within an aggregated time period.
- 5) With the data reduced and presented in a matrix, the matrices were printed and sifted through to look for higher level themes and patterns within the eight datasets (mapping and interpretation). Recurrent themes were highlighted and notes or 'memos' added in the margins (Bazeley, 2013). Analysis also considered what was missing from the dataset and what the absence of expected events or actions says about the implementation process (e.g. meeting minutes not being recorded, or lack of project documentation after the project manager left). This was possible because of the conceptual framework which provides insight into some things which might be expected during implementation (Patton, 2002). If these things do not happen then we can say they did not happen, rather than perceiving them as just not having been observed.
- 6) Higher level themes and notes were then compared to the other datasets to verify whether these themes recurred in data collected via other methods or other sources. Any discrepancies between observed data and documents were noted and interrogated.
- 7) In addition to the content and thematic analysis described above, the documents were also analysed quantitatively to build a picture of functional programme activities. This involved tabulating the frequency of meetings and attendees which were represented in an Excel spreadsheet, and drawing out performance data from the audits as this pertained to implementation outcomes. This was then used to contextualise the qualitative data.

The steps in the analysis process here depict an iterative process of moving back and forth between raw data and higher levels of abstraction which is common in qualitative analysis (Ritchie et al, 2003b).

4.1.6 Ethical issues

Carrying out research with people and particularly in the health care setting requires attention to a number of ethical issues (Goodwin, 2006) which will be briefly summarised in this section. The study received NHS ethics approval from the NRES Committee South East Coast – Kent on 13 November 2012, reference 12/LO/1311 (Appendix 6). A summary of study findings which was disseminated to study stakeholders and participants is provided in Appendix 7.

Firstly, carrying out a telephone interview with carers of patients who may be in their last days of life or are recently bereaved raised a number of ethical issues. Letters of invitation to participate in the research, an information sheet, consent form and pre-paid reply envelope were sent to carers by post allowing them to consider whether to participate in their own time (Appendix 8). Interested carers replied direct to the researcher by sending in a signed consent form and contact details. The researcher then telephoned the carer to make initial contact, answer any questions and carry out the first interview. Carers who elected to participate did so by telephone which allowed for flexibility as interviews could be cancelled or rearranged as per the carer's needs. At the start of each telephone interview, the researcher enquired as to the patient's and carer's well-being to identify whether the carer was happy to continue with the telephone interviews at that time; if not the interview was postponed. Carers were reminded that they did not have to answer questions if they did not wish to and always had the option of ending the interview or withdrawing entirely. If there was no answer at the arranged time, a message was left asking for the carer to return the message or the researcher would phone again in a few days' time. If again there was no answer, a second message was left to state that if the carer wished to continue with the telephone interview he or she should phone the researcher, but if they did not wish to continue then they were thanked for their time. Therefore carers who did not return messages were assumed to have withdrawn from the study. After the carer completed six interviews, their participation in the study ended so that they would not be overburdened with interviews carrying on indefinitely. In seven cases, the patient died in between phone call appointments. When this happened, the researcher suggested cancelling the interview and asked for permission to phone again in a month to carry out the interview. In some cases the carers declined in preference to carrying out the interview during this first phone call; all others agreed to the postponed interview.

With regards to the observations, fully informed written consent is often impractical with ethnographic methods as the aim is to preserve a natural setting which fully informed written consent procedures can disrupt (Hammersley and Atkinson, 2007). Also, researchers need to consider how much to tell the subjects of their observation about what they are observing as too much information can cause people to change their behaviour (Hammersley and Atkinson, 2007). Rather, it has been suggested that in overt observation, steps are taken to ensure that those being observed are aware of this, such as through obvious note taking (Goodwin, 2006). With these issues in mind, the consent process was designed to be minimally intrusive on the group setting so as to not affect natural behaviour and practical as people would likely arrive late or leave early from meetings, or pop in and out of the Navigation Centre. Consent was not taken from people who were observed, but rather the researcher explained the purpose of her presence at the start of each meeting or site visit to the Navigation Centre and gained verbal consent from those present to be observed. The researcher also openly took notes and answered any questions that people had about her work. Project documentation, such as meeting minutes, also listed her presence as an observer. This was felt to be a good balance between being explicit about the overarching aims of the research and purpose of observations with participants, and preserving a sense of normalcy among those being observed. For unsolicited hallway discussions, it was impractical to gain consent as the relevance of the conversations to the study was not always apparent at the time, but rather gained significance in reflection and therefore noted retrospectively. These discussions always took place following a meeting during which the person would have been made aware of the researcher's role and activities. Information gleaned from these discussions was largely about Project or Hospice operations and was not judged to be sensitive.

Interview and focus group participants were given an information sheet to consider and asked to sign consent on the day of the interview (Appendix 8). Verbal consent was sought for follow-up interviews with the project manager and hospice director.

Documents were downloaded from the Project computer files held at the Hospice. Access to the computer files was arranged by the project manager. The researcher obtained an honorary contract with the Hospice and signed a data protection agreement. All electronic study documents were stored on an encrypted hard-drive using Microsoft's BitLocker encryption and paper documents were stored in a lockable filing cabinet.

In studying the implementation process of a programme that involved a large number of organisations and individuals, it was important to understand individual roles and actions within

that process. This meant that observations, interviews and documents made reference to named individuals and organisations. Because there were over 30 people directly involved, it was not practical to anonymise transcripts and notes prior to analysis as references to individuals or organisations would have been lost which would have compromised the dataset. Additionally, organisations were usually represented by only one or two individuals which would have meant that they may have been identifiable in any case. The risks to participants were that their views might jeopardise their work relationships (Erickson, 1986); to minimise this risk, quotes used to illustrate consensus or deviant cases were carefully selected with consideration to the speaker. To maintain confidentiality, access to the NVivo database was restricted to the researcher and the data has been anonymised in the reporting of the study findings. Where quotes have been used that may identify individuals, a copy was sent to the participant to approve before publication and changes were made at their request without altering the study findings; the possibility of identification was described in the participant information sheet.

Service user involvement

The involvement of service users in the design and conduct of research has been shown to benefit the research process, particularly with regards to developing research tools, recruitment rates and improving the quality of data collected (Staley, 2009; Szmukler et al, 2011). Therefore, at the start of the project a group of four Hospice patients and three carers were identified by the Hospice service user facilitator and was convened with the aim of improving recruitment and retention for the telephone interviews with carers by exploring service user informational needs and understanding what challenges might prevent carers from engaging with the research. A presentation was made to the group about the research and aims of the session and service users were presented with the proposed participant information sheets and data collection tools and were asked for feedback. Overall they felt the telephone interview questions were not too invasive, but that some carers might not be comfortable answering the questions if the patient was in earshot. They felt the participant information sheet was too long and suggested having a shorter letter to gain interest followed by a longer information sheet; it was therefore decided to include a shorter cover letter with the participant information sheet so carers could decide whether to proceed.

4.2 The case of ‘the Project’

A thorough description of the Project has already been given in the first chapter and the evidence base for it was described in the literature review in chapter two. The aim of this section is to situate the Project as a case within the wider area of research on implementation and specifically

in health services. The Project was selected as a case primarily for practical reasons. The Project management team required an evaluation of its implementation so that project outcomes could clearly be linked to project activities (King et al, 1987). It is an example of a movement in health and social care in which implementation is driven by service and policy imperatives, rather than a scientific evidence base. This is likely because the development of a reliable evidence-base for community based palliative care interventions has been slow to develop because of the heterogeneity of interventions and methodologies to evaluate them (Gomes et al, 2013). Indeed, with regards to coordination of care for patients with palliative needs, there is no good evidence for advocating one particular model of care and thus coordination is driven by policy and commissioning imperatives (Higginson and Gysels, 2004). The variety of palliative care interventions developed likely reflects the desire to meet local needs and policies, such is the case here, and thus generalisability is problematic (Higginson and Gysels, 2004). Therefore, professional experience is often relied on as the basis to drive improvement in care and practice (Billings, 2013).

The Project represents an example of a complex programme, particularly in that there are multiple interrelated innovations proposed. This differs from many examples of implementation research which are focussed on the adoption and implementation of single innovations within one organisation. This complexity means that the data collected in this study is multi-layered meaning that conclusions can be drawn about implementation of the programme of innovations as a whole, and regarding the implementation of distinct innovations within a programme of work. The partnership approach involving numerous organisations adds to the complexity of the programme. In terms of the programme's composition, it has many features of Hjern and Porter's (1981) "implementation structures" which are defined by informal, non-authoritative relationships in which participation is based on consent and negotiation. However, multi-organisational approach presents challenges in terms of how to conceptualise the implementation process. In this case, data collection represents the project group level rather than taking on an organisational perspective as has more often been achieved in cases of single innovations.

Such partnership working is representative of new forms of service delivery which is becoming increasingly common in UK health services (NHS England, 2013a) and is thus a timely evaluation. Most implementation research comes from the US as indeed many of the first studies came from an apparent disconnect between US national policy and changes on the ground (Schmid, 1996; Pressman and Wildavsky, 1984). However, the UK context is slightly different in that there is arguably a closer connection between national policy and service delivery as the NHS is state-

funded whereas US policymakers are further removed from implementing organisations (Schmid, 1996). This may have implications for how the wider political context influences the implementation process and potentially prior research which has informed the conceptual framework may under-represent the direct influence of the wider political climate which may have more impact within the UK.

These characteristics regarding the complexity of the programme and context of implementation give an overarching perspective of how this study should be situated within implementation literature.

5 Data One: Implementation strategies and the shape of the implementation process

Introduction

This first of two chapters presents data on the implementation process, particularly focussing on the strategies that were used as these were proposed to form the core of the process as represented in the conceptual framework and the shape it took. The chapter starts with a description of the Project plans for implementation, specifically what was to be implemented and how. This sets the scene for the second section on what happened during the Project and how the implementation process unfolded. The first chapter is largely a descriptive account of the two-year Project whereas the second chapter is more explanatory and will present data on what influenced the process and implementation outcomes.

Data sample

This section describes what data was collected using each of the five methods described in the previous chapter and how sources will be referenced in this and the next chapter.

Observations

In total, there were 16 observational sessions which were recorded and analysed (including those from the scoping exercise). Observations included: 4 Executive Project Board meetings, 6 Project Delivery Group meetings, 4 Navigation Centre visits, 1 training session and 1 hospice meeting. Observations lasted between 25 minutes and 4 hours 5 minutes for a total of 24 hours 51 minutes. There were also a number of occasions where unsolicited 'hallway' discussions were had following meetings. These impromptu discussions, which constitute a form of ethnographic interviewing (Hammersley and Atkinson, 2007), provided rich data and so were included as an appendix to meeting observations.

Interviews

Thirteen stakeholders were approached for an interview, to which 10 agreed, 2 declined and 1 did not respond to the invitation. The mix of invited participants and the format of the interview if they participated is described in Table 5.1. Four interviews (including one scoping interview) were carried out with the project manager and three with a hospice director who provided a day to day management view when the project manager role ended. Interviews were conducted face

to face where possible, or on the telephone if the participant's schedule could not accommodate a face to face meeting. Interviews were digitally recorded with permission and/or hand written notes were taken, and interview length ranged from 20 minutes to 56 minutes.

Table 5.1 Project management and stakeholder interview invitees and participants

Role in project	Interview format
Project manager	4 face to face interviews
Hospice director (project management)	3 face to face interviews
Project Delivery Group chair, Communication work stream chair	Telephone
Pharmacy & Drugs work stream chair	Telephone
Workforce Education & Training chair	Telephone
Patient Pathway work stream chair	No response
IT, Audit, Research & Evaluation work stream chair	Face to face
Patient and Users work stream chair	Face to face
Navigation Centre management	Face to face
The Hospice, Project Champion	Face to face
Hospital Trust representative	Face to face
Ambulance Trust representative	Face to face
Community Health Trust representative	Face to face
Commissioner as project funder	Declined
Hospice representative	Declined

Focus group

Four female care navigators participated in the focus group and whose experience of working in the Navigation Centre ranged from 8 to 22 months. There were no male care navigators working in the Navigation Centre during the study, which likely reflects female dominance in the care-sector. The mix of participants covered all working shifts: day, evening, weekend, and night shifts. The focus group lasted 1 hour 29 minutes and was digitally recorded for transcription.

Documents

Documents collected from the Project file included: project initiation documents, minutes from meetings, communication letters, audits of service use and Navigation Centre call records. These documents represent data from the individual, programme and organisation levels. Local and national policy documents were also included as these situated the Project within the wider context (Ferlie and Shortell, 2001). All documentation was checked for study relevance using the

conceptual framework (Miles and Huberman, 1994). In total 183 documents were reviewed of which 112 were included for coding. The full list of included documents is presented in Appendix

9. Documents were grouped into six categories based on their content:

1. Audits: documents produced for the purposes of evaluating project outcomes. Contain mostly quantitative data.
2. Monitoring: documents produced for the purpose of monitoring, tracking or reporting on project progress.
3. Operational: documents for the overall management and operation of the project. Includes documents such as terms of reference, aims and objectives of working groups, and communications/emails to partners.
4. Outputs: documents produced as outputs from work streams or other meetings. These provide evidence of project productivity.
5. Meetings: documentation of meeting activities.
6. Other ongoing work and project reference materials: documents that have been collected by the project manager or other partners as examples to guide the project or to be aware of other ongoing or previous related work.

Table 5.2 shows the distribution of these documents by time period in the project.

Table 5.2 Number and type of documents by time period in the Project

Document type	Total sources	Coded	Coded data sources collected during period									
			Prior to start	Q2 2012	Q3 2012	Q4 2012	Q1 2013	Q2 2013	Q3 2013	Q4 2013	Q1 2014	Post project
Audits	4	4	-	-	-	-	-	1	1	-	-	2
Monitoring	9	8	-	3	3	1	-	1	-	-	-	-
Operational	75	54	31	3	8	2	5	1	4	-	-	-
Outputs	12	12	3	1	2	4	2	-	-	-	-	-
Meetings	54	32	7	13	5	2	3	2	-	-	-	-
Other ongoing work & project reference materials	29	2	1	-	-	-	-	-	-	-	-	1
Total	183	112	42	20	18	9	10	5	5	0	0	3

Telephone interviews

In total, 196 carers or patients were invited to participate to which 28 carers consented. This is a response rate of 14.3% which is lower than previous studies carried out in Canada which used the Ambulatory and Home Care Record (AHCR) (41.8%, 70.4%), but a similar response rate to a postal questionnaire of carers carried out in the same area of the UK (15.9%) (Guerriere et al, 2010; Leong et al, 2007; Holdsworth et al, 2015). Three carers were unable to be contacted and never had a first interview. Two carers were interviewed, but it transpired that the patient had already died and so were excluded. Therefore 23 carers were included in the final analysis and their demographic details along with the patient they cared for are summarised in Table 5.3. In total 93 interviews were completed. The length of the interviews was variable, lasting anywhere from 3 minutes to 40 minutes depending on how much the carer wanted to say, with most taking between 5 and 10 minutes. Table 5.4 shows how many carers completed a sequence of between 1 and 6 interviews and how many of those carers either withdrew from the study or completed all study interviews. The carer was deemed to have completed all possible study interviews if: the patient died and the carer was interviewed after death so that service utilization was reported up to the patient's death, or if the carer completed six interviews.

Table 5.3 Telephone interviews: carer and patient characteristics, n= 23

Carer (participant)		n (%) or median (range)
Gender	Female	16 (69.6)
Age	Years	63 (44-81)
Relationship to patient	Spouse / partner	17 (73.9)
	Child	4 (17.4)
	Parent	1 (4.3)
	Other	1 (4.3)
Lives/ staying with patient		21 (91.3)
Patient		n (%) or median (range)
Gender	Female	10 (43.5)
Age	Years	70 (43-93)
Diagnosis	Cancer	20 (87.0)
	Non-cancer	3 (13.0)

Table 5.4 Number of telephone interviews completed by carers and whether they completed all study interviews or withdrew, n=23

Number of interviews	Number of carers who completed interviews	Carer completed study	Carer withdrew
1	2	--	2
2	3	2	1
3	4	4	--
4	5	1	4
5	1	1	--
6	8	8	--
Total		16 completed	7 withdrew

While the AHCR collects structured data for cost analysis, this was deemed outside the scope of the study question and therefore structured data is not presented nor was it analysed quantitatively. Instead, because interviews frequently had characteristics of storytelling despite the structured format, individual interviews were turned into narratives and the structured data was used to supplement and organise the story in these narratives. Thus, while the AHCR data was not analysed as intended by its authors, all data was included in creating the narratives, e.g. the number of home visits by the GP would be reported as part of the narrative of what had occurred in the previous two weeks.

The data collected using the five methods over the duration of the project is summarised in Table 5.5.

Table 5.5 Timeline of data collection by method and source

Data collection method and sources	2012										2013												2014			
	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	
Ethnographic observations			*	●	*				●	●	●	●	●		●	●		●	●							
<i>Executive Project Board</i>			*						●			●			●											
<i>Project Delivery Group</i>			*	●					●	●	●	●														
<i>Navigation Centre</i>					*					●		●			●											
<i>Other meetings</i>											●		●						●	●						
Interviews		*						●		●			●		●		●					●		●		
<i>Project manager</i>		*						●		●			●													
<i>Hospice director</i>																●		●				●				
<i>Stakeholders and professionals</i>																								●		
Focus group with care navigators																							●			
Document review	●	●	●	●	●	●	●	●	●	●	●	●	●		●	●	●	●				●	●	●		
Telephone interviews with carers								●	●	●	●	●	●	●	●	●	●	●	●			●	●	●		

Subgroups of observations and interviews aggregated in top level method

* scoping exercise to refine data collection

● data collected

References to data sources

All data is presented in italics throughout this and the next chapter and the reference to the data source is given in brackets. The data was labelled so as to provide a quick reference to the data type and when it was collected as it was felt that time order was important for observations, documents and project manager/ hospice director interviews which were repeatedly collected over time. The label indicates the type of source (Obs – observation, Doc – document review, Int – interview, FG – focus group), time period of collection (for observations, documents, and management interviews), and number if multiple pieces of data of the same type were collected within the same period. Square brackets within a quote have been used for anonymization, to clarify when pronouns have been used, or with ellipses to truncate a quote. A complete list of data with full explanation of the naming structure is given in Appendix 9.

The terms ‘stakeholder’ and ‘partner’ refer to the individual member of the Project and the organisation they represent. ‘Professional’ refers to clinical and frontline positions on the ground which many stakeholders also held. The project manager role was terminated midway through the Project as a cost-saving measure and this role was partially filled by a Hospice director who was interviewed to provide a project management perspective, though references in the text refer to the first project manager only.

5.1 Project planning

The Project had two basic phases: planning, which took place prior to the Project start date and involved discussion among partners and agreement to participate, and implementing, which involved enacting the plans with the allocation of funding. Documents that were created prior to the start of the two year project (April 2012) were analysed to understand the plans and implementation strategies. This was done retrospectively as the Project had already commenced prior to the start of this study. Planning documents were largely comprised of operational and management documents, meeting notes and reference materials. Using the conceptual framework as a guide, the documents were interrogated to build a picture of the Project and particularly what aspects would be relevant to the implementation process. Two questions were used to structure the analysis:

1. What were the service changes to be implemented?
2. What were the plans or strategies for implementation?

Many of the documents were undated and so could not be put into a chronological order, but their progression could be surmised based on how the content of the documents developed. The purpose of these documents was to give a descriptive overview of the implementation plans to later assess adherence, thus their exact ordering was not essential.

5.1.1 What were the service changes to be implemented?

The Project introduced two new service changes: a Navigation Centre and an Electronic Palliative Care Coordination System (referred to as EPaCCS or register), both of which depended on partnership working to have the expected benefit of coordinated palliative care. The Navigation Centre was established at one of the hospice sites and staffed with care navigators 24 hours a day. It is not clear from the documentation how exactly the structure and features of the Navigation Centre were determined, but it was noted that the Hospice was already running a dedicated out-of-hours service between 5pm and midnight and 7:30am to 9am and thus the new Navigation Centre would extend this current service overnight between midnight and 7:30am.

The second proposed change was for the introduction of an EPaCCS in each of the partner organisations. The planning documents note that an existing patient record system owned and operated by the out-of-hours service was already in use by both the out-of-hours service and numerous GP practices and was thus at least partially established within the regional care setting.

The documents also proposed that the working arrangement for the Project would be a partnership approach because this would provide the most seamless approach to care for patients:

The proposal would be to pilot the extension of the hours of operation of this service [hospice existing telephone advisory service] and add value by evolving it as a central point of access and coordinating centre which helps both patients and professionals in a bespoke way through supporting the work of an 'end of life partnership' where existing providers can agree the most appropriate pathways for patients 24/7, 365 days per year. (Doc Operational prior-04)

The project would build on existing service provision (as with the Navigation Centre) and introduce new ways of working (EPaCCS and changes to patient pathways) through a project partnership. In terms of innovation, the substantive change was not only the vision of having a single point of access for all end of life patients and the coordination of services from that one point, but that services could be altered to accommodate

these two changes. Meeting documents indicated that the Project aims and changes were acceptable to stakeholders, though at this point in the Project there was little detail as to what the change process would involve:

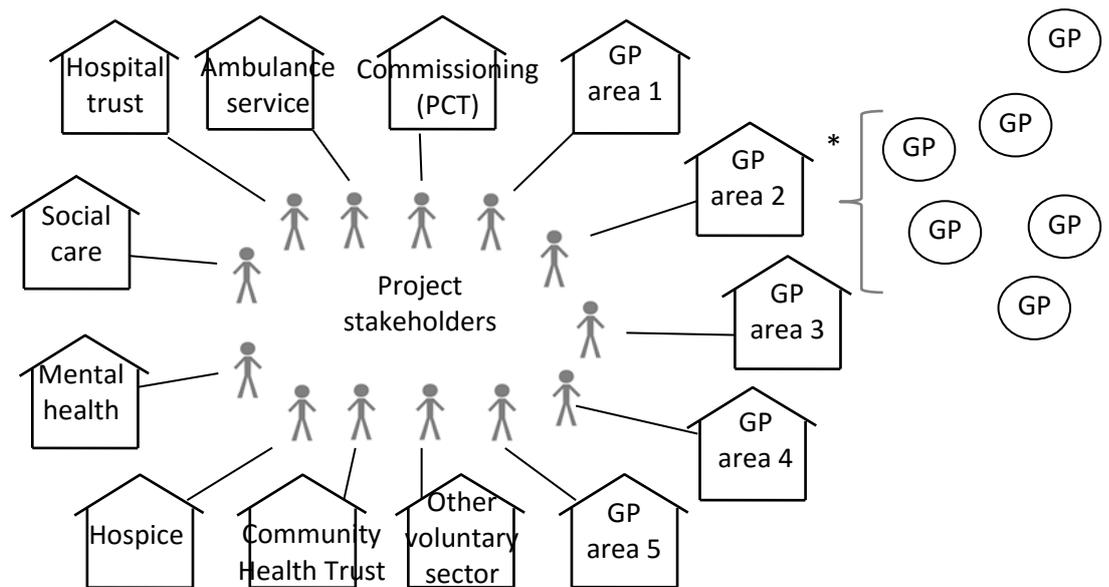
- *CEO meetings with GP's in sector*
 - *General outcome – warm to principle of co-ordinating centre*
- *18/03/11 – [Stakeholder]. Community trust – agreement in principle*

(Doc Operational prior-14)

5.1.2 What were the plans or strategies for implementation?

The Project implementation plans were laid out in a Project Initiation Document which was disseminated to the partners and also in supplementary presentation documents. Project plans were largely focussed at the individual stakeholder level as the means of entry to the various organisations represented in the Project partnership (see Figure 5.1). Using the *a priori* themes from the conceptual framework and also scanning for emergent patterns in the data, implementation activities identified in planning documents were grouped into seven types of strategies. These strategies were identified through prior theoretical and empirical reading of the literature and follows Proctor et al's (2013) guidance for specifying implementation strategies where possible. However, implementation plans in project documentation were not explicitly spelled out as Proctor and colleagues (2013) argue that they should be for transparency in implementation. This study reflects the real world of 'implementation as usual' where implementation is not always conceptually explicit (Powell et al, 2013).

Figure 5.1 Stakeholder representation from partner organisations in the Project

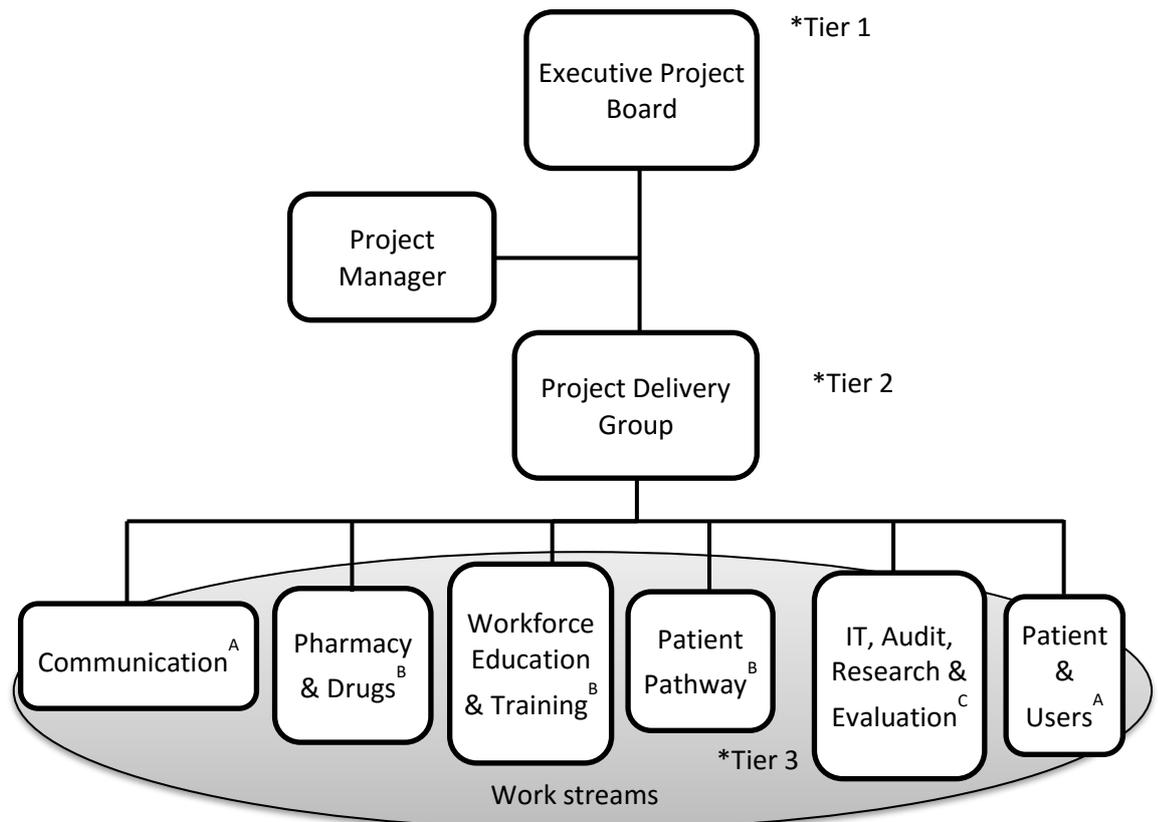


*GP area 2 as an example of the relationship between the GP stakeholder representative for the area and autonomous GP practices; later these areas became the boundaries for the Clinical Commissioning Groups

Management structure and stakeholders

The most prominent strategy was a management structure which would engage stakeholders in tasks relevant to their organisation's work and formed the foundation for establishing the partnership. The Project relied on this structure to promote the partnership approach and deliver the Project's aims. The Project was managed and delivered through three tiers of stakeholders (Figure 5.2).

Figure 5.2 Management structure, adapted from Doc Operational prior-11



^A Implementation focused activities

^B Activities to develop innovations for implementation

^C Both implementation and innovation activities

The Executive Project Board formed the top tier with 17 individually named senior stakeholders with executive authority within their respective organisations (or department within an organisation) invited from 12 different health and social care organisations. These stakeholders would provide the link between the Project and their organisation or department and were accountable for the outcomes of the project.

The second tier was the Project Delivery Group (PDG):

The Project will be delivered through the Project Delivery Group (PDG), this group will be formed from members of the local health and social care sector who are participating/leading on predetermined work streams to ensure the Project is delivered. The Chair of this group will be part of the Executive Project Board and will be a Senior Health or Social Care Clinician or Manager. The

Project Delivery Group will meet monthly to review the status of each of the work streams, identify issues or challenges and consider appropriate solutions for presentation and approval at the [Executive] Board. (Doc Operational prior-12)

The bottom tier was formed of the work streams:

There will be seven Work Stream Groups (WsG), each group will have a chair who will be a member of the Project Delivery Group. These groups will meet at least once per month but may need to meet more frequently to deliver their element of the Project. The members of each WsG will be taken from appropriate areas of health and social care that are affected by end of life care. (Doc Operational prior-12)

From this pyramid structure it is apparent that the Executive Project Board had management responsibilities, the work streams had 'project delivery' responsibilities, and the Project Delivery Group had both types of responsibilities within their remit. The members of the Executive Project Board, Project Delivery Group and work streams were expected to participate as part of their normal workload rather than being contracted to the Project. This suggests that members would have to be personally or professionally motivated to participate as there was no financial or other reward or consequence for non-participation in the partnership.

Workforce capacity

'Workforce capacity' refers to the addition of human resource to complete specific project tasks and is a term generated here to describe how monetary resources were used in the Project. While various stakeholders were expected to contribute to the overall management and delivery of the Project within their organisational roles, most of the Project money was allocated to the hiring of new staff to deliver key aspects of the Project. Firstly:

A project manager will be appointed to oversee the delivery of the Project and this person will report to the Chair of the EPB. (Doc Operational prior-12)

This role was based at the Hospice along with a data analyst who was appointed specifically with the task of gathering data for key performance indicators to assess programme efficacy such as inappropriate hospital admissions, preferred place of death, and end of life experience. Money was also granted for an evaluation of the Project and was used to fund this study.

The plans also included hiring additional staff to increase capacity and support care delivery including: care navigators for the Navigation Centre, a consultant in palliative medicine, clinical assistants, and Advance Nurse Practitioners to support prescribing in the community.

Division of work

The Project plan described a number of work streams through which tasks in the Project would be divided into smaller work packages for delivery by separate groups, which is illustrated in the bottom tier of Figure 5.2. Each work stream aimed to have representation from the various health and social care organisations to which the work would be relevant and demonstrates the partnership approach. The chair of each work stream also participated in the Project Delivery Group to feed up the work of their group to the rest of the Project. The work streams included: Drugs & Pharmacy; Patient Pathway; Workforce Education & Training; Communications; IT, Audit, Evaluation, & Research; and Service Users. The first three were focussed on developing ideas (innovations) and plans for change by reviewing current practice. For example, one of the aims of the Drugs & Pharmacy group were:

To review the current access to medication for end of life care patients, ensuring that access both in and out-of-hours is available to patients and that medication provided using syringe driver can be established within 1hr of prescription being required. (Doc Operational prior-29)

The latter three focused on supporting the implementation of those ideas, such as in the Communications work stream:

The group will have a responsibility to communicate the vision and aims of Project to relevant stakeholders and group members will undertake to communicate the aims of and progress with the overall Project within their own organisations. (Doc Operational prior-19)

Creating these work groups focussed around different aspects of the Project was meant to make the overall project delivery more manageable, but again members were expected to participate as part of their normal work.

In addition to the work streams, the implementation of the Navigation Centre was allocated specifically to the Hospice for implementation as it was sited within their facilities and drew primarily on Hospice resources for navigating and advising callers. In terms of planning how to embed the Navigation Centre into the care system, there is

little planning documentation for how this would be achieved and there was no documented strategy within the project planning documents for how the existence of the Navigation Centre would be communicated to and accessed by non-hospice patients.

Monitoring

Monitoring as an implementation strategy was used to analyse progress against process goals or milestones so that problems or delays could be identified and rectified. This is different to evaluation of project outcomes which is related to the efficacy of the intervention. The planning documentation stipulates that the project manager, Executive Project Board and Project Delivery Group were each tasked with monitoring the project. It was noted that the Project was a radical change in access to services and therefore there had to be some flexibility within its scope.

Communication

Communication was highlighted in the planning documents as the primary method of raising awareness about the Project and it was assumed that once aware, action would logically follow:

To ensure that all involved understand the vision, aims, roles, functions and how and when changes will be implemented, enabling staff and organisations to participate as required. (Doc Operational prior-11)

It was expected that management teams from partner organisations would be provided with the necessary information to communicate about the Project to enable change in their organisations. The Communications group was given the task of communicating both within the Project team and with external parties.

User Involvement

The plans included involving service users to ensure that the services developed in accordance with their needs which would give the Project outputs legitimacy amongst partners for implementation:

It is hoped that by undertaking feedback from the [...] users this will facilitate support, influence and assist with the development of the new service. Regular meetings will be held throughout the Project to ensure that carer and patient feedback is obtained on the service. (Doc Operational prior-11)

Training and education

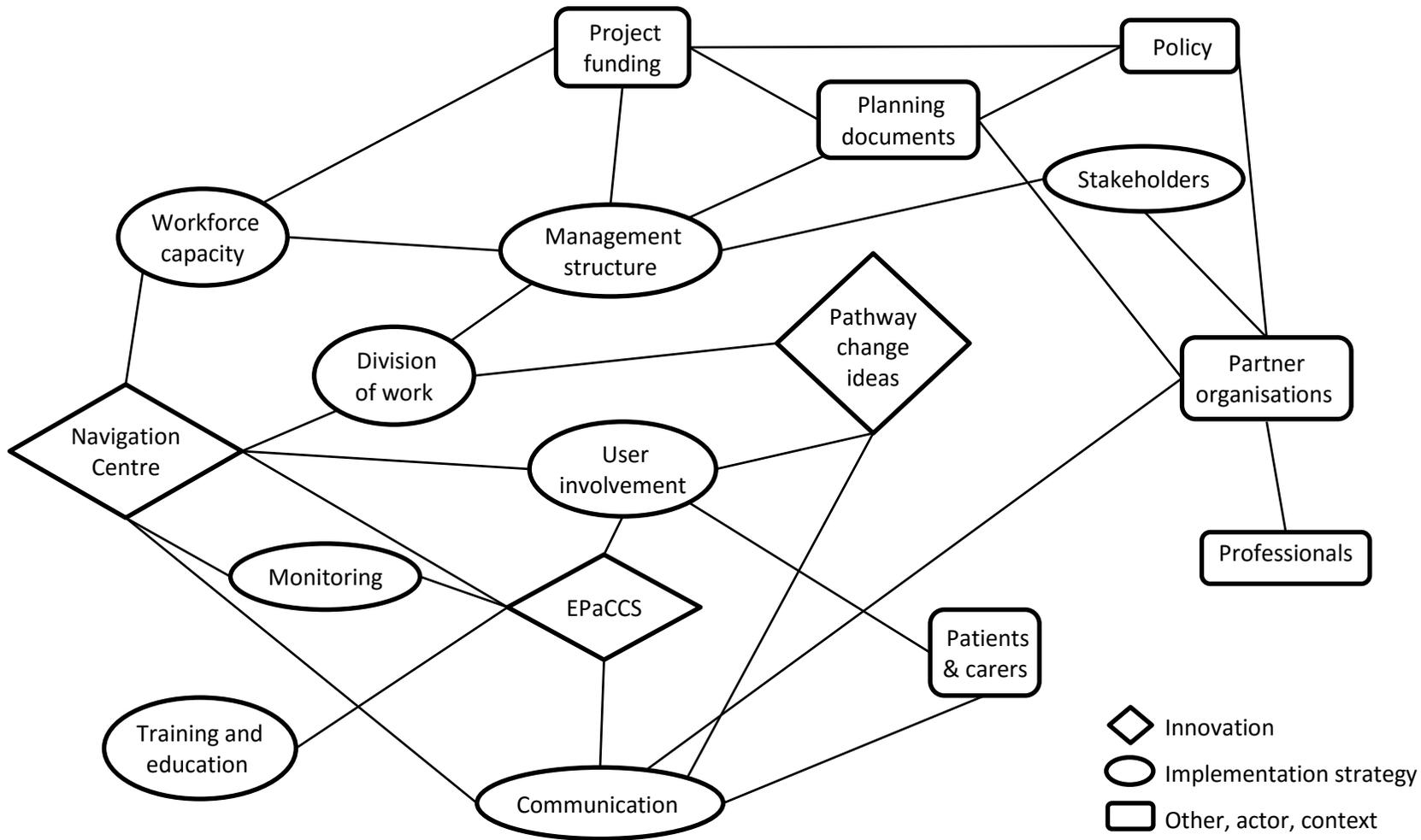
Training and education as a strategy was focused primarily on establishing use of the EPaCCS at the professional level. Training for GPs, which would have been the largest group of users of the EPaCCS, was planned at the outset:

Each practice [...] will need to nominate a lead clinician for the End of Life pilot and be able to attend ½ day training in anticipatory management and the implementation of the palliative care register [EPaCCS] which will commence in August at various locations (Doc Operational prior-13)

Following training, GPs were then expected to sift through their patient records to identify appropriate patients to add to the EPaCCS register. It was anticipated that the EPaCCS would first be implemented in the Hospice and primary care before being rolled out to other areas, though no training programme was identified for other users.

The assumed connections between implementation strategies, innovations, actors and setting characteristics is depicted in Figure 5.3.

Figure 5.3 Connections between implementation strategies, innovations, actors and setting characteristics



5.1.3 Analysis of the implementation plans

It seems that at the outset implementation had been conceived as progressing linearly with plans expected to lead to outcomes. The planning process itself demonstrates a more managerial approach to implementation as opposed to service changes which evolve in a more passive process. While a number of strategies for facilitating this change were identified in the planning documents, the formation of the Project itself in terms of getting the various organisations together to form a partnership could be viewed as a strategy in its own right to create regional change. Indeed, the effectiveness of each of the strategies is likely to reflect the effectiveness of the overall partnership approach which pervades every aspect of the Project. There were a number of assumptions made about how stakeholders would engage with the Project, how they would work together and respond to the service changes being proposed. The working relationship proposed was hierarchical and required each tier in the hierarchy to fulfil its tasks and be accountable to the tier above it. However, the higher tiers only had influence over the tiers below insofar as they were able to set tasks. In terms of demanding participation by each stakeholder, the project groups had very little power as participation was voluntary.

The Project also assumed that there was equality among stakeholders as there is an emphasis on partnership throughout planning documents. This implies perhaps that that decision making would be consensual and power was shared pluralistically. Some service changes would be developed over time as part of the implementation process and therefore needed ongoing agreement by all partners to be implemented. The project manager reported in the course of the planning process that stakeholders had initially agreed the Project was a good idea and would be of benefit. However, these views reflected the prevailing conditions prior to the start of the Project. There did not appear to be anything within the plans to address whether it was felt that the context for implementation was right, e.g. the state of readiness to change in each of the partner organisations or commitments which might conflict with project goals. Managing contextual issues seemed reliant on the participation by stakeholders who could contribute their views and problem solve where necessary to smooth the course of implementation within their organisation. However, this arrangement meant that success was dependent on all organisations such that failure in one organisation could lead to overall failure.

5.2 The implementation process

Having described and analysed the plans for the Project, this next section provides a narrative account of how the Project progressed over the two years and the overall outcome of the Project with respect to the implementation of the Navigation Centre and EPaCCS. This will include an

analysis of what the Project did and did not achieve in respect of its aims and introduce some of the key events in the Project to provide background process information for the data presented in the remainder of this chapter and the next.

5.2.1 Navigation Centre

Installing and developing the service

The Navigation Centre was set up within one of the Hospice sites in stages and was opened initially to all 600 hospice patients from June 2012. By only fielding calls from hospice patients for the first three months, care navigators were able to build their confidence in call handling and the Hospice was given the time to identify what the unmet need was among end of life patients for workforce planning. While training was given to all care navigators, they felt that the training was too focussed on hospice operations rather than on practical experience of how to handle calls:

we had six weeks of going to various hospices but no practical application whatsoever. I would have personally liked to have sat down with a computer system, seen people working with the computer system, talking to people about what sort of call, how to deal with those calls and in my opinion none of that happened (FG care navigators)

Care navigators developed their own style and support systems for answering and directing calls, such as creating a directory of personnel in the hospice:

Navigator 1: all we've done actually is make our own directories up [...] we share that information amongst us.

Navigator 2: I think we have worked very effectively as a team to support each other because there have been a few difficulties. (FG care navigators)

One of the major challenges facing the Navigation Centre during the first year was the high volume of inappropriate calls, such as calls for charity shop information or Hospice staff using it in lieu of the telephone switchboard, which was a major risk to the success of the Centre. There was a particular concern expressed among stakeholders that external care professionals would be unable to get through because lines were busy with non-clinical calls and this negative experience might result in low uptake of the service by professionals:

I mean at one point they were getting all sorts of phone calls, like you know, making donations and phone calls for the Friends of the Hospice and all kinds of bizarre things which I think then did impact on the ability of other people to actually get through to the

Navigation Centre so I think if you had a bad experience once you won't necessarily use it again. (Int Stakeholder 02)

Stakeholders indicated that the benefits of the service needed to be felt by callers to the service in order to reinforce its continued use. It was suggested by professionals external to the hospice that the Navigation Centre should prioritise phone calls from professionals to improve their access to the service, which perhaps would have been at the expense of patient and family callers:

one output from the work stream meeting was that it was felt, particularly by [a GP], that there should be a dedicated telephone number for professionals to call so they can get through quickly for advice or support. (Obs PDG 12Q4-07)

Despite this apparent need for an improved service, the care navigators reported that it took nearly a year to reduce the number of inappropriate calls received through a call screening system.

The development of the Navigation Centre also involved creating and testing algorithms which could be used by the care navigators to give advice or navigate calls, but these were not ready for implementation until approximately six months after the Navigation Centre opened. Prior to this, care navigators could not give clinical advice and had to rely on the patient notes available and their own knowledge to navigate calls:

Currently mainly working from [select sections of the Hospice record system]. Working from 'their head'. (Obs NC 12Q3-01)

The algorithms for handling calls were in fact never really used as intended because they took too long to go through which meant a high number of incoming calls were abandoned. Care navigators also believed them to be ineffective and that any questions they asked of the caller would likely be repeated by the nurse they navigated the call to. This suggests that health professionals did not have trust in the algorithm system:

I think [the algorithms] would take about 20 minutes usually. If you have a distressed person and go through all that for 20 minutes, asking them questions, it wouldn't give you a route how to direct the call, so it was always the same outcome. It would go to the nurse who would then ask all the same questions (FG care navigators)

Implementation outcomes

A call audit conducted after one year of operation revealed that the majority of phone calls were received from or made to a professional (internal or external to the Hospice) (Table 5.6). Only about a third of calls were to or from patients or their family.

Table 5.6 Average number of calls per weekday and weekend day to/from the Navigation Centre during July 2013, adapted from Doc Audit 13Q3-01

Calls to/from	Average weekday (July 2013)		Average weekend day (July 2013)	
	n=130	%	n=71	%
Professionals	65	50.0	39	54.9
Patient	8	6.2	4	5.6
Family/carers	32	24.6	20	28.6
Other	20	15.4	7	9.9
Unknown	5	3.8	<1	1.0

While the audit suggests high use by professionals, the care navigators reported that they felt that most of the incoming calls came from carers or patients and that they received very few from other care professionals:

Navigator 4: I have outgoing calls to 111 but I don't have...very, very rarely will I have them call me [...]

Navigator 2: I would have said it was more patient or the carer's families next to the carer

Navigator 1: Because we usually get, if it's 111 we're ringing, the doctor or the district nurse will contact the patient direct so we don't get the calls. (FG care navigators)

While there appears to be a discrepancy between the audit data and care navigator experience, the audit did not distinguish between incoming from outgoing calls and therefore the care navigators' experience provides insight into how the Navigation Centre was used by each of the groups which the audit misses. Thus taking the audit and care navigator experience together, this suggests that the high number professional calls in the audit were due to navigators making a majority of outgoing calls to professionals as the audit did not distinguish between outgoing and incoming calls. This seems to indicate a uni-directional flow of information whereby patients and carers phone the Navigation Centre, and the care navigators disperse information to various professionals who then liaise with patients directly, rather than the Navigation Centre working as a hub of information.

There is little evidence that the Navigation Centre was used by any non-hospice patients, even though it was open to all end of life patients and their families after the first three-month trial period. Throughout the life of the Navigation Centre, care navigators answered phones as “*Good [morning], the Hospice, how can I help you?*” (Obs NC 13Q1-02). This greeting did not indicate that the caller had reached a Navigation Centre and therefore determining the caller experience of the service was difficult because many carers did not differentiate between the Navigation Centre and Hospice usual services. Whether carers had called the Navigation Centre sometimes had to be determined by the researcher based on clues about the timing, nature and response to their call.

Patient had 3 visits from district nurses, one seems to have been on a Saturday which was arranged via the Hospice. Carer says she was concerned about the patient so called the Hospice and they arranged for the district nurse to come out. I asked if this was an out-of-hours phone call, she said no because they are 7 days, but then said perhaps that it was an out-of-hours phone call because it was a Saturday. (P14 carer telephone interview 5)

Of the 23 carers who participated in a telephone interview, it was determined that eight carers used the Navigation Centre, and a further four may have used the service but this could not be confirmed from the information given. Table 5.7 summarizes an example of the contact that each of eight carers had with the Navigation Centre.

Table 5.7 Examples of types of calls to the Navigation Centre (NC)

Carer	Purpose of Call	NC response	Carer comments
P02	Advice for swelling	Advice from consultant; arranged for GP to visit	Would probably have called 111 or waited for longer if NC did not exist
P07	Patient called frequently for advice and emotional support about dying alone	-	-
P09	Patient was in pain, phoned for help	Advised that patient needed medical help; care navigator phoned 111	Call back from 111 took too long so phoned 999
P10	Phoned for faster access to district nurse visits out-of-hours	-	Only used out-of-hours; would call GP surgery direct during practice opening times
P18	Carer called because she was feeling down	Arranged a call back	Carer relieved to explain to the care navigator what was going on
P22	Patient had deteriorated	Advised to phone GP surgery at opening, GP arranged to have DN visit	-
P23	No details given	-	Happy with response
P27	Advice for pain	Nurse called back; advice given	Found reassuring

The Navigation Centre was largely used by carers for advice about a problem or to relay information, which sometimes resulted in a home visit by a district nurse or GP:

[Carer] also called the [Navigation Centre] to tell them about a nosebleed the patient had. The call handler said she would pass message onto the hospital who would then contact the carer if necessary. (P02 carer telephone interview 1)

At the same time that the Navigation Centre was being established, the new NHS 111 service was being implemented nationally to deal with urgent, but not life-threatening medical help and advice. Carers used both services depending on their needs and how quickly they wanted a response, indicating their actions influenced how the service operated:

Carer rang the Hospice on the 14th and the Hospice called her back which was just a normal keeping up to date call. [...] When the patient went for his MRI scan they took the

syringe driver out and when they got home it was then out-of-hours so she rang 111 to get a district nurse to come out and set it up again. Has been told to call 111 directly rather than call the Hospice if they need a district nurse out-of-hours. (P25 carer telephone interview 5)

The implementation of the Navigation Centre could be characterised as a learning process of trial and error over approximately the first year of operation. By the end of the Project, the Navigation Centre had been set up largely as envisaged with some adaptations, though the extent of its impact and reach to the intended population seemed to be limited. The Navigation Centre aimed to be a single point of access for all end of life patients, however it appears to have primarily only supported hospice patients. Also, it appears from the telephone interviews with carers that the Navigation Centre was just one of a number of resources used by patients and their families, rather than the single point of access that was envisaged. Thus the Navigation Centre has had mixed success in achieving its aims, though this is may be due to other aspects of the Project having limited success which will be described in subsequent sections.

5.2.2 Electronic Palliative Care Coordination System (EPaCCS)

Software selection and installation

The selection of the EPaCCS (or 'register') software was made at the start of the project period with some background work in making that selection having commenced prior to the start. The document review showed an options appraisal of three IT systems at various stages of development undertaken in March 2012. Selection of the software was based on readiness to fulfil the requirements of an EPaCCS as spelled out in national guidance without delays (NEoLCP, 2012):

The group had researched 3 options, 2 of which had been piloted in different parts of the country along with [Red System], the clinical system used by [the out-of-hours service]. The [Blue System] was recommended as this system met all the requirements. An options paper was presented to the Project Board recommending [Blue System] and agreed. (Doc Meetings 12Q2-08)

The two primary contenders, Red and Blue System, contained the same basic information, however there were some striking differences. Only the Blue System met all of the new requirements for EPaCCS systems and was a web-based platform which meant any provider could be given access to it; however, no providers were using it in the area. The Red System was operated by the out-of-hours service and used by many GP practices, however it did not meet all the requirements for an EPaCCS and the software was not easily accessible by other providers.

Some stakeholders had concerns with the decision to use the Blue System because the existing Red System was already being used by 85% of GPs and the out-of-hours service and would thus have to compete (Obs PDG 12Q2-03). At the end of the Project, one stakeholder reflected that there was no consensus among the wider project group in the decision to use Blue System:

I'm not even sure how that agreement was made and I think there did seem to be a little bit of the Hospice taking what felt a bit like a unilateral decision on that one (Int Stakeholder 02)

In this case of conflict it seems that the Hospice exerted its power as fund-holder to make a decision which might not have gone this way had responsibility for purchasing the software lain elsewhere. It became apparent in the first months of the Project that the implementation of the register could not be achieved under the proposed structure of the Project:

A separate work stream was required regarding the implementation of the register due to how crucial this work is to the success of the Project. (Doc Meetings 12Q2-01)

Though this was suggested as a way forward, a separate work stream was never set up. Instead, implementation of the EPaCCS became the primary responsibility of the project manager who worked alongside a PCT stakeholder.

[the hospice trustees] [...] obviously want to ensure that the [Blue] register is embedded in-- basically they want to set priorities and their priorities as far as I think, although we've got another meeting, is around ensuring that the [Blue] EPaCCS system is embedded in the local community, and they've asked me to focus almost exclusively on that (Int Project Manager 13Q2-04)

This meant that much of her time was spent on this one activity rather than overseeing the entirety of the Project, thus threatening the management strategy for the implementing the Project. The Hospice was first to implement the software, but there was little information regarding the Hospice's internal process for implementation within the project documentation. The focus of project meetings and of the project manager's work was therefore on the external implementation of the register which began with GPs.

The process of implementing in GP practices was not easy as each GP practice had to agree to use the software, sign-up staff members as users and undergo training to use it. It was intended to pilot the register with six GP practices in one locality, but this did not materialise. As an alternative, the project manager identified seven practices from two other areas to carry out the

pilot. The pilot mainly consisted of keeping track of who was using the Blue System EPaCCS. Implementing the register focused on functionality: arranging for login details, showing professionals how to use the EPaCCS and how to enter new patients and make changes to records. Additional training on how to do advance care planning and how to use various end of life tools was also offered to maximise the benefit of the EPaCCS, but rarely taken up. The purpose of this additional training was to demonstrate good practice and the patient benefit of the system. Only one carer mentioned how the EPaCCS influenced the care the patient received; in this case the information contained in the EPaCCS averted a trip to hospital as per the patient's wish:

During this visit the patient showed [the paramedics] a letter which the carer says is on the [Blue System] to say that she wants to be treated at home, so they respected this and seemed to have done what was needed at home. (P07 carer telephone interview 4)

Implementing the EPaCCS in GP practices started to pick up speed towards the end of 2012 when the end of life lead for one of the emerging CCGs agreed on behalf of the locality's GP practices to implement the Blue System EPaCCS. Also at this time the details of all hospice patients were added onto the register by care navigators in their spare time. GP practices were then sent a letter informing them that their patients had been added to the EPaCCS in a bid to encourage GPs to use the register:

we've just finished the process of putting all the patients known to the Hospice on the system [...] so now I'm currently writing to all the GP practices telling them which patients are on the EPaCCS system and then asking them if they want to be set up, trying to, well trying to encourage them to be set up as well (Int Project Manager 13Q1-03)

However, this progress seemed to unravel at the beginning of 2013 around the time of the dissolution of the PCTs and formation of CCGs. While some GP practices had been early adopters of the EPaCCS, the project manager was making little headway with the remaining practices and found it to be a "mammoth task" (Obs PDG 13Q1-10) to visit every GP and get them signed up. Around this time it was acknowledged that despite the efforts of the project manager, GP practices were unlikely to add patients onto the three separate registers in use in the region:

[X] said that GPs already don't want to have to use the [Blue System] Register and [Red System], so they are unlikely to want to put patients on [the ambulance system] too <she laughed at the thought>. (Obs PDG 13Q1-09)

This tension between the competing registers was present at the start of the Project when stakeholders had voiced their concerns, but selection of the EPaCCS was based on comprehensiveness for need rather than on potential for implementation.

Implementation outcomes

At the end of one year (1 October 2012 to 30 September 2013), only 24 practices of the approximately 88 in the region had a registered user within their practice. The majority of patients on the register had been added on by hospice staff with only two patients added by GPs indicating that while some GPs were signed up to use the Blue System EPaCCS they were in fact not using it in day to day practice. Thus GPs were characterised as either non-adopters or limited adoption. In June 2013 it was decided to abandon the use of the Blue System register because professionals, such as GPs and the ambulance service, objected to having to use multiple systems:

[Blue System] and [Red System] – this was the key issue and it was agreed that practitioners would not double enter information on more than one system. [Hospice] Trustees had met to discuss progress and funding of the Project with the recommended outcome that the Project integrates [Blue System] with [Red System] to develop a robust register. This was discussed by the group and it was agreed (Doc Meetings 13Q2-01)

During the first year of the Project the Red System had been upgraded so that in the second year it met the requirements of an EPaCCS, and so it was felt that the use of both Blue System and Red System was redundant. The unexpected development of the Red System during the Project clearly posed a threat to the use of Blue System as the main reason for GPs to switch to the Blue System from the Red System (compliance with EPaCCS guidance) was lost. The switch to advocating for the Red System as the EPaCCS was thus made in the second half of 2013, but by this time the partnership had begun to disintegrate which meant that apart from advising partners of this decision, no substantial action was taken to get partners to use the system as had been done with the Blue System. Ultimately the Project was not able to achieve widespread implementation of an agreed EPaCCS system during the project period. Without the establishment of a system-wide EPaCCS, the Navigation Centre would likely have been able to do very little for non-hospice patients as they would have had no information about them.

5.3 Seven strategies for implementation – to what effect were they used?

This section analyses how the seven implementation strategies identified in the plans were employed and offers explanation as to how they influenced the implementation process described in the previous section using the conceptual framework presented in chapter three.

5.3.1 Management structure and stakeholders

The management of the Project was primarily dependent on the engagement of a range of stakeholders at both the Executive Project Board (EPB) level and Project Delivery Group (PDG). On a day to day basis, members of the EPB had little to do in terms of the operation of the project (i.e. Navigation Centre, EPaCCS and work streams). Whereas the EPB met quarterly, the PDG met on a monthly basis and was more engaged with the running of the Project, overseeing the progress of the Navigation Centre, EPaCCS rollout and tasks within the work streams. From the observation of the meetings and interviews with stakeholders, it seemed that ideally the relationship between the three tiers of the Project would have consisted of the work streams completing tasks, the PDG would have facilitated cross-fertilisation of ideas between the work stream groups ensuring that they were working in congruence, and then the EPB would approve their ideas which would then go forward for operationalising and implementation into practice. Essentially this set up should have allowed for tasks to progress in stages from developing, to approving, to implementing:

We had the Executive Board for more sort of rubber stamping on the recommendations from the Project Board and then maybe they'd send it back down to say 'yes we agree on this now discuss about implementation' (Int Stakeholder 03)

There was a feeling among PDG members that the EPB was not providing feedback to the work streams or making decisions which would have allowed them to make more progress with their tasks and provide the necessary strategic level perspective:

I think there was a bit of a gap because what, what we didn't get was sort of feedback from the Executive Group (Int Stakeholder 03)

Yet it was felt at EPB level that the work streams had not produced anything to comment on:

the workstreams didn't progress the work that they were asked to progress (Int Stakeholder 10)

However, the work streams had produced some outputs: recommendations were put forward for e-learning modules for the workforce and the 'palliative medicines pathway' was produced, but these did not appear to be disseminated beyond the work stream or PDG level for discussion and 'rubber stamping' at the EPB. Both the PDG and EPB meetings generally consisted of progress updates with little constructive feedback being shared between the groups. The relationship between the groups seemed to be characterised by conflicting expectations and lack of communication, as the above comments demonstrate. The literature review suggests that facilitating communication and conflict resolution would be managed by the project manager, however, there was a feeling among some stakeholders that this was not done effectively.

I think you know, holding the work streams to account, keeping the momentum going and the pace just wasn't there from a project management perspective. (Int Stakeholder 10)

Another stakeholder suggested that lack of effective management may have been because the project manager did not have any authority over partner organisations and therefore perhaps lacked the stick that was needed to manage the Project:

I think the other thing that was missing was the definite use of a project manager who was totally integrated with the locality, the Project and had a degree of authority to push things along, wasn't there either. (Int Stakeholder 05)

Each partner organisation was meant to be represented within the Project management structure in order to feedback between the Project and their respective organisation to provide a strategic overview for the Project. This would have also possibly given the Project credibility to implement the EPaCCS and work stream outputs within partner organisations in lieu of an authoritative project manager. It was expected that the seniority of the people involved in the EPB would actually lead to organisations adopting the changes proposed in the Project, though this did not materialize:

implicitly the Project Board people were originally very senior people in organisations with the intention that if they signed up to the principles, they would then have a responsibility for leading that organisation to deliver. In reality that certainly hasn't happened and as I said for some organisations, particularly CCGs one wonders whether there is any mechanism for actually getting people to do (Int Hospice Director 13Q3-05)

Project partners participated in the management structure by choice rather than by mandate. A partnership based on goodwill was felt to be inadequate by one stakeholder:

Developing a pathway and developing a whole set of principles and good practice is fine but sometimes you need a stick as well and it didn't really feel that there was a stick there. (Int Stakeholder 07)

Irregular attendance by stakeholders had a detrimental effect on the management of the Project. In total 23 different people attended the six EPB meetings: 5 people who were originally nominated to participate never attended; 8 people attended as deputies who were not originally listed as members; and only 6 people attended at least half of the meetings (Table 5.8).

Representation from GPs and CCGs was minimal at all levels, from work streams to the EPB. The lack of participation was blamed on the NHS reforms which started during the project period:

There was a lot of change and flux in the system at the time, particularly with the transfer of the PCTs to the CCGs and I think [the county council] were also undergoing quite a significant reorganisation at the time so I think that actually affected the level of engagement from key people which is why the overall Project I don't think got delivered in the way that was envisaged. (Int Stakeholder 02)

There were some committed stakeholders who were present throughout, more so within the PDG than the EPB (Table 5.9). Representation from social care was missing from both levels at all but one meeting, and CCG representation was missing at PDG level, which stakeholders suggested was due to the health and social care reforms. As members of the EPB were selected based on their executive authority within their respective organisations, it was perhaps more important for particular individuals to attend, whereas with the PDG it was perhaps more important to simply have organisational representation; therefore the EPB table is presented at the individual level and the PDG table at the organisational level; an individual level table for the PDG is available in Appendix 10.

Table 5.8 Individual attendance at Executive Project Board meetings

Listed as EPB member at start of Project	Organisation	Individual Code	Meeting number, month and year of meeting							Total attendance	
			1 Dec 2011	2 Mar 2012	3 Jun 2012	4 Sep 2012	5 Dec 2012	6 Mar 2013	7 Jun 2013		
*	Hospital	A	A	A				A		3	
	Ambulance	B	B					B		2	
*	Ambulance	C		C						1	
	Ambulance	D			D					1	
*	GP/CCG area 1	E	E	E	E				E	E	5
*	GP/CCG area 2	F									0
*	GP/CCG area 2	G	G	G	G						3
*	GP/CCG area 3	H							H	H	2
*	GP/CCG area 3	I									0
*	GP/CCG area 4	J									0
*	GP/CCG area 4	K		K	K						2
*	GP/CCG area 5	L			L					L	2
	GP/CCG area 5	M							M		1
*	Commissioning	N	N					N			2
	Commissioning	O			O			O	O	O	4
*	Commissioning	P	P		P						2
	Community care	Q								Q	1
*	Community care	R									0
*	Community care	S			S						1
*	Community care	T			T						1
	Hospice	U	U	U	U			U	U	U	6
*	Hospice director	V	V		V						2

Meeting cancelled

	Hospice	W	W		W	2
*	Mental health	X		X		1
	Social care	Y		Y		1
*	Social care	Z				0
*	Project developer / manager	£	£			1
*	Project manager	\$			\$ \$ \$	3
	Total representatives	28	10	6	13	6 7 7

Table 5.9 Attendance at Project Delivery Group meetings by organisation/ Work stream chair

Organisation type/ Work stream (WS) ¹	Meeting number, month & year of meeting										Number of meetings attended by representative	Total attendees per organisation/ WS
	1 ² Mar 2012	2 May 2012	3 June 2012	4 Jul 2012	5 Aug 2012	6 ³ Oct 2012	7 Dec 2012	8 Jan 2013	9 Feb 2013	10 Mar 2013		
Hospital Trust										q	1	1
Commissioning – PCT		O	O	O	O		O	O	O		7	1
Community care				d	d,i				i	i	4	2
Data analyst		g									1	1
Hospice		W,c	W	W,p			W	W	p	W	7	3
Project manager		\$	\$	\$	\$		\$	\$	\$	\$	8	1
Social care				e							1	1
Voluntary 1		b		b			b		b		4	1
Voluntary 2		h			h				h	h	4	1
Unknown			j	a,n			o				3	4
WS chair – Communication		N	N	N	N		N	N	N		7	1
WS chair – Drugs & Pharmacy		r		r			r	r			4	1
WS chair – IT& Audit		m		m					m	m	4	1
WS chair – Patient Pathway				t	t						2	1
WS chair – Service Users		k	k	k			k		k	k	6	1
WS co-chair – Workforce Edu. & Training		f,s	f	s	f			f	s		6	2
Total attendees by meeting		13	7	15	8		8	6	10	7		

¹ Only those who attended at least one meeting are included in the list as there were no named representatives for who should attend as was the case with the EPB.

² No attendance list recorded in minutes of the first meeting and no observations

³ No minutes recorded for meeting and no observations

Identifiers are unique across EPB and PDG tables 5.8, 5.9 and Appendix 10; therefore individuals who attended both meetings have one identifier in all tables.

Lack of output production by the work streams seemed to indicate that the management structure was not effective at holding partners to account, particularly with regards to attendance and engagement. However, members of the Executive Project Board did not have authority to demand participation by partners external to their respective organisations. Poor attendance by some partners conveyed a sense of lack of cohesion which may have discouraged partners from participating which then led to a negative cycle of poor participation and poor progress:

the reason people don't bother with something is if they think it's not going to deliver anything. That's why people drop away, so at the beginning obviously it all sounds like a good idea unarguably, so no problem in getting people to come along initially, then people just vote with their feet if they don't think it's going anywhere don't they? (Int Hospice Director 13Q3-05)

5.3.2 Workforce capacity

Money was allocated to the Project for additional human resource for two reasons: 1) to drive implementation (through the appointment of a project manager and a data analyst who could provide feedback on progress); and 2) to create capacity or slack in the system which could be used to fill gaps in care and achieve the Project aims of improved care for patients.

A project manager was in position prior to the start of the project and was involved in the project planning, but left the role and was replaced by a second manager who took over just after the launch of the Project. As partners had begun meeting prior to the official start date of the Project, most stakeholders were aware of this change taking place and several commented that this change had been unhelpful in the overall progress of the Project.

I think the fact that one of the biggest setbacks was the change in project lead you know the fact that one project manager left and another one came in and so basically it was – I think they had just taken one step forward and then they had to take about five steps back. (Int Stakeholder 06)

Indeed, the project manager felt there was a lack of clarity regarding what her role would be in certain aspects of the Project.

[project manager] unclear about what her role will be in implementing the register, how is she meant to get the partners to use the register? (Obs PDG 12Q2-04)

I don't think it's ever been clear what [the Hospice] want to achieve for the Project [...] I think there's a lot of unknowns in the internal work and I think as a Hospice we need to sit down and work out where we're going with that. (Int Project Manager 13Q1-03)

Stakeholders expressed a sense of a lack of overall management and direction in driving the project:

the actual project management maybe could have been more structured I think. We would have no sort of contact in between one group and the next, other than the people in the group contacting each other via email or it seemed to be very loosely monitored. I don't know what the remit for the project manager and how much they should have really pulled it together and you know worked with all the different groups to make sure they had communication channels but it felt very, being part of it, very unstructured, if that's the right word. (Int Stakeholder 03)

ultimately most people need to be managed. We all have managers otherwise we wouldn't need them so it didn't really feel like we were being managed so we just kind of drifted away, you know if the appointments stopped coming and you stopped getting chased (Int Stakeholder 07)

Stakeholders seemed to feel that the project manager did not facilitate the project tasks and they were not being held to account, but likewise the project manager did not have any authority over the stakeholders to ensure they contributed their share to the Project. Perhaps stemming from an apparent lack of effect, the project manager role was dissolved in the second year and subsequently from a documentation and meeting point of view nothing further happened within the partnership for the last nine months of the Project.

The second role created for the purposes of implementing the Project was the role of data analyst. The data analyst was appointed at the start of the Project to produce audit data to monitor outcomes. As the focus of this role was on the production of documents for monitoring, this will be discussed in more detail under the section on 'Monitoring'.

The Project also allocated funds to increase capacity within the health and care system in order to deliver key project outcomes which hinged on the hiring of additional clinical staff, particularly Advance Nurse Practitioners (ANPs) for community prescribing:

the ANP will have the added value for patients and colleagues they work with of being able to complete more of the 'first contact care' as a complete episode [...] This aims to

help reduce the complexity of the system for patients, free up as much professional time as possible both internally for the hospice and externally for professionals by way of us all not duplicating elements of care or assessment where we do not need to. (Doc Operational 12 Q2-02)

While the care navigators were recruited with little trouble, the recruitment of the ANPs and a palliative care specialist consultant proved challenging. Of the planned workforce increase, only two trainee ANPs were recruited from within the existing Hospice workforce which meant that capacity was not actually added to the system but rather moved around within the Hospice workforce.

Adding human resource to boost the numbers of professionals in the care economy and to deliver the Project aimed to create a supportive and facilitative context within which stakeholders could participate and improve care. How effective this increase in capacity is seemed to depend on the characteristics of the individuals fulfilling those roles.

5.3.3 Division of work

Project activities were divided into separate strands of work in an attempt to make project delivery more manageable. As has already been described, the Navigation Centre was one strand as were the various work streams. Three work streams were focussed on development tasks: Pharmacy & Drugs; Patient Pathway; and Workforce Training & Education. Three other work streams were focussed on implementation related activities: Communication; IT, Audit, Evaluation & Research (IT & Audit); and Service Users. Thus development and implementation activities took place simultaneously.

Both types of work streams had variable success. The Pharmacy & Drugs work stream made relatively good progress with their tasks compared to the Patient Pathway and Workforce Training & Education work streams. The success of this group was felt to be due to utilising the partnership approach:

The [Pharmacy & Drugs] group had met regularly and had good attendance from all parties. Significant progress has been made. [...] The [PDG] all agreed that the work undertaken was excellent and felt this should be highlighted to CCGs. (Doc Meetings 12Q4-01)

Likewise the IT & Audit work stream completed several tasks quickly: they assessed potential software solutions and made a recommendation to the Executive Project Board, appointed the data analyst to collect audit data, and facilitated the evaluation which would be ongoing

throughout the Project. While the progress made in both the Pharmacy & Drugs and IT & Audit work streams may have been down to the scientific background of many of the people working in these groups, the multidisciplinary nature of these groups and the observations and comments from the stakeholders suggests that these two groups progressed because they had clear, concrete aims and tasks whereas the tasks of other groups were more nebulous and thus progress was slower. Both the Communications and Service Users work streams struggled to find activities suited to their aims. After just one or two early meetings it soon became apparent that group members felt that their work was dependent on the work of others. This was evident in one of the aims of the Communications work stream:

- *To ensure that all communications in relation to the Project are presented in an open and jargon-free way and are customised to the needs of the audience. (Doc Operational prior-19)*

This was also the case for another work stream which was dependent on the outputs of others:

the other work streams weren't as far ahead as us and therefore [the work stream output] just fell at that last hurdle really. (Int Stakeholder 04)

Another barrier to work was having nebulous and wide reaching aims which made them seem unfeasible:

I don't think it did achieve its aims and I think part, actually part of the reason was, I'm not sure that we were totally clear about what the aims of the work stream were when we set it up. (Int Stakeholder 02)

With lack of clarity of purpose and tasks linked to the outputs of others, it seems unsurprising that the work streams stagnated. While many of the work stream activities were interrelated and therefore not entirely separate packages of work, the implementation of the Navigation Centre was solely the responsibility of the Hospice which may have contributed to its relatively successful implementation.

I think there is an element of we have total control over it, we were having that site with us so we were able to manage the whole thing as we saw fit and have control over it. (Int Stakeholder 05)

However, being led only by the Hospice may have contributed to its lack of integration within the end of life care system more widely as had been planned. It was recognised in a progress update from July 2012 that its launch "*Probably could have been communicated better*" (Doc Operational

12Q3-05). Indeed, other stakeholders were not able to comment on the Navigation Centre because of their lack of involvement in its implementation.

In looking across how work was packaged, there seemed to be a number of barriers and facilitators to how effective dividing work was as a strategy. Where the aims and activities of the package were clear, such as in the Pharmacy & Drugs work stream, people were able to produce the work required. Where the aims and tasks were less clear, such as in the Communications or Patient Pathway work streams, these groups struggled to produce their expected outputs. Clarity of task seems to also be linked to whether the package of work was truly an independent parcel or whether the expected work was perceived to be dependent on the work of others. In some cases pieces of work were not actually divided, such as with the Service Users group being expected to *“Test and evaluate outputs from other work streams with service users/carers”* (Doc Operational prior-31). Where work was felt to be independent progress was made up until the point where the next steps relied on the outputs of other groups.

All stakeholders interviewed at the end of the Project agreed that lack of progress within the work streams hampered overall achievement of Project aims. This lack of progress seemed to stem from low engagement by stakeholders which then produced a negative feedback cycle of low attendance and lack of progress.

5.3.4 Monitoring

There were three types of monitoring activities that took place during the course of the Project: planned audit reports, piloting of the EPaCCS and data which was collected *ad hoc* as issues arose.

The data analyst was employed to collect and analyse regional system-wide end of life data to monitor the effect of the Project on patient and service outcomes which included: patients dying in their preferred place, experience of care, admissions to hospital, resuscitation orders, reduced duplication of work, and number of patients with end of life medications at home. Three audit phases had been planned for April 2012, January 2013 and July 2013 in order to show progress over time. Though the Project began in April 2012, the baseline data report was not ready until the beginning of 2013 by which time many of the work streams had stopped meeting. The data collected aimed to be comprehensive in describing all deaths suitable for palliative care in the region, though some datasets were only available for certain groups of patients, such as preferences for place of death which were only accessible for patients who died under hospice care as this was not recorded as standard practice across all care providers. While the report aimed to describe all deaths, variable recording practices across services meant that it presented

a limited picture where standard data was not available. Given the breadth and complexity of the audit report, it was felt among stakeholders that it was unclear what actions should be taken in light of the data and that the data needed to be turned into information for them to act on. Thus monitoring did not result in action:

I did get various attachments to emails. Again I would look at them and it would have been nice to sort of have a little bit more explanation. [...] You have statistical evidence but you need to make sure you are going to do something with it. There's no point collecting data for data's sake if it's not going to actually be turned into something tangible really. (Int Stakeholder 09)

The second monitoring activity was the piloting of the register in GP practices. The pilot seemed only to consist of the project manager training the sites in how to use the EPaCCS and keeping a record of who had received training. The term 'pilot' in this case seems to just refer to early adopter sites and so was not used as a monitoring activity for feeding back into the implementation cycle.

Audit reports and the pilot were both planned monitoring activities, but as the project progressed additional data was collected as needed when issues arose. *Ad hoc* data was primarily collected on the Navigation Centre as there had been no specific plans to assess how it was working. Calls were initially monitored by the project manager on a monthly basis from the beginning of 2013 when the call handling algorithms were available for use, though the system capability only allowed for extracting details of call volume and not of the details of the calls or how they were navigated. Subsequently, it was decided to carry out an in-depth call audit in July 2013 over the course of a month to try to understand what types of calls were being received and how they were handled:

for the month of July obviously we collected the dataset about the calls which the [care navigators] filled in but really it's almost all sort of operational information rather than any clinical information, so we just know about when the calls are coming in, the duration of calls and where they tend to be navigating them, but in fact the data show what we suspected which is that very few calls are actually navigated anywhere other than internal to the Hospice. (Int Hospice Director 13Q3-06)

No observable changes were made to the operation of the Navigation Centre in light of the findings of the audit.

Monitoring of the EPaCCS simply involved the project manager feeding back to the Project Delivery Group how many patients had been added to the register and how many GPs were signed up to use the Blue System EPaCCS.

[Project manager] updated the group on progress of the [Blue System] Register.

- *The roll out to practices continues with most practices in [CCG area 1] signed up or in the process of being set up. About 6 practices have been set up in [CCG area 2] and 4 in [CCG area 3]. A plan is in place to widen this and to target [CCG area 4] GPs.*
- *All appropriate patients under [the hospice] have been added to [Blue System] and the total number is standing at 350 patients on the register (Doc Meetings 13Q1-03)*

In reviewing the documentation, there was little produced to report on progress apart from a report to the Hospice trustees. The lack of reporting was reflected by one stakeholder who felt that there was little clarity around who should be doing what and when:

when I've done projects before, we have this amazing Gantt chart of what we should all be doing in what time frame, what we should deliver, and I was hoping that was part of the Project so we would have; what we should be doing with our work stream (Int Stakeholder 08)

There appeared to be two barriers to the successful use of these monitoring activities. Firstly, the Project plan underestimated the governance difficulties that would be encountered in accessing sensitive patient identifiable information and the approvals processes took nearly a year. The data analyst was unable to access the relevant data in a timely manner which meant that monitoring reports were unavailable at key points in the Project:

maybe we should have concentrated on getting that baseline data first before we actually started to implement the Project I don't know because I think it was almost as if the Project had sort of almost began to fade away by the time we actually got a good set of data. (Int Stakeholder 02)

Additionally, the call handling system used by the Navigation Centre did not have the capacity to produce useful information for monitoring purposes so the Project team was unable to assess whether the Navigation Centre was meeting its aims or what impact it is having.

The second barrier was that the data that was available did not seem to be used to its full potential or was not investigated in detail. Specifically, the reports and *ad hoc* data that were generated did not seem to lead to many changes despite mediocre progress. This is reflected in some of the comments from the stakeholders in which they said they were presented with information but then nothing further seemed to come from it:

there seemed to be quite a lot of missing data or data that needed further investigation you know such as why were people terminating [phone calls] because there were some queries about whether it was GPs coming in on the professional line that were hanging up and not waiting for the call to be answered so again they weren't sure. There are a lot of 'not sures'. (Int Stakeholder 06)

Planned monitoring activities, therefore, did not appear to be particularly influential in the implementation process in the way that might have been expected. However, this is not to say that the Project did not make corrections as it evolved, as clearly the decision to abandon the Blue System for the Red System was in response to experience, but it seemed that monitoring activities were loosely if at all related to the decisions that were made. Instead it seems that more experiential, qualitative forms of monitoring influenced decisions that were made. For example, lack of access to GP practices for setting up the Blue System EPaCCS was not formally recorded in a 'monitoring' sense, but did influence the views among the PDG and project manager and ultimately drove the switch to Red System.

[GP] just wanted to raise the issue that [GP area] practice managers were concerned that there are a lot of systems out there which don't talk to each other (referring to role of EPaCCS); [meeting chair] said that this is a noted problem (Obs EPB 13Q2-06)

the take up of the use of [Blue System] by GPs has been limited. A number of practices have expressed concerns about having to enter information into separate systems. The Executive Project Board acknowledges this problem and have been holding discussions with [the out-of-hours service] about ways in which the Electronic Palliative Care Co-Ordination System (EPaCCS) element of [Red System] could be improved and access by a wider group of users introduced. (Doc Operational 13Q3-01)

Additionally, the project manager's contract was not renewed for the second half of the Project and was explained as a cost-saving measure. It seems likely that the role was not felt to be influential in the process given the difficulties with partner engagement and thus the decision was made to proceed without a project manager.

5.3.5 Communication

Communication was a key strategy in engaging stakeholders and organisations in implementing the project outputs, particularly with regards to the EPaCCS. There was an assumption that just telling organisations and professionals about the system would lead to change:

I think people thought that we'd go to the CCGs, they'd say yes implement it, they would support it, you know write to the GP and everybody would be saying; 'oh no lets implement [Blue System]' but of course it hasn't happened (Int Project Manager 13Q2-04)

There were three types of communication strategies: formally arranged, face to face meetings; informal, word of mouth; and written and online material.

Formal meetings

Face to face meetings were the primary strategy for engaging service providers with the Project and particularly in spreading the uptake of the EPaCCS register. The project manager, PCT stakeholder and members of the hospice staff allocated to the Project met with key people from community nursing, social services and the numerous GP practices across the area to encourage them to use the Blue System EPaCCS. Communication with these services seemed to be limited to these meetings in which the Project and specifically the register were explained, they were shown how to use the register, informed about the Navigation Centre, and then assuming those present agreed to use the EPaCCS, were then set up with login details to use the system:

so I've seen all the district nursing leads, explained, gone through [Blue System] and I'm just setting them all up with logins and they're very keen -they all like it. Social Services have all been seen and they're all getting in the process of getting their logins, so we are getting there, so we've got district nurses, Social Services and nearly all of [area 1] GPs (Int Project Manager 13Q2-04)

However, the project manager expressed concern that this work did not seem to lead to service providers adding patients to the register:

but they're still not putting patients on there. I don't know why. I don't know how to- I don't know whether to email them again or go back and see them and say 'why aren't you putting patients on there?' (Int Project Manager 13Q2-04)

The EPaCCS implementation plan assumed that once informed of its benefits and trained in its use, professionals would then use the system. The project manager's concern indicates that no monitoring activities were planned to assess non or low usage. She does speculate that lack of

use of the register might have been because of the general difficulty that professionals have in actually carrying out advance care planning:

but I still think that we're not having the advance care plan discussion in the Hospice, in the community, anywhere. I just don't think it's happening, personally. (Int Project Manager 13Q2-04)

Therefore, in addition to the technological challenges of installing the Blue System EPaCCS, having to ask patients about their end of life choices posed an additional challenge to professionals and the implementation strategy was not sufficient to address both technological skills and confidence issues.

Word of mouth

In addition to formal project communication via meetings, communication was also done by stakeholders and 'non-project' related Hospice staff in more informal ways to raise the profile of the Project and encourage organisations to implement the Project outputs. For example, both stakeholders from the ambulance service and community nursing stated that they cascaded relevant information about the Project within their organisations:

we haven't got a specific guide anymore for end of life so this guide that we developed through the pathway, through this work stream has been cascaded throughout all of [the Community Health Trust] and it has gone down incredibly well. (Int Stakeholder 09)

However, this sort of provincial communication could lead to variability in the messages being delivered. Hospice managers were encouraged to spread information about the Project, but because they were not a part of the Project group, there were concerns over how they were representing the Project:

she was concerned that Hospice managers were being sent out to meet the various different locality 111 managers to represent the Project but she was unsure about how consistent they were being in their message. (Obs PDG 13Q1-08)

Written and online materials

Written forms of communication were also utilised as part of the Project, including a Project website. The Project was promoted through bulletin updates to hospice staff and via a GP weekly bulletin, though it was not clear over how many weeks the Project was advertised.

On the whole there seemed to be a feeling of poor communication throughout the Project. One stakeholder commented that she did not think that the Project was advertised as something that service providers needed to be involved in:

I can't remember it being sold as a great concept that we all really needed to get involved with to make a difference, to get those changes made. (Int Stakeholder 03)

Indeed even hospice staff seemed to not know the function of the Navigation Centre which was provided by the Hospice:

Issues still remain in the Navigation Centre relating to inappropriate calls. Hospice staff seem unaware of the purpose of the Navigation Centre (Doc Operational 13Q1-04)

It was suggested by one of the stakeholders that perhaps the Project communications were not right for the scale of the project:

maybe it comes back to communications, maybe we didn't have the right strategy to ensure that it did get implemented in all the different organisations and I think that was one of the challenges because it did involve so many organisations that could get it implemented successfully was going to be a huge task I think. (Int Stakeholder 02)

It seems that as the Project did not progress as expected, partners had difficulty knowing how to adapt the communication strategy or indeed what needed to be communicated.

One of the big gaps in the communication strategy seemed to be in regards to the opening and purpose of the Navigation Centre which seems likely to have affected its utilisation. While eight carers clearly indicated that they had used the service, many were not even aware of its existence:

Whereas last time [carer] hadn't heard of the Navigation Centre, this time she believes she was given a number for it, but I had to explain what it was. (P03 carer telephone interview 2)

[Carer] says she hadn't made any phone calls and hadn't heard of the Navigation Centre. (P06 carer telephone interview 1)

5.3.6 User Involvement

User involvement as a strategy was to be organised through the Service User work stream. The group represented the patient and carer perspective and ensured that Project outputs would be

acceptable to the end user. The group only met once because their work depended on the outputs from other work streams and there was little for them to discuss:

we were asked to look at the outcomes and how that would impact on service delivery from the user perspective but as very little was delivered to us we couldn't – you know there was no point in meeting because there was never anything to feedback. [Int Stakeholder 06]

The work of the Service User work stream was intended to follow the work of other work streams, but as outputs were not forthcoming there was nothing for them to support in implementation.

5.3.7 Training and education

Training was used primarily as an implementation strategy for the EPaCCS register, but also as part of the Project to upskill the workforce to improve the delivery of end of life care. For implementing the Blue System EPaCCS, the project manager and an IT technician met with interested professionals to demonstrate how to use the register. It was then expected that those professionals would in turn train other people within their organisation in a 'train the trainer' or cascade training model.

Dates	Times	Implementation	People required
04/09/2012	10:00 – 13:00	End of Life Care Register (Web Access)	Managers / Cascade Trainers
04/09/2012	14:00 - 17:00	End of Life Care Register (Web Access)	Managers / Cascade Trainers

Doc Output 12Q3-

Data was not collected on how many professionals were trained within each of the organisations using this method. To go with the 'train the trainer' sessions, written materials to educate professionals were produced by the project manager adapted from existing documentation used for an EPaCCS in a different region. Thus training within an organisation adopting the Blue System EPaCCS was more diffuse rather than centrally controlled.

While the training for the register focussed on its practical use, additional training was also planned in order to improve professional understanding of end of life care issues to maximise the benefit of the EPaCCS. The Workforce Education & Training work stream recommended a number of e-learning packages for different groups of professionals to increase their knowledge.

The drawback to such learning modules was that they were self-regulating meaning that their implementation could not be controlled:

Our only issue is that we are not able to administer the information, so unless staff complete and print certificates, and then send them to us, we have no way of knowing who has/has not completed, or which modules staff are attempting. (Doc Operational 12Q3-08)

The project manager felt that education was an important part to how effective the EPaCCS register would be:

unless you go round to the GPs trying to influence them with training packs and the [Supportive and Palliative Care Indicator Tool], how to identify patients earlier you know you're not going to get any benefits of the register (Int Project Manager 13Q2-04)

As discussed under communication, training and education activities assume that once informed and trained, professionals would use the system. But this process assumes that individuals would perceive the innovation (EPaCCS) to have some benefit to their work. Some individuals may have felt this to be true, but it seems more likely that many professionals perceived this to increase their workload without sufficient benefits to their work or their patients because of the low overall usage.

5.3.8 Analysis of the use of implementation strategies

The foregoing sections present seven strategies which were identified by using the *a priori* conceptual framework, but these do not seem to have been thought of as implementation strategies by the project team because it was not clear from documents or interviews exactly how each strategy would lead to change. Instead, there seemed to be a number of assumptions about how change is created, such as involving senior people from different organisations would result in organisational change, or that being presented with an explanation of the register would lead people to want to adopt and then implement it. There seemed to be assumptions that the changes on offer were assumed to be simple and therefore not requiring a detailed implementation strategy for change. Only one of the implementation strategies (communication) loosely targeted the involvement of patients and carers, even though their engagement with the Navigation Centre (implementation outcome) would largely influence what patient and service outcomes could be achieved. From the data collected, the strategies do not seem to have been used in their fullest sense, so it does not seem appropriate to state whether they are effective strategies in their own right, simply that they were not used effectively here.

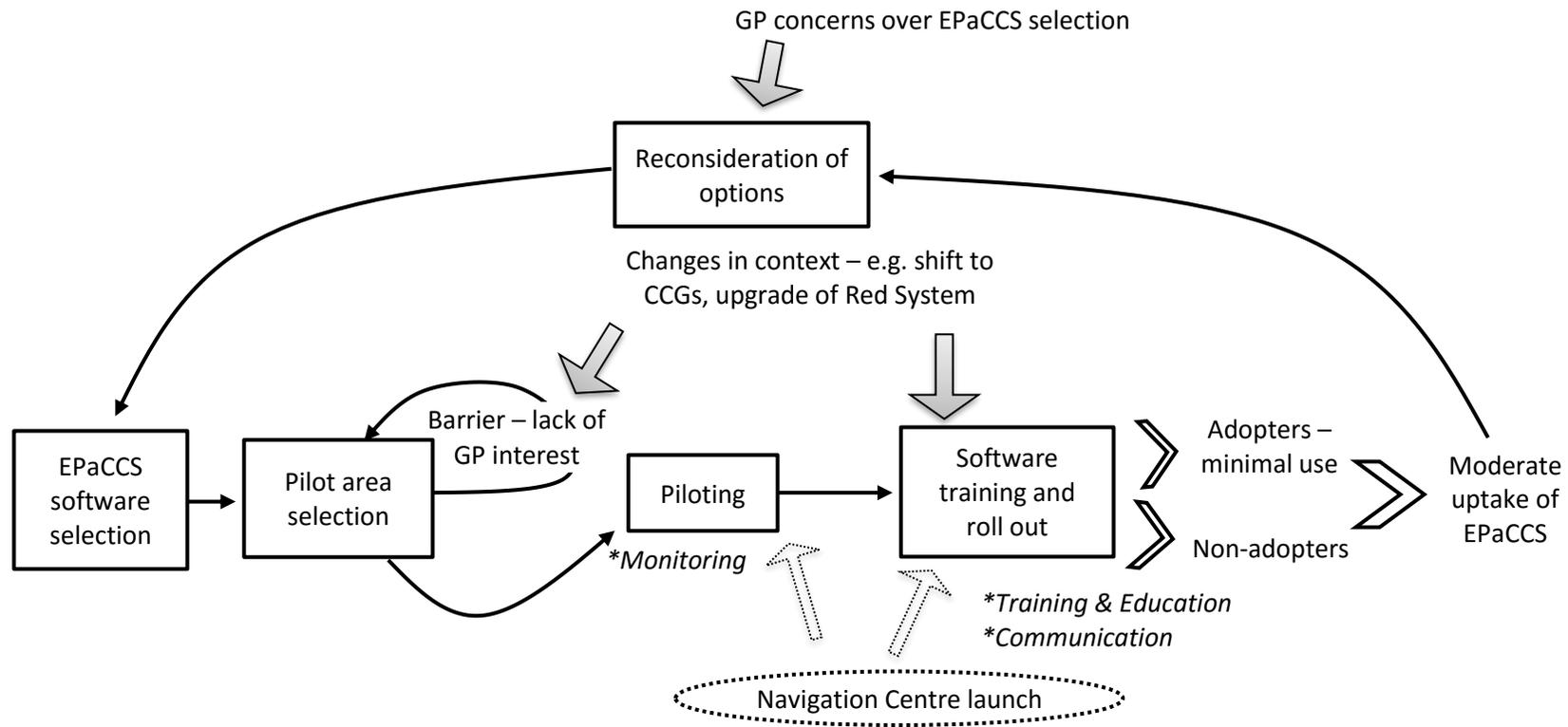
The implementation process seemed typical of service improvement initiatives whereby there is perceived to be a deficit in current practice and solutions are proposed which intend to rectify the problem; i.e. implementation as usual. The analysis of the implementation strategies appears somewhat negative, but they were only effective insofar as the other influences on the Project would allow, which will be discussed in the following chapter. These strategies comprise much of the work of the Project and therefore provide a useful starting point for understanding the shape of the process.

5.4 What shape did the implementation process take?

The foregoing sections have attempted to describe how a complex, dispersed programme of work unfolded over two years, particularly highlighting the seven strategies that attempted to drive implementation. The first thing to note is that the Project was a compilation of ready-made innovations and development activities: the EPaCCS, Navigation Centre and tasks within the work streams. In this sense it was more of a 'programme' with 'projects' under it and each of the 'projects' had their own requirements for implementation. While these components were meant to interlink to achieve the most effective outcomes, their implementation evolved separately. As this is the case it is sensible to discuss the shape of implementation for each of these components and then what this means for the implementation of the Project as a whole.

The progress of implementing the EPaCCS has been mapped out in Figure 5.4. What this shows is that implementation started with the selection of the software for the EPaCCS, was challenged by low adoption rates and acceptance of advance care planning training, and 18 months later, finished with a second selection for changing the software. It appears then that implementation of the EPaCCS was circular in that despite over a year of work the process had to be started again. In actual fact, the second EPaCCS register chosen (Red System) was already in use in many GP practices and so was essentially already implemented in some areas. It was this competition from Red System coupled with the improvements that had been made to it that proved to be a barrier to the widespread uptake of the Blue System EPaCCS. The improvements could not have entirely been foreseen in the planning phase and resulted in changes which indicate a non-linear process. However, at the end of the Project, apart from the Hospice, GP practices and out-of-hours service, no other services were using the Red System EPaCCS so it was not implemented across the region as intended. The implementation process of the EPaCCS did not go as planned and was characterised by a number of barriers, some of which became insurmountable and forced changes to be made, first with the pilot sites and then ultimately with the chosen software. While it appears somewhat linear, having to start over again due to lack of uptake and use indicates that the process is perhaps more circular.

Figure 5.4 Model of the implementation process of the EPaCCS register and progress during the project period

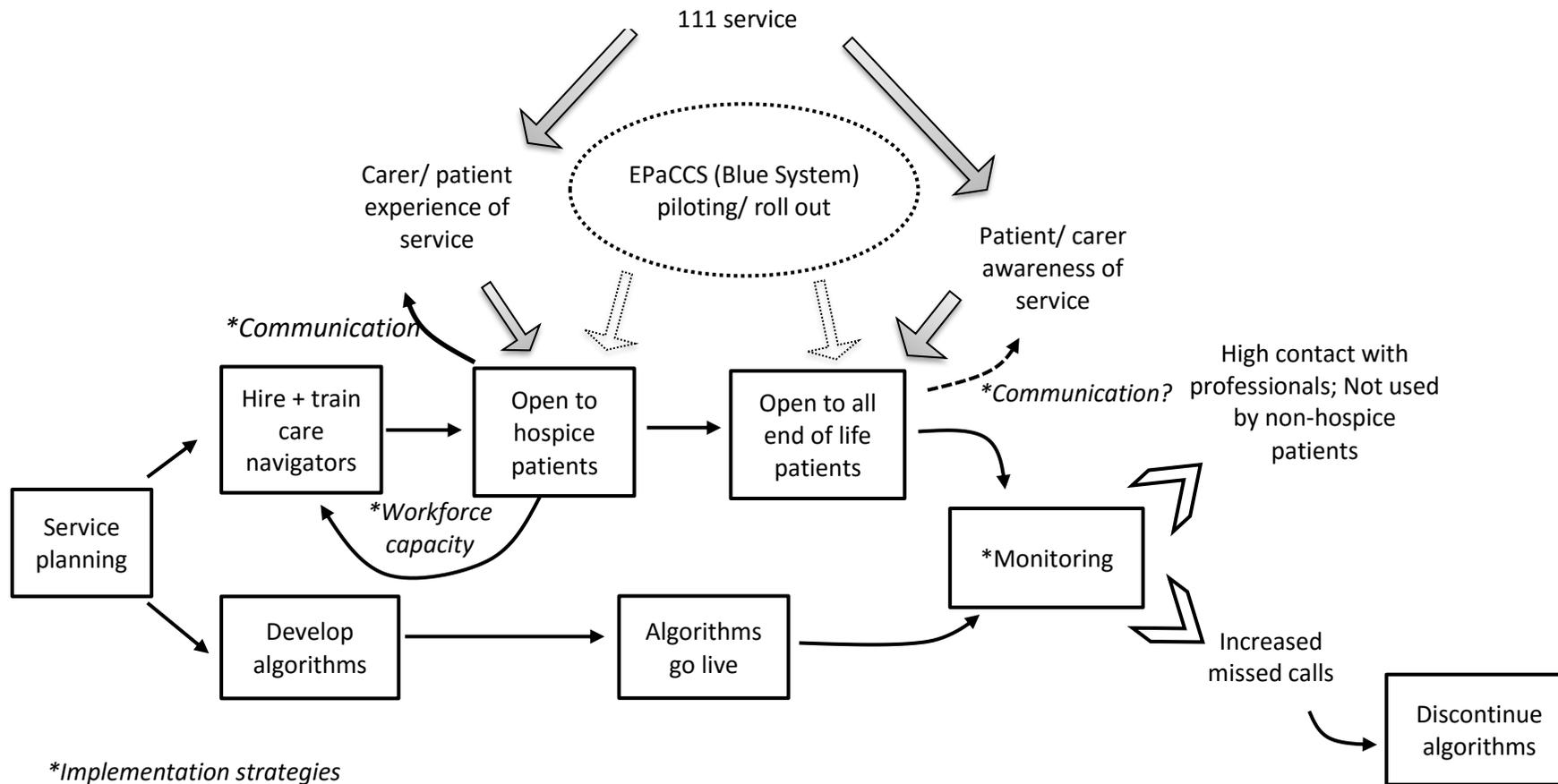


* Implementation strategies

The Navigation Centre proceeded closer to plan and therefore appears more as a linear process with step following step (Figure 5.5). However, a long time passed between development phases, thus there may have been some negotiation or difficulties which were not observable from documents or meetings because they were being dealt with by the Hospice internally. There were two parallel activities taking place: one was the initiation of the navigating service and the second was the development of the call algorithms. The algorithms should have actually been utilised by the care navigators but their development was more prolonged and so they were not available to use when the Navigation Centre launched. They were finally ready for implementation after approximately six months into the running of the Centre and the effect of using them was an increase in missed calls. It also seems likely that because care navigators had already had several months to develop a style of answering calls effectively, having to incorporate the algorithms into their work felt unnecessary, particularly because it did not seem to reduce work downstream (e.g. to referred professional). Therefore a more rational approach to implementation might have seen the algorithms developed prior to the training of the navigators.

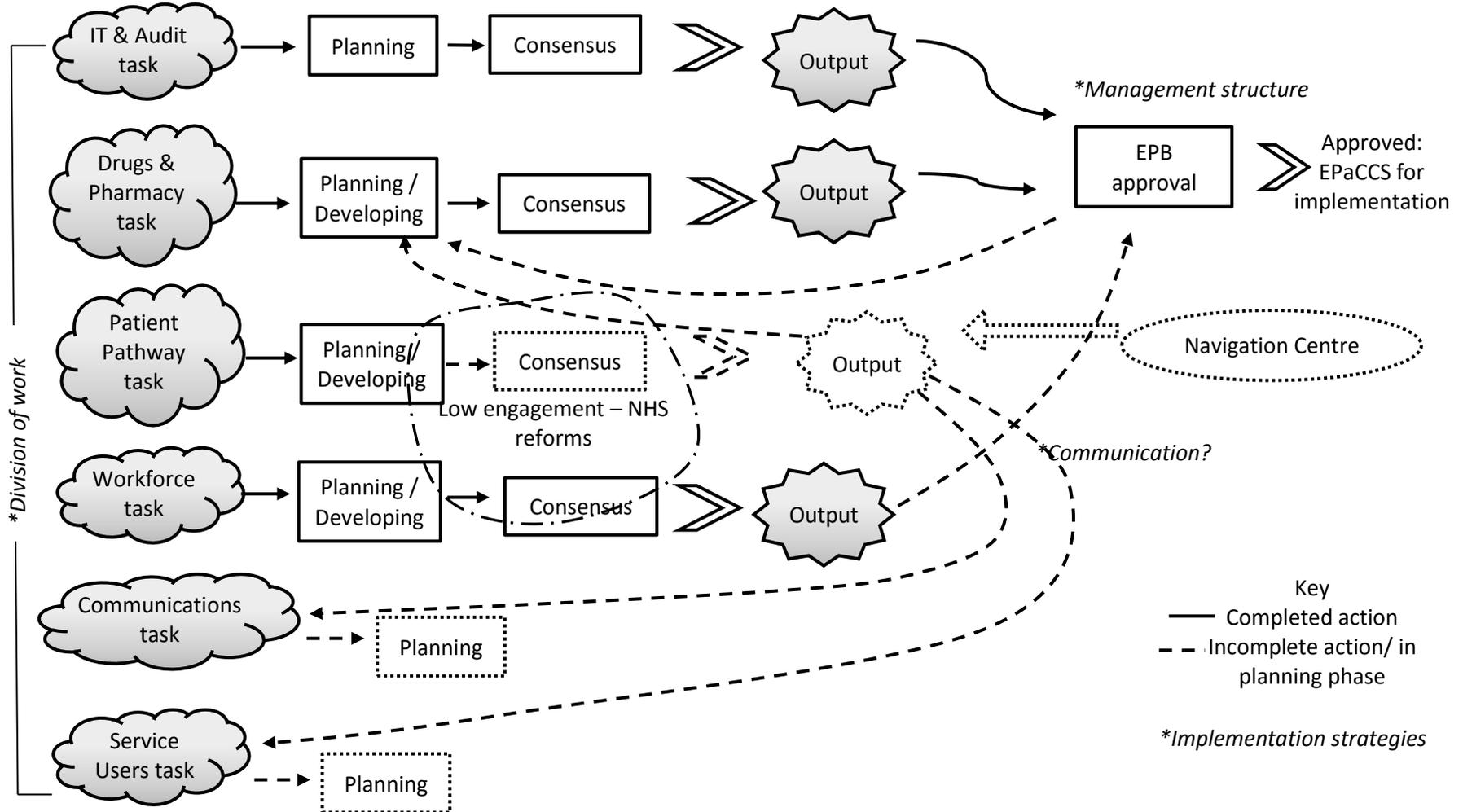
In theory the EPaCCS should have had an impact of the Navigation Centre, essentially that it should have been used by the care navigators, especially in dealing with calls from non-hospice patients. However, the care navigators reported that they rarely engaged with the EPaCCS and this was also observed, though this is possibly because they rarely received calls regarding non-hospice patients so had no real need to use the EPaCCS as the internal Hospice record system was sufficient. Therefore the tenuous relationship between the EPaCCS and the Navigation Centre is represented by dotted lines in Figures 5.4 and 5.5 because while there was an expectation that the two should interact, there was little data which showed this actually happening. The implementation of the Navigation Centre seems to have been little effected by either external events or internal project arrangements as it was essentially a standalone piece of work. Its implementation, while encompassing some development work, seems to have progressed in a fairly linear fashion.

Figure 5.5 Model of the implementation process of the Navigation Centre



The work streams achieved very little in the Project and therefore it is difficult to judge what shape their process took. Figure 5.6 shows what progress the work streams had made by the end of the Project. It also highlights how a number of the work streams were connected, where the tasks or development activities were dependent on the outputs of others which in some cases never materialised. There were a mixture of development and implementation activities taking place at the same time with some things progressing faster than others. Workforce Education & Training, Pharmacy & Drugs, and Patient Pathway work streams were essentially developing and producing outputs for implementation, whereas Communications and Service Users were implementation focussed. As planning activities did not progress in a timely manner, the implementation elements were not utilized accounting for their lack of activity. This process is clearly messy and interactional.

Figure 5.6 Model of task initiation to completion within work stream groups



One stakeholder seemed to feel that if tasks had been planned more sequentially then there may have been more success:

I think looking back some of the key things that were holding, held us up or stopped us achieving further and implementing things was because, for me, was that if they'd agreed the patient pathway at the beginning (Int Stakeholder 04)

At the outset there did seem to be some expectation that implementation, particularly the EPaCCS, would progress linearly in stages, but as has been described in the forgoing sections this did not go according to plan due to a number of internal and external influences:

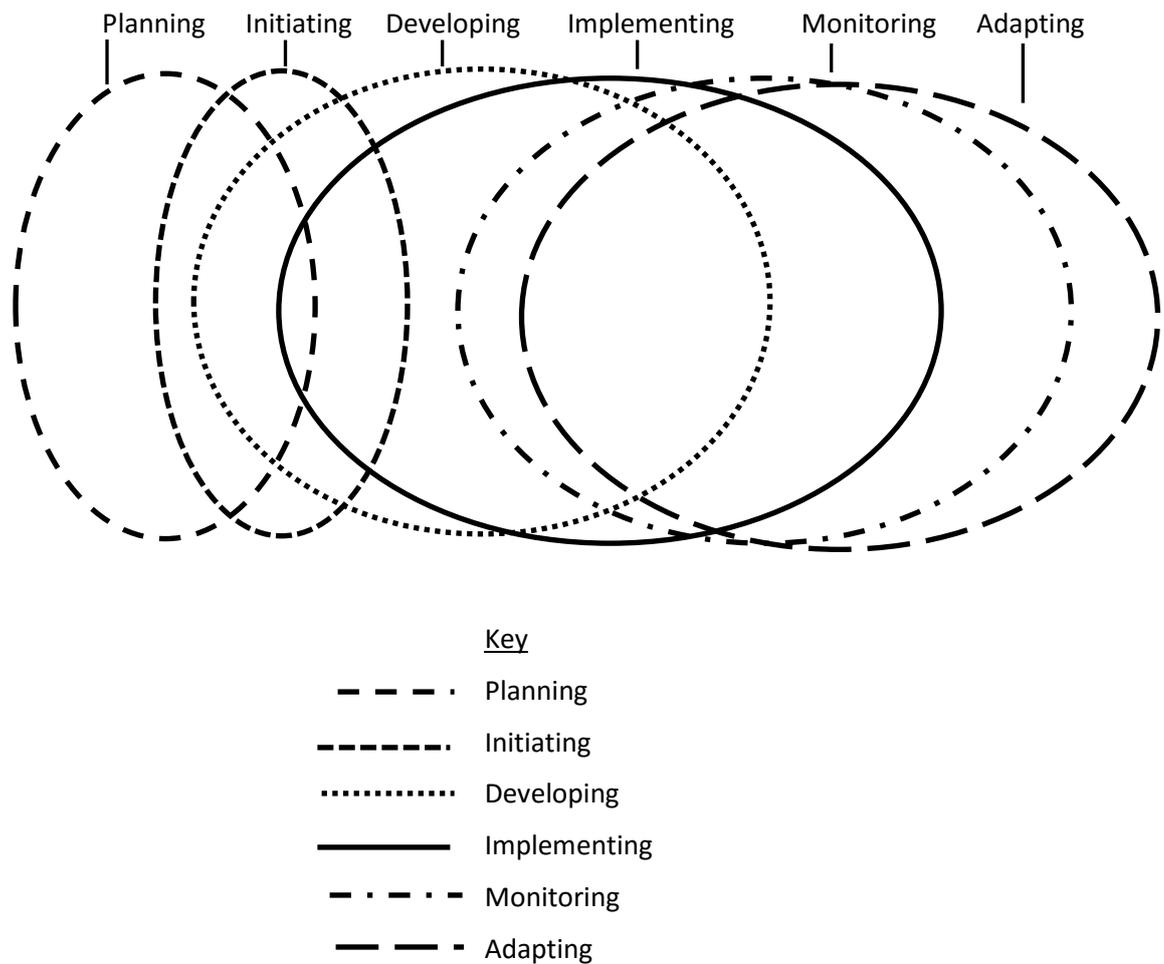
We're behind schedule with the [Blue System], with the register because I think the plan was; we set up the Navigation Centre, we'd implement [Blue System], I've got the plan for the implementation but I think people thought that we'd go to the CCGs, they'd say yes implement it (Int Project Manager 13Q2-04)

There were clearly assumptions being made about the preparedness of the partner organisations to adopt a new system of practice. This new system included the use of the EPaCCS, interaction with the Navigation Centre, and whatever the outputs of the work streams, such as the medicines pathway, might have been. The Project relied on national policy and the desire to improve patient care as cause for partner participation. While this perhaps did encourage stakeholders to come together, it was perhaps not enough to keep all partners around the table as the NHS reforms started to take shape.

The Project represents a complex programme with work at various stages – from elements having some evidence to others being developed during the Project by the partners to meet local needs. Problems for implementation seemed to arise when the elements were dependent on each other, essentially when the plans for development were circular and interdependent rather than linear and independent. The way that all elements of the Project progressed together seemed to be fairly organic, which may be a result of the loose management and idealistic assumptions about how the partnership would work. There seemed to be few expectations that certain steps needed to be completed prior to others and this was only discovered once the Project was underway, so the group had to adapt and make plans up as they went. The shape of the implementation of the Project could be described as interactional and messy which indicates an overall non-linear pattern. Figure 5.7 illustrates approximately how the phases of the different types of activities based on Fixsen et al's (2005) normative model of implementation overlapped during the implementation process. This sort of overlapping, continual process of negotiating changes may be typical of large partnerships whereby multiple stakeholders from various

backgrounds must all come to consensus in order for the Project to move forward. There is some order to the activities taking place, such that initiating takes place before adapting, but that many activities take place simultaneously and iteratively inform each other.

Figure 5.7 Activity phases in the Project in the Project implementation process based on Fixsen et al's (2005) normative model of implementation



Summary

This chapter has presented the Project plans, described the work that was done and focused on how the implementation strategies were manifest. The implementation strategies were subtly dispersed throughout the Project plans and perhaps for this reason were not well used as a means of facilitating change and achieving the Project aims. This also seemed to indicate an 'implementation as usual' approach typical of service improvement implementation in which change was assumed to follow simplistic approaches to communication and education about the EPaCCS and Navigation Centre. However, these strategies were threatened by external political changes which will be the focus of the next chapter. Within this context, the strategies led to an

implementation process which was characterised as non-linear with overlapping and interacting activities.

6 Data two: Implementation process influences and outcomes

Introduction

The previous chapter described the implementation process: what happened, how the planned strategies for creating change worked or not, and what shape this process took. Describing the process has alluded to some of the barriers and enablers that influenced this process and the outcomes. This chapter will discuss these influences in more detail as well as the role of power relationships within the Project. It will also look at the implementation outcomes and consider how project success was judged.

6.1 What influenced the implementation process?

Four themes were identified as being influential in shaping the implementation process: context, project characteristics, innovation characteristics, and the partnership approach. These higher level themes and their subthemes were derived from the previous chapter and patterns across the datasets.

6.1.1 Context

Programmes are not implemented in a vacuum; the context (political, social, economic, historical etc) in which a programme is implemented influences the implementation process (Greenhalgh et al, 2004a). In this case, three distinct contextual issues had varying degrees of influence on the Project: the NHS reforms as a result of the Health and Social Care Act 2012, the launch of the 111 urgent telephone service, and the demise of the Liverpool Care Pathway.

NHS reforms

The most commonly cited influence on the course of the Project as stated by nine of the ten stakeholders were issues arising from the extensive structural changes in the NHS that occurred at the same time as the Project. On 1st April 2013 the changes proposed in the Health and Social Care Act 2012 came into force. This coincided with the start of the second year of the Project, though planning for the NHS changes had commenced in the year prior and even in the planning stages were felt to have created a barrier in the progress of the Project:

so the barriers, I think undoubtedly health service reorganisation which just was incredibly bad timing wasn't it, the whole Health and Social Care Bill and as soon as that

was even on the horizon everything started to turn, you know turning upside down all over the place. (Int Hospice Director 13Q3-05)

Briefly summarised, the key changes in the Act 2012 involved shifting commissioning powers from Primary Care Trusts (PCTs) to GP consortiums (Clinical Commissioning Groups – CCGs) and financially linking health care providers to local authorities to join up health and social care provision. Both of these changes had an impact on some of the partner organisations and therefore the individual stakeholders involved in the Project:

There are extensive and wide-ranging changes affecting the delivery of health services in England. In April this year Clinical Commissioning Groups will take over commissioning of services from PCTs. The progress of the project has been a challenge within this landscape (Doc Operational 13Q1-02)

It was observed that the Project Delivery Group members felt that the formation of the CCGs drew away partners because of the power that the CCGs offered in terms of commissioning decisions. Stakeholders were concerned with having a role in this new landscape and therefore the Project lost a number of influential people:

There are so many groups going on now with the CCGs forming so it's overshadowing the Project because the CCGs have commissioning clout where the Project has none. Members of the work stream are being approached to participate in these various CCG groups so their time is being stretched and the CCGs are taking priority (Obs PDG 12Q4-07)

The newness of the CCGs were felt by some stakeholders to be a barrier because of their lack of experience which led them to act cautiously and therefore not engage with the Project:

I think it would be different now because the organisations were in their infancy and they were sort of building themselves up and weren't sure of what they could and couldn't share. Whereas I think now the organisations are that little bit more mature and would be more willing. (Int Stakeholder 04)

The lack of collective experience as an organisation seemed to prevent the CCGs from engaging with new ways of working. Initially CCGs appeared to lack a decision-making structure to support collective initiatives; some GP practices appeared to act autonomously which particularly made establishing the Blue System EPaCCS across the region difficult:

so supposing that [GP lead] for arguments sake has said 'yes [local] CCG will do X', well actually if you go round to the individual practices you will find they'll say 'no, we're not doing that.' So what is the mechanism for them agreeing to something if you see what I mean. (Int Hospice Director 13Q3-05)

This clearly had a negative impact on the planned implementation process as it meant that the project manager had to individually negotiate with each GP practice to adopt the Blue System EPaCCS. In sum this had a delaying effect on the Project and also meant that some GP practices elected not to use the Blue System, i.e. they were non-adopters. In addition to creating uncertainty in the hierarchy of authority, these organisational changes trickled-down to affect the employment of a number of the stakeholders which affected the stability of the partnership:

I think one of the problems was that we chose to do this right at the time there were all the changes in the NHS and I think that was really unfortunate because I think there is just too much turmoil going on and we started with people in one job and then they moved to another and the commitment that people were giving was probably not as it should have been (Int Stakeholder 01)

Many of the Project decisions required agreement by the whole partnership because they had system wide implications, such as in determining a patient pathway. However, the uncertainty in employment led to poor attendance at the meetings affecting such decision-making abilities:

This group has struggled with attendance in this time of intense change and agreeing work that was needed. (Doc Meetings 12Q4-01)

Social care services were almost entirely absent during the project period (as illustrated in Tables 5.8 and 5.9 in the previous chapter). The health and social care restructuring which affected organisational arrangements may have therefore affected the organisation's capacity to participate in new activity. This is supported when considering that the hospital and hospice were both relatively unaffected by the reforms and maintained a continuous presence throughout the Project. One stakeholder indicated that these changes did not directly impact on the Hospital Trust, but acknowledged that the changes were influential on the progress of the Project:

there was a lot of change going on outside of the hospital and I think that people were reapplying for different jobs, it got very confusing and I think it's taken a good year to settle down, so perhaps now would have been a better point to have started with all these people in post understanding what their roles are, whereas when this was all going

on it was very much as I say, it was all up for change out there, lots of people covering different jobs and it wasn't an easy time really. (Int Stakeholder 03)

Only one stakeholder disagreed and felt that the difficulties encountered in the Project were more to do with weak project management arrangements and not related to commissioning changes:

I think it's a bit of a cop out to say just because the Commissioners are in transition that- so I think it's disappointing if that's the view, because I think as a Steering Group we should have held ourselves to account. (Int Stakeholder 10)

The NHS reforms appeared to have little impact on the organisational structure within hospitals and so these stakeholders could continue to focus on the Project whereas the attention of other stakeholders whose employment was at risk was elsewhere. The minimal participation by GPs, CCG representatives, social services, and community services can be largely explained by the NHS reforms. Lack of participation was identified as a barrier to progressing the work of the work streams and it appears that the NHS changes were a barrier to participation. Low participation as a result of these changes also negatively affected the partnership management strategy described in the previous chapter because decision making depended on group consensus which could not be achieved.

Introduction of the 111 NHS non-emergency telephone service

Also coinciding with the start of the second year of the Project was the introduction of the 111 non-emergency telephone service. While few stakeholders interviewed retrospectively at the end of the Project discussed its influence on the implementation process as compared to the NHS reforms, the introduction of the 111 service was regularly discussed at Project meetings. Of particular concern was whether the Navigation Centre and 111 service would be duplicating work and therefore whether the Navigation Centre was needed:

[X] said that what she wanted to avoid, from a patient point of view, was a triage to triage system, whereby 111 would triage the patient and then pass them off to someone else who will want to triage them as well. She was wondering whether it should all just be rolled up into 111 to avoid that. (Obs EPB 13Q1-05)

The launch of the 111 service created a sense of uncertainty around the role of the Navigation Centre and the Blue System EPaCCS:

so how does that then link with other issues around single points of access you know, what was emerging was the 111 service and so how was that gonna sit, what were the pathways of communication (Int Stakeholder 10)

The unknown impact of the 111 service on the Project was of sufficient concern to warrant being an agenda item at the Executive Project Board meetings. At meetings and from the project manager's point of view, a persistent concern was how the Project would work with 111 and how the separate electronic systems used by each service would interconnect:

<i>3.2</i>	<i>The 111 service and how it impacts on the project</i>
<i>The impact of the 111 service was discussed at length due to its impact on the project. The soft launch had gone live a few days earlier. [GP] reported that there were significant problems experienced/</i>	
<i>The group agreed the following:</i>	
<ul style="list-style-type: none"> • <i>111 call handlers need to have access to the [Blue System] register as it is crucial that 111 operators can identify End of Life patients to ensure they are passed to clinicians in a timely and appropriate way</i> • <i>Ideally 111 system and [Blue System] should link</i> • <i>The project needed to link with 111 and the urgent care lead</i> 	
Action	
<i>Project leads to work with 111 to determine way forward with links</i>	

(Doc Meetings 13Q1-01)

Despite this agreement at the meeting, closer ties with the 111 service were slow to materialise and indeed ultimately the lack of progress led to the abandonment of the Blue System and instead the Red System, which the 111 service was already using, was adopted by the Project. Both the Navigation Centre and the 111 service were single points of access into the health care system, though the former was focussed on supporting patients nearing the end of their lives while the latter was for the general population. Use of both services was nearly equal among carers interviewed as part of the telephone interviews: seven stated that they called 111 and eight had called the Navigation Centre suggesting both services served a purpose for the patient population. The 111 service appeared to be a barrier insofar as its parallel emergence created uncertainty and it was competing for the same patient population.

Demise of the Liverpool Care Pathway (LCP)

Also unfolding at the same time as the Project was the highly publicised demise of the Liverpool Care Pathway (LCP) and generally negative press coverage of end of life care provision in the NHS in 2012 (e.g. Doughty, 2012). While the Project was not directly dependent on the LCP, the negative press coverage seemed to create an atmosphere of concern among some stakeholders that service users would be deterred from engaging in end of life discussions which formed the

core of the EPaCCS. The direct impact of this concern on the Project was for the Hospice to take a cautious approach in advertising the EPaCCS to existing hospice patients and was viewed as a potential barrier:

Letters were sent to existing hospice patients to let them know about the register and to let the hospice know if they consent or not to the sharing of their information. Again, there was some concern that these letters went out at the time of the LCP uproar in the Daily Mail. Because of this it was decided to only send the letters to patients who had had ACP discussions, i.e. [preferred place of death] or [do not attempt CPR]. (Obs PDG 12Q4-07)

However, one stakeholder queried the actual impact of such press suggesting that these fears were perhaps unfounded:

I suppose one other thing in the mix which to a lesser or greater degree would have affected things were the changes around the Liverpool Care Pathway as well, whether in reality or perceptions (Int Stakeholder 01)

The abandonment of the LCP did have a real impact on the working practices of clinicians and so for some partners the outputs of the Project became even more important:

we didn't have a pathway as such which we formulated, we had like sort of an aide memoire [...] so it was more like a guide for the nurses to go back to, and with the demise of the Liverpool Care Pathway, we haven't got a specific guide anymore for end of life so this guide that we developed through the pathway, through this work stream, has been cascaded throughout all of [the Community Health Trust] and it has gone down incredibly well (Int Stakeholder 09)

Though the perception may have been that the LCP issues reduced acceptability of the Project given its end of life focus, in fact it seems to have been a positive development for the Patient Pathway work stream as the output could serve to replace the LCP thereby facilitating its uptake. Conditions were therefore improved for the Project outputs to be implemented as they were seen to fill a gap created by NHS recommendations to abandon the LCP.

Context shaping stakeholder priorities

Emerging from these contextual issues of restructuring in the NHS, introduction of the 111 service, and withdrawal of the LCP is a pattern of how such circumstances shaped the priorities and practices of actors:

I think what was also complicated was all the moves, the changes in the NHS you know the changes in the CCGs from PCTs, the PCTs were being disintegrated so the staff that were from the PCTs were worried about what [...] employment they were going to have (Int Stakeholder 06)

Therefore ensuring employment was a primary need and engaging in extracurricular work, such as the Project, was given a low priority among those who were threatened:

we found it really difficult to engage with commissioners on anything because all they were doing was trying to get a job, and even if they had one they were choosing what colour they wanted the carpets in their office. They just weren't really interested. (Int Stakeholder 07)

There were also differing opinions on whether end of life care was viewed as a priority as compared to other issues facing the NHS. Some stakeholders perceived that end of life care was not a priority:

we're not a priority, end of life care [...] You know it's not urgent care, it's not keeping people out of hospital in vast quantities and they're the priorities (Int Stakeholder 05)

Whereas another stakeholder felt it was a priority among many:

One of my primary objectives will be to improve pathways and I will be proactively looking at each individual patient criteria and looking at what ways I can offer more, and improve service and improve the efficiency of our services [...] it's certainly in our interest to make sure areas and patient pathways like end of life care stay at the top of our agenda (Int Stakeholder 08)

It was suggested that the prioritisation of end of life care seemed to be tied to the availability of free time; essentially that end of life care is something that stakeholders engage with when there are no other competing priorities:

I think end of life care is one of these subjects that everybody says is really important and I'm sure they believe that, and if you make a suggestion about it everybody says; 'well yes of course we should be doing that', or 'we must do that' but in reality when the rubber hits the road it clearly isn't in their priority list. (Int Hospice Director 13Q3-05)

Thus in this context of changing commissioners and service reorganisation, programmes such as the Project might be viewed as on the periphery of priorities for stakeholders who must first

ensure their own employment and then ensure organisational priorities are met. Such an environment is clearly not conducive to projects which are based on a partnership formed from virtuous intentions and goodwill. The overall influence of context on implementation was largely negative in distracting stakeholders from the Project; though issues surrounding the LCP may have been positive for some in spurring them on to find solutions.

6.1.2 Project characteristics

Project characteristics as an influencing theme encompasses the intrinsic elements of the Project which made it more or less implementable from the start: the allocation of funding and resources, and the Project's distinctiveness from other work.

Funding and resources

Funding and the resources available to the Project proved to be both a facilitating and constraining factor. The local authority funded the Project as part of its commitment to deliver the National End of Life Care Programme. This was facilitative as it meant that money was available to hire staff, provide training and purchase the EPaCCS necessary to deliver the Project. This funding was an indication to stakeholders of the seriousness of intent to deliver the programme aims as money was not always made available to deliver national policy:

I really felt that it could have achieved a lot more because it funded position; each time we've tried to do some work in the past with different groups in the community, because it's not funded or commissioned or it hasn't got anything behind it, it falls down, but I thought that maybe that the Project would have driven some of the necessities out there so perhaps my expectations were quite high. (Int Stakeholder 03)

The funding seemed to be a motivating factor for some partners and helped facilitate some aspects of the Project such as monitoring activities through the data manager post and management through the project manager. However, the length and conditions of the funding award was felt to be problematic for the Pharmacy & Drugs work stream in moving the medicines pathway from development to implementation:

Stakeholder: We fed back to [the Project Delivery Group] but pharmacists, in community pharmacies when they had a palliative care patient, would be able to look at the overall, the notes so that they could improve the service they were providing rather than just being presented with a prescription but unfortunately that never actually happened. [...] It became an aspiration.

Interviewer: Why do you think that didn't happen?

Stakeholder: Because the funding was pulled. One, the funding was pulled before we'd got to that stage; two – that the other work streams weren't as far ahead as us and therefore it just fell at that last hurdle really. (Int Stakeholder 04)

Though the group had created a medicines pathway during the period, they were not yet ready to implement within the Project period and therefore lost the money needed to implement. Limiting the time during which project funds can be spent may be an incentivising factor to complete project work on time, but it does not reflect the reality of the implementation process, particularly when only two years were allowed for development of the patient pathways and implementation.

Funding was also felt to be a constraint with the running of the Navigation Centre in the sense that a limited budget precluded the Navigation Centre from developing as it might have done had cost not been a factor:

we had to work to the budget rather than work to actually what we felt and we've had to learn (Int Stakeholder 05)

While the first year of the Project was funded via an award from the PCT, the second year was funded by the Hospice. One stakeholder perceived a change in the course of the Project which coincided with the change in funding:

I think in the first year there was a clear- there was clarity around the whole project and all the key areas but in the second year it definitely became hospice led and more operational rather strategic. (Int Stakeholder 08)

With the Hospice funding the second year, it was the Hospice trustees who seemed to set the agenda, rather than the Executive Project Board:

[X] said that the trustees want [the Project] to get the register as robust as possible if nothing else comes out of it. They also said they would explore the governance of the Project as they would be funding it for the next year. (Obs PDG 13Q1-10)

The Project lost momentum in the second year, possibly because the shift in funding and lack of engagement by CCGs made the Project appear to be a Hospice project rather than one owned by all stakeholders. The funding and resources allocated to the Project had a mixed influence. Clearly it could be argued that without any funding the Project would have achieved very little, if anything, as there would have been no money to purchase and develop the EPaCCS, hire a project manager, and collect and analyse data for monitoring and learning. Thus funding is clearly

a facilitating influence. However, conditions of the funding may have limited the degree to which the Project could be flexible and adapt to challenges.

Distinct purpose

The Project seemed to lack a distinctiveness from other health care and Hospice activity happening simultaneously in the area. During the project period, there were a number of related pieces of work ongoing in the region, for example care villages, various training, risk stratification etc. Some stakeholders were not certain which pieces of work were related to the Project and which were separate indicating that the boundaries of the Project were not clear:

it's difficult for me to distinguish what was part of the actual project and what we've subsequently had discussions about really (Int Stakeholder 10)

Even within the Hospice, which hosted the Navigation Centre and provided leadership, the Project was not clearly differentiated from other hospice activity:

Since we commenced on this journey it has become clear that internally there is some confusion and misunderstanding about what roles and functions the hospice and staff working for the hospice will play. (Doc Operational 12Q2-02)

The purpose of Navigation Centre in particular and how it fit together with existing services was not clear to some stakeholders:

I don't know how it all links in to – so my understanding of how what happens when that's activated I'm not sure, but I know quite a few people we see coming into hospital out-of-hours will generally, if they've gone through the Navigation Centre with a crisis type scenario, will end up coming into hospital. (Int Stakeholder 03)

The lack of clarity at stakeholder level seemed to also be present at the frontline. Care navigators reported that some external care providers were referring inappropriate cases to the Navigation Centre indicating that referral criteria had not been made clear to them:

Navigator 2: and I understand the district nurses are all giving our numbers to patients haven't they? [...]

Navigator 1: But these aren't end of life patients [...] one of them was a drug addict wasn't she? (FG care navigators)

From the patient and carer point of view, there seemed to be little difference to them between the Navigation Centre and the 111 service. This was apparent in the telephone interviews when

carers could not clearly identify which service they had used, which likely reflects a lack of publicity as part of the communication strategy to patients:

When I asked if she had called the 24 hour [Navigation Centre], she said yes she had rung the 111, and then I had to clarify that they were in fact different services. (P21 carer telephone interview 1)

Certain aspects of the Project were more easily understandable and defined such as the EPaCCS, which possibly accounts for why these elements made greater progress than those which were seen as vague, like the patient pathway:

the [patient] pathway stuff, I just don't think anyone really knows what that means or where it's going but the EPaCCS register I think we can implement (Int Hospice Director 13Q3-05)

Much of this lack of clarity stemmed from the Project planning documents. The Project partners struggled to make sense of these materials and to turn these into workable objectives:

I think if it had started with them agreeing it all and signing up to a shared document and shared vision something that we all then were quite clear what we had to deliver, it would have been clearer for us to see whether we had done it or not done it (Int Stakeholder 07)

6.1.3 Characteristics of the innovations

Two characteristics were influential in how the innovations were received by the partners and users of the innovations: whether the innovation met users' needs and what competing innovations existed which influenced how the Project's innovations were utilized.

Meeting users' needs

The adoption of a new innovation depends on how the new system compares to the existing way of working (Rogers, 2003); people are only likely to be persuaded to take up a new way of working if there is some benefit to their work. In the case of the Project, there was no evidence that the changes proposed would be more effective than the current way of working. Indeed, some stakeholders even questioned whether the existing system needed changing:

Certain practices I know from speaking from my locality and I'm sure other localities, you've got stand-alone practices who say 'well it was working well the way we're working, why should we change it', and I think any project that you try to implement that happens, you get some really positive GPs on board and then you get some who say 'why

do something different if it works already', and I think that could have been a bit of a barrier. (Int Stakeholder 09)

The Blue System EPaCCS and Navigation Centre were the two new innovations introduced at the start of the Project. The reception of both of these innovations by care providers and service users were dependent on their individual needs or aspirations and whether they felt these innovations benefitted their work or experience. Each will be discussed under a separate section.

Blue System EPaCCS

The Blue System met the national guidelines for an EPaCCS and also met normative ideals around sharing information to improve end of life care provision which a number of stakeholders were positive about:

very recently, we have had more GPs enquiring when it will be ready for use. This is great news and tells us interest in the Project and its potential to help improve care for patients is growing. (Doc Operational 12Q3-01)

However, there were high expectations of how the new Blue System EPaCCS would need to be an improvement over the existing Red System. It was expected that the new system should help reduce the existing amount of work that GPs had to do for end of life patients:

project may encourage GPs to add to the register if they see that it reduces their workload. (Obs EPB 12Q2-03)

GPs in particular wanted a simple system which would require little effort on the part of users:

[GP] said that she just wants a system that will flag up that a patient is end of life on the first page, she doesn't want to have to trawl through pages to find the information she needs. (Obs EPB 13Q1-05)

While GPs indicated that the new system would have to reduce the workload and at the same time improve the information available, the realistic chances of this happening were questioned. One stakeholder seemed to indicate that there might be little actual benefit to GPs in using the system because the patient caseload to which it would be applicable might not warrant the effort that would go into maintaining it:

GPs still need to be educated to do it, they only have a limited number of end of life patients themselves, it's another box to fill in (Int Stakeholder 01)

This seems to question what extent any system can be created to reduce the work down to a level acceptable to all professional partners – essentially that there must always be a minimum amount of work required. However, the difficulties of IT interoperability meant that in actual fact the use of the Blue System increased the amount of work required of professional users:

[Blue System] Register and [Red System] – [X] reported that GPs do not wish to double enter palliative care patients onto [Red System] and [Blue System]. (Doc Meetings 13Q1-01)

The care navigators might have been a group which would most have benefitted from a functioning EPaCCS because they were expected to help navigate patients to appropriate services and having as much information available as possible would likely have supported such work. However, the care navigators did not use the system very often because existing systems contained the information they needed:

The [care navigators] don't tend to use the [Blue System], just [hospice record system] for patient info. (Obs NC 13Q3-04)

While the Blue System did not substantially meet professionals' needs to encourage change, particularly since many may not have perceived a need to change, what evidence was there from a carer and patient point of view for its need? The EPaCCS was largely implemented to address informational needs of professionals and therefore its use was largely hidden from the patient and carer perspective. Only one carer talked with awareness about how the information contained in the Blue System was used to help ensure that care was given in accordance with the patient's wishes:

When the carer arrived the patient was on the phone to 111 and then handed the phone over to the carer. An ambulance came out and spent about 2.5 hours with the patient, testing her blood sugars, ECG, etc, they phoned the GP to ask if they could give her an injection which they did. During this visit the patient showed them a letter which the carer says is on the [Blue] Register to say that she wants to be treated at home, so they respected this and seemed to have done what was needed at home. The carer said that this exceeded her expectations. (P07 carer telephone interview 4)

In this case, the fact that the information was held on the Blue System seemed to give legitimacy to the patient's request to stay at home. However, it also seems that very basic information, such as whether a patient was alive or not, was not shared among providers:

I had a letter come through addressed to [patient] two days ago; 'could you please attend an ultrasound for the abdomen on the [5th March]', so I rang them and I thought I'm going to be very careful what I say here so I said; "oh you've just sent this letter through to Mr [Ferguson] for an appointment on the 5th", and just said what it was for and I said; "I'm afraid he won't be attending as he is being cremated on the 4th", "oh my goodness" she said "I'm so, so sorry". I said "would it be possible for you to please amend your records so that I don't get any more of these letters". (P09 carer telephone interview 3)

In terms of the need for the Blue System, carers did not have much to say directly, but the above comments do reflect how their experience of the coordination of care is reflected in information availability which the EPaCCS was meant to address. It is difficult from the telephone interviews to assess whether the Blue System met service user needs as experiences of care overall seemed to be very disparate. For example, one patient seemed to have all his needs met:

Patient seems to receive a lot of support, DN visits twice a week, carers that she pays for but is subsidised, physio, dentist, GP, and Crossroads so she can have some respite. She doesn't seem to be wanting for anything. (P15 carer telephone interview 3)

Whereas other carers perceived there to be general gaps in communication, but with no indication as to whether communication might have been improved through an EPaCCS or the Navigation Centre:

Carer said it seemed that the "right hand doesn't know what the left is doing". (P27 carer telephone interview 6)

Navigation Centre

Stakeholders had mixed views on the need for the Navigation Centre. From the start it was unclear how the new service would fit into the local system and especially the 111 service.

they are unsure of what unmet need there is and therefore what demand there is likely to be (Int Project Manager 12Q2-01)

During the course of implementation, it became clear that such concerns seemed tied to whether stakeholders perceived that the Navigation Centre actually benefitted their organisation's work. For example, the ambulance service benefitted from the Navigation Centre and it could fit into their model of working in which getting relevant information quickly was essential:

staff saying they've used the service, they use the telephone number provided and they sorted things out very quickly (Int Stakeholder 08)

There were some concerns from external stakeholders about whether the service was actually fit for purpose. Concerns were repeatedly expressed regarding access by professionals:

Concerns still exist regarding appropriateness of calls to the centre and the nervousness of partners that health professionals may not be able to get through. (Doc Meetings 13Q1-02)

While NHS stakeholders were concerned about the professional user of the service, hospice stakeholders were unconvinced that professionals should have preferential access over patients or carers:

we've had this debate about whether you know; is it then more important to answer a phone call to a GP rather than or a health professional to a patient who might need... (Int Project Manager 13Q1-03)

This possibly reflects a lack of clarity of purpose in the service in who exactly the Navigation Centre was meant to be targeting. Some NHS stakeholders felt strongly that the Navigation Centre needed to more efficiently support professionals, whereas hospice stakeholders seemed to perceive a greater need among patients and carers. The needs of patients and carers were variable as reported in the telephone interviews. Some carers talked about how access to home visits by district nurses were difficult to arrange, and one carer talked about how he used hospice services to circumnavigate the usual, but slower routes of access:

[Carer] said that last Friday [patient] had developed bed sores and he phoned the "district nurse health centre" once in the morning and then a few hours later but nothing came of it. So he phoned the hospice. When asked if it was the Navigation Centre he said he just phoned the hospice as he was told to do when they came out to see him. He said they then phoned the community nurse team and called him back to let him know what had been arranged. He seemed quite happy with this. The district nurse then came out on the Saturday and following Monday. (P01 carer telephone interview 3)

A number of patients and carers relied on the Navigation Centre as an outlet to simply express that they needed help, and indeed it seemed that the Navigation Centre was best at supporting those who did not need immediate help as those patients typically ended up calling 999:

The carer had called the [Navigation Centre] while the patient was in respite in a care home because she was feeling a bit down about the whole thing. She found it very reassuring to just speak to someone; even though it was arranged for someone to call her

back she felt it a relief just to explain to the call handler what was going on. (P18 carer telephone interview 1)

For some patients and carers the Navigation Centre did appear to meet a need and for those who it did, carers usually became repeat callers. However, one of the challenges that continued to face carers and patients was knowing who to call for which issue. In theory, the Navigation Centre should have been a catch-all, but it seems that patients and carers still tried to make decisions about who best would serve their needs, which potentially indicates a lack of clarity about the purpose of the Navigation Centre and would certainly influence how it was implemented:

the one problem she says the patient is having is differentiating between what she should call health services for and what are social care needs. She says she calls the DNs or GP but then they tell her she should call social care, so she feels this is a difficult thing for an older person to have to try to understand. Quite often the patient just wants someone to talk to which is perhaps why she keeps getting passed around and so often calls the Samaritans. (P07 carer telephone interview 3)

From the perspective of those who worked in the Navigation Centre, they felt they gave a good service which met both the patient and carer's needs and the needs of the professional user to give reassurance to their patients:

I think [hospice] nurses have told us that they do like it when they go and see a new patient that they're able to say it's a 24 hour service you can call up at any time of the day or night (FG care navigators)

[carers and patients] like that kind of familiarity with it that they haven't got to go through everything all over again about the diagnosis, because you know what's happening, you've spoken to them and they feel safe with you and they will tell you a lot more things. (FG care navigators)

The personalised service offered by the Navigation Centre was reflected in a carer's comment, but only applied so long as the person responding to the call actually knew the patient:

[Carer] normally phones [the Navigation Centre] and a nurse phones back. She says it is good because they know her and the patient, but she says this mainly applies to when the [area 1] nurses are on duty. Finds the phone advice very helpful as long as it's not [area 2]

or [area 3] because she doesn't really know any of those [nurses]. (P14 carer telephone interview 6)

Potentially though this service could have been improved if the Blue System had been used more effectively by other professionals. The care navigators did not routinely engage with the Blue System EPaCCS because it did not contain information which they did not already have through the Hospice record system. Also the care navigators felt that the algorithms which were designed to help them in their work were not fit for purpose because they did not support them in their decision making:

If you have a distressed person and go through all that for 20 minutes, asking them questions, it wouldn't give you a route how to direct the call, so it was always the same outcome. It would go to the nurse who would then ask all the same questions (FG care navigators)

Thus while the Navigation Centre was generally felt to give a good service by those who used it, it perhaps did not fully meet stakeholder expectations because the underpinning support systems were not activated to ensure that the service worked at its most effective. However, as the literature review indicated, there is no existing evidence base for such a service to demonstrate what effect it would have and what elements are needed to produce good outcomes. Instead, the basis for the service was grounded in clinical experience and the perception that the EPaCCS and Navigation Centre would solve some of the systemic problems. The proposed real benefit of both the Blue System EPaCCS and Navigation Centre depended on all stakeholders actively inputting and extracting information, which did not happen consistently within the two-year project period. While stakeholders and professionals might have experienced the intended benefits after full implementation, some benefits were hard to perceive in the early stages because the Project components were interdependent and were not all fully established. Additionally, the way in which patients and carers chose to interact with the Navigation Centre would have also influenced the way it was implemented.

Competing innovations

The adoption and utility of the Blue System and Navigation Centre were also affected by the competing innovations within the local area which made them more or less attractive to partners. Firstly, the Blue System EPaCCS was in direct competition with Red System which was already implemented across the local area. While the Red System was judged to be insufficient to meet the requirements of an EPaCCS at the start of the Project (hence the proposed use of Blue System) its functionality had been developed in the same time period as the Project. But even

prior to this development, the Blue System perhaps did not appear sufficiently different or substantially improve on the existing practices and therefore the case for change was not perceived equally by all professionals, especially GPs. While the existing version of the Red System was acknowledged by one stakeholder to be deficient in comparison to the Blue System, the Red System was incentivised through the Local Enhanced Service agreement which was a major barrier to implementing the Blue System:

GPs are being paid for using [Red System], so [GP representative's] advice to GPs would be to continue working as is rather than adopt the [Blue System] register because they get paid a few thousand pounds for using [the Red System]. (Obs EPB 13Q1-05)

Thus not only did the Blue System have to compete with an existing system over which it did not substantially offer an advantage, but its competition was encouraged through monetary incentives.

Like the Blue System, the Navigation Centre also had a service to compete with – the 111 NHS telephone service. The availability of two services which essentially aimed to meet the same need likely impacted on the uptake of the Navigation Centre. This seems evident from the telephone interviews in which carers seemed to split their calls between the Navigation Centre and 111 service, depending on what their needs were and what advice they had received:

She had called 111 for a doctor around 11:30am, but he didn't show up til 4:30pm which she said was a long time. In the meantime she said she phoned the [Navigation Centre] about 3 times. (P14 carer telephone interview 6)

Carer called the Navigation Centre to get advice about some swelling that her husband was experiencing. Says they got some advice from [the doctor] who advised that the GP visit, so the Navigation Centre organised that for her. When asked what she would have done if the Navigation Centre was not available she was hesitant, but said she probably would have left it longer, perhaps would have called the 111 service. (P02 carer telephone interview 2)

It therefore seems that the Navigation Centre was used insofar as it offered a benefit to users or was preferred to alternatives, but did not replace the 111 service.

6.1.4 The partnership approach

Characteristics of the partnership approach describe the last group of influences which shaped implementation. The partnership established at the start of the Project was the cornerstone for

project delivery and particularly the work streams. It was also key to realising the full potential of both the Navigation Centre and Blue System EPaCCS as each partner needed to engage with these innovations in order to realise the benefits of shared information. Each of the Project partners was offered representation in the various project groups in order to contribute their organisation's perspective in resolving long-standing problems and devising proposals for future working which could then be implemented. While some of the implementation strategies described in the previous chapter were not well formed, the partnership was the one element of the Project which was clearly expected to be influential:

I mean implicitly you clearly try to target influential people – that's obvious (Int Hospice Director 13Q3-05)

The success of the partnership approach relied on having the right people involved at the right level who could enact change in their respective organisations. However, there were mixed views about what would constitute success using this approach. Some stakeholders felt that just getting the partners together was an achievement:

I think the successes have been the engagement of key stakeholders which actually, although sounds very simple actually is quite complex (Int Stakeholder 10)

Others had expected the group to achieve more because of long established relationships:

I think my disappointment really was that when we first came together as the bigger group, the PDG group, the faces round the table were all familiar and people that I'd worked with over many years so my aspirations were we would be actually able to drive this into achieving a lot more because of the money behind the Project (Int Stakeholder 03)

Four themes characterised the way the partnership functioned and influenced the implementation process: variability in working practices, individual characteristics and priorities, leadership of the partnership, and engagement of the partners.

Variability in working practices

The partnership included a wide array of professions (doctors, nurses, specialists, therapists, social workers) from various organisations (NHS – primary, secondary, and tertiary care, voluntary organisations, local authority). Inevitably this meant bringing together people from different backgrounds. Some stakeholders discussed that the working tradition in their profession was different to others and that this proved to be a barrier in implementing the outputs of the Project consistently:

Well I think it's different varieties of work in parts and paramedics are very much, are quite process orientated so if they've got a process they use it, and it's drilled into them to use their processes within their training and their support [...] but they are not autonomous practitioners; nurses and doctors are (Int Stakeholder 05)

There was a sense that some of the partners were not flexible in changing their ways, though potentially this was because the vision for change was not clearly aligned and therefore stakeholders had different views on what needed changing, which also indicates a lack of awareness of other organisations' needs:

I did find there was some barriers with the acute trust because they've got their set way of working [...] say the acute trust would have their ideas which would cascade right through down to the patient into the home but there wasn't really I would say a unilateral agreement of where we all wanted to go with it (Int Stakeholder 09)

The outputs from the Patient Pathway work stream might have aligned some of these practices, but they could not get agreement because of patchy engagement within the group. There was reluctance among partners within the work stream to make changes in their working practices to align more closely with others:

[X] felt that a problem in the patient pathway group is that as representatives of each of the organisations, no one wanted to commit their organisation to a way of working which might have arose as part of defining the patient pathway. (Obs PDG 13Q1-08)

Even within organisations that were open to change there were differing views on how best to implement changes within the organisation. For example, there were differing views on how the Blue System EPaCCS should be implemented within the Hospital Trust with one wanting to try it out to see what the information could do and another not wanting it rolled out until the patient pathway had been agreed:

[Hospital stakeholder A] then asked if [X] could share the register with us, meaning the Hospital Trust. They then discussed that it might be useful to just open the register up to the Hospital Trust so that they can view it and this can be done now without training or without an implementation plan which requires planned training. [Hospital stakeholder B] had concerns about rolling out the register without having the patient pathway sorted out, but just opening the register to viewing only might address this problem because it isn't being fully rolled out for hospital use; it would just be for informational purposes (Obs PDG 13Q1-10)

This shows how it may be partners' roles within an organisation or individual views and not just the organisation itself that influences the way people approach a problem. Increasing the range of stakeholders in the partnership would make achieving consensus more difficult, particularly if there is a lack of awareness of the needs of other organisations. Even when decisions were made, they did not reflect the expectations of some of the partners. In the case of medicines, the Hospice decided to implement an emergency medicine box because they felt it was needed even though this was considered and decided against by the Pharmacy & Drugs work stream:

The WS considered the use of a medicine box which is kept stocked with a range of medicine which has been used in other parts of the country, including [the next county], but they decided against this in favour of promoting prescribing practices on an individual basis (Obs PDG 12Q4-07)

This decision to implement the medicine boxes seems to have undermined the partnership approach as the decision made by the partners in the work stream was deemed to be insufficient by other partners. The variability in working practices seemed to be a barrier to the partnership approach given the patchy meeting attendance because partners could not reconcile their different ideas for how to improve the delivery of end of life care.

Individual characteristics and priorities

Partners' individual interests, either as a result of personal experience or because of organisational pressures influenced their involvement in the partnership and proved to be both a facilitator and a barrier in partnership working.

One of the stakeholders who was active throughout the project had a strong personal interest in the subject matter which motivated him to participate:

where my capacity allowed I got involved in the sub groups to try and help with the operational perspective of whatever the sub group is, and with it being end of life care at that time my brother was at his end of life so it helped me understand and try and relate some of the problems I was experiencing as well, so I really, if it's the right word, I really found the project of benefit. (Int Stakeholder 08)

Personal interest in the Project, such as this, appeared to be essential because there were no structural or financial incentives for participation. It might be considered that the partnership held together reasonably well given the intense NHS changes that were ongoing at the time with nothing more than personal or organisational motivations to keep people at the table. However,

reliance on individual interest to drive the Project meant that to some partners the Project lacked a sense of cohesion because there was no contractual mechanism to bind people to the Project:

you need those enthusiastic people there to drive it forward and I don't think that was there. It was too much of an add-on to people's jobs and there was different degrees of enthusiasm. (Int Stakeholder 04)

Lack of a contract is not to say that stakeholders were not committed to the Project, but rather that they interpreted their role in the partnership differently. Some felt they were accountable for the outcomes of the Project which was a facilitating view, while others felt that it was more voluntary and participated because they were interested, which could be either a barrier or facilitator because though they were interested, they did not feel pressured to achieve the aims. Engagement in the Project also depended on whether partners felt that the Project was going to help them achieve their priorities within their job or deliver outcomes that were of direct relevance to their goals in work. For example, the ambulance service was particularly keen on the Project achieving its aims because end of life care was a time consuming aspect of their work:

Our job cycle times are presently increasing, that's a fact. Our average, and this is for all emergency calls and it's complex as to why this is happening, our average job cycle time was 75 minutes, it's now increased in [one area] to 87 minutes, that's for all calls but their very nature of complexity, end of life care can be very protracted, I'm talking it can run into the hours. (Int Stakeholder 08)

Whereas the hospital had other competing priorities that took precedence:

it feels to me as though the work we were doing was something that we thought would be a good thing to do, so we should go and do it, and sometimes those things slip behind you know the 4 hour target in A&E and hitting the 18 weeks target and those kind of things (Int Stakeholder 07)

The fact that partners had different priorities became particularly evident during the NHS restructuring:

Members of the [work stream] are being approached to participate in [...] various CCG groups so their time is being stretched and the CCGs are taking priority (Obs PDG 12Q4-07)

Implementation also required that individuals be open to change as those who were not were seen to be a barrier to partnership working:

[X] said they need people in the WS who are less fearful of change and are more radical in their views of what can be achieved. (Obs PDG 13Q1-08)

Leadership

Leadership as an aspect of the partnership reflects both leadership at both an organisational and individual level. From an organisational perspective, initially the Project was led by the Hospice and the PCT, but with the NHS reforms the Hospice was left to lead the Project on its own as no leadership from the CCGs was forthcoming. Many stakeholders felt that the Hospice was suited to lead because they had the expertise:

I do think the [hospice] would be [leaders] really, because they've got the expertise, they've got the nursing and consultants and medical staff there that are very well respected. I think that's really important to have somebody who's well respected by all other clinicians. (Int Stakeholder 04)

However, it was felt by others that the Hospice did not have the authority to lead a project which spanned multiple organisations:

I'm not convinced they had the [...] infrastructure and expertise to lead on something that was so multidisciplinary, multiagency. (Int Stakeholder 06)

Indeed, some felt that there needed to be more leadership from commissioners in order to give the Project legitimacy among some partners who had other priorities. One of the stakeholders reflected that the lack of commissioner involvement indicated that the Project was a voluntary activity:

I think the Hospice leading on it kind of reinforces the idea that it was a well-meaning group of people getting together to do something that's a good thing to do whereas if it had felt like the commissioners kind of making us come to the table to save x-million pounds or x-number of inappropriate A&E admissions or whatever, it might be more effective (Int Stakeholder 07)

At an individual level, it was observed that the leadership styles within the partnership may have also impacted on the groups' ability to deliver outputs. The leadership of some of the groups (work streams and management groups) was observed to be quite inclusive, which perhaps reflects an equitable approach to the partnership. However, this also meant that at times there seemed to be little progress because it was difficult to achieve consensus with absent partners:

I remember coming away thinking that was two hours and not quite sure what happened there. (Int Stakeholder 07)

In such instances where the approach to leadership was democratic, few decisions appeared to be made because of the lack of engagement. This was in contrast to groups where the leadership was more directive and where leaders took action:

[X] had cancelled the December meeting because it appeared she would be attending it on her own, all other members had seemed to disappear. She opted to do some work on her own to keep the momentum of the group going (Obs PDG 13Q1-08)

It was noted during one of the observations of the Project Delivery Group meeting that there appeared to be different leadership styles among the work stream leaders which seemed to lead to differing rates of progress on completing tasks:

perhaps [X's] leadership is not as effective as [Y's] who seems to drive her group by creating something for the group to then work with and comment on (Obs PDG 12Q4-07)

While progress seemed to be made faster in groups where there was more autocratic leadership, it was not clear whether consensus had been achieved in those groups for work that was pushed forward. Also, this is not to say that these decisions were accepted by the wider project group, but simply that a decision had been made at the work stream level and more seemed to happen. Different leadership styles might account for why some of the work streams were more productive than others, though agreement by all partners was needed for any decisions to be implemented within organisations regardless of how those decisions were reached.

Engagement

Individual characteristics and priorities, availability within work commitments, and group leadership all impacted on the engagement and participation by the various partners. Overall the effectiveness of the partnership approach was felt to be compromised by a general lack of engagement by stakeholders:

so you have key people who had key roles would come and say 'yes we will do this' and then they never seem to turn up again (Int Stakeholder 06)

Success in the work streams was predicated on partners each contributing their organisation's view to the issues. Thus tasks within the work streams which required input by all partners were left unfinished if partners failed to show up to meetings or respond to emails:

in the end in the work stream in Education and Training there was only three of us [...] so you know, three people trying to sort out all the education and training across [the region] was not gonna really work in that group. (Int Stakeholder 03)

The success of the work streams has been patchy, it has been incredibly difficult to get regular attendance from all organisations during this time of intense change with people changing roles and other pressing priorities. (Doc Operational 13Q1-02)

There were clearly some dedicated partners who were committed to the Project, but without consistent engagement they found it hard to achieve their aims. Additionally, it seemed that the project manager was unable to bring the right people to the table, largely due to the changing health and social care landscape. A high turnout to meetings was clearly encouraging to partners, but likewise lack of engagement fed a negative cycle in which little progress was made which was discouraging to those who had been attending:

I was surprised how many people were there [at the meeting] and [X] and I were very motivated by this and we met with [project manager] a couple times and we had email exchange, phone calls because we really wanted to get our teeth into it, so we were disappointed. The further the Project went on the less people attended. [...] so we tried to keep it going but sadly people just didn't come to those meetings. (Int Stakeholder 09)

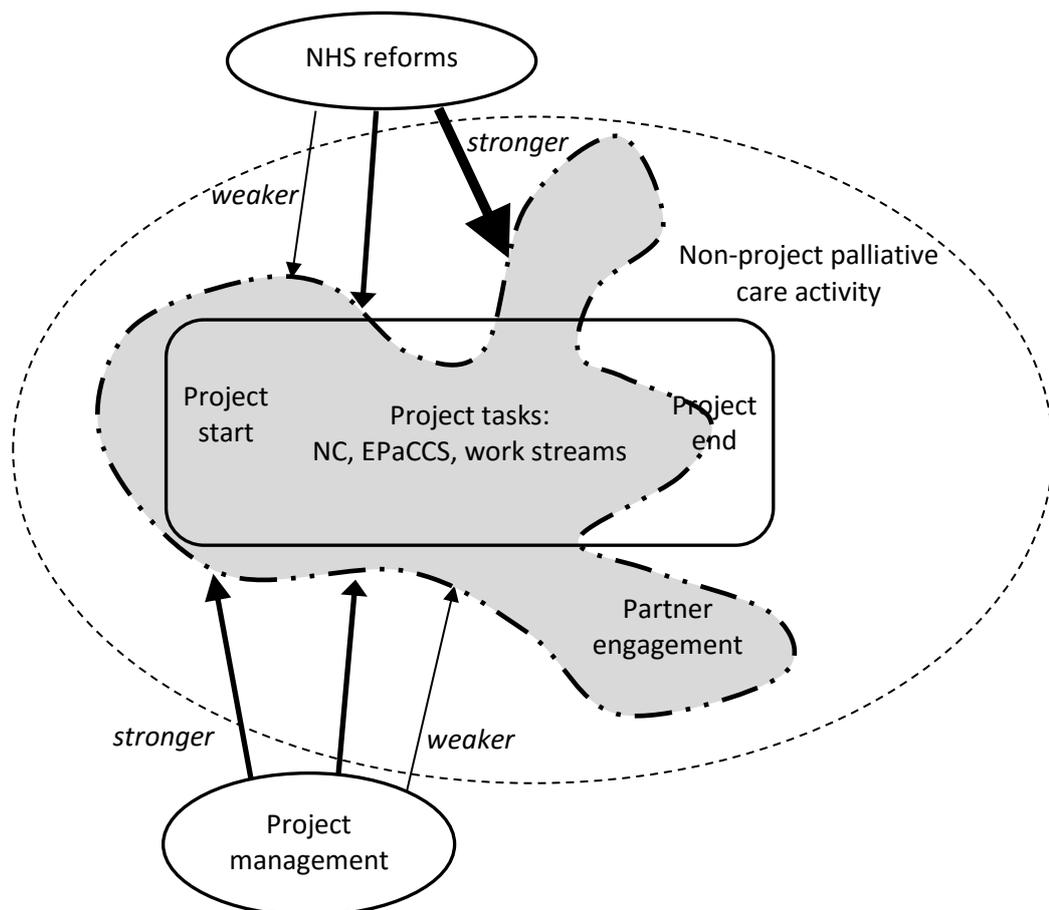
Many of the Project meetings spent time discussing who was not present and whether it was possible to move tasks forward without them; this discussion was usually in reference to the absence of commissioning representatives, particularly from CCGs at PDG meetings. There was some disagreement within the group as to how involved the CCGs needed to be in order for the Project to achieve its aims with some feeling that their involvement was crucial and others feeling that they could be brought into the fold further down the line. This perhaps represents a lack of unified vision of how to achieve the Project aims.

[W] said that [X] has previously made it clear that the CCGs really need to be involved in the workshop; but [Y] and [Z] disagreed. [Y] said that if they can demonstrate to the CCGs that the pathway is reducing hospital deaths and costs then they would probably come on board then. (Obs PDG 13Q1-10)

While lack of engagement seemed primarily to be a by-product of the NHS reforms for some, lack of structured project management and perception of poor progress may have been discouraging for others. However, nearly every meeting did have a variety of stakeholders present which indicates that they were in fact engaged in the Project, albeit sporadically. It may instead be that

expectations were unrealistically high in expecting every stakeholder to be at every meeting. Because the Project aimed to create regional system wide change, the loss of any representative of one piece of the system seemed catastrophic. Figure 6.1 visualises the relationship between partner engagement and project activity as influenced by two key elements of project management and NHS reforms. Project tasks (rectangle) are situated within the wider sphere of all palliative care activity ongoing in the region. The dotted grey shape indicates stakeholder activity in relation to palliative care activity over time and the influence that project management and NHS reforms had on participation. At the start of the Project, management was stronger and NHS reforms were weaker, thus participation was more focussed within the Project activities; but as this started to reverse, stakeholders drifted away from the core project activities and instead became engaged with other palliative care related activity.

Figure 6.1 Influence of NHS reforms and management on partner engagement in relation to project tasks



6.1.5 Power in partnership working

It has been hypothesized that the exercise of power within a partnership approach would mainly feature in decision making as it implies shared motivations and working for mutual benefit. Thus it was assumed that in such an equitable approach a degree of pluralistic power sharing would be prevalent in decision making even if the Hospice was leading the partnership.

At the start of the Project, some key decisions were dominated by the Hospice rather than achieved through group consensus, namely in the selection of the Blue System for the EPaCCS and when to open the Navigation Centre. As the Project progressed, more decisions needed to be made by the partnership, for example in determining the patient pathway. However, there was little evidence of decision making in the meetings, potentially because the work streams were not progressing their work. Instead, it seemed that some decision making needed to involve those not present in the partnership, namely commissioners from the newly formed CCGs who, though invited, did not participate in the Project. Thus decision making was not under the control of the Project partnership:

It was agreed that the work undertaken by this group needed to be taken to the CCGs for them to give the go ahead. (Doc Meetings 13Q1-02)

What does this delaying of decision making tell us about the power relationships within the partnership? It indicates that those present were not able to make decisions on behalf of those not present. Does this indicate that power was shared because missing stakeholders were respected enough to not have decisions imposed on them? Or does it tell us that those not present held the power because their absence prevented the group from making decisions? Postponed decisions were often those that required a commissioning perspective. Thus it seems that decision making was implicitly tied to money as many decisions would have workforce or resource implications. The project manager indicated that the group's decision making was ineffective without the backing from a commissioning organisation:

Now what I was saying to the trustees is you absolutely have to include the commissioners in this discussion because all this is really about what the commissioners want to commission. (Int Project Manager 13Q2-4)

Rather than power being shared pluralistically, the perception among some stakeholders was that it was held only by commissioners. The fact that the Project was not led by commissioners was suggested to be challenging because it was felt that the Hospice had insufficient influence to hold the partners to account:

there's lots of different people in the mix, you can't police them all and keep them on message, and we certainly couldn't because as I said earlier, we didn't have the power or the influence. (Int Stakeholder 01)

Hospice stakeholders seemed to view the partnership more negatively, mainly because it seemed that they were preoccupied with what effect the changes in the NHS would have on the Project and perhaps felt that commissioners had deserted the Project which they were leading:

The flow of the meeting seemed to move away from checking on what each of the work streams were doing and focussed more on key issues and risks that need to be dealt with, many of which related to the wider context of the NHS, namely the role of the CCGs and how the Project would sit within the new organisational system (Obs PDG 13Q1-08)

However, this seemed to be somewhat less important to other stakeholders and instead they were reassured that the partnership was led by experts in end of life care, suggesting the relative importance of expert leadership over coercive leadership (French and Raven, 1959). What was important was whether they felt that partners were committed to the Project and improving care. One stakeholder indicated that CCGs were perhaps not best placed to lead the Project because it was not a primary concern for them:

CCGs -you know GP led, yeah what are their priorities and it may be end of life care isn't their priority because work I've been doing outside of the Project, there's a whole host of other things in GP's agendas rather than just end of life care. (Int Stakeholder 06)

Emerging from the question of leadership was the relative prominence of primary care, specifically GPs, and what impact this had in upsetting relationships between 'equal' partners.

Prior to the NHS reforms GPs were commissioned by Primary Care Trusts (PCTs) which retained some levers to hold GPs to account. With the changes in commissioning, GPs suddenly became disconnected from a governing body temporarily while the CCGs were being established. Unfortunately this change happened in the middle of the Project. What this led to was a lack of consistency and unpredictability among GP practices. The prime example of this was when the end of life care lead for one of the newly formed CCGs agreed on behalf of the CCG to implement the Blue System. All GP practices within the area followed suit bar one large, and therefore influential, practice which decided they did not want to partake and essentially undermined the authority of the CCG leaders. It was suggested by one stakeholder that this was because of the newness of the CCGs and that perhaps the legitimacy to lead comes from experience in addition to the power to fund services.

where does the power lie is the question. And for me the power lies with the Clinical Commissioning Groups-the GPs or should – I still don't think they're in the right place to be able to make those sorts of decisions because I don't think they're mature enough organisations. I think the maturest organisation in terms of making things happen at the moment would be the hospital trust. (Int Stakeholder 01)

The struggle to organise GPs had a direct influence on the progress in the Project and distracted some of the Project stakeholders, especially the Hospice which perhaps felt that the loss of a commissioning influence in the Project undermined their authority to lead.

I mean I think we took on a very, very ambitious task and a small organisation on the periphery i.e. not a mainstream NHS organisation but an independent organisation. There are just questions for me now about how much influence we can have, it's clearly limited and undoubtedly we had supporters and enthusiasts here but it wasn't able to coalesce into something that really got momentum. (Int Hospice Director 13Q3-05)

Rather than partners exerting influence or power in the Project through decision making, it appeared to be their lack of engagement which was influential in the decision-making process, in that a lack of engagement led to delays in decision making. If power is conceptualised as being exerted through decision-making (Dahl, 1957; 1958; Bachrach and Baratz, 1962), then this perhaps suggests that those who did not participate held power since their non-participation prevented decisions from being made when needed. Power did not seem to be overtly exerted, but rather people were seen to be 'nice' to each other or diplomatic.

facilitating style is rather democratic [...] The decision making of the group seems a bit vague (Obs PDG 12Q4-07)

Power was exerted covertly or perhaps even unintentionally, such as by not engaging in the process, as the out-of-hours provider did. By not engaging with the Project, this made it impossible to achieve interoperability between the Red and Blue Systems making the Blue System unworkable. The Project was reliant on all partners, and some of those outside of the partnership (such as the out-of-hours provider), agreeing to work together for mutual benefit. But this proved to be an inadequate foundation for the Project in the context of competing priorities and the Hospice was not able to influence others as needed:

I think what we learnt from it is, as an organisation we don't have sufficient power or adequate influence to be able to move major players away from the position that they're

in and we certainly didn't at the time, and, I'd be very reluctant to get involved in a project like that again for that reason (Int Stakeholder 01)

6.1.6 Barriers and facilitators

The foregoing analysis of the implementation strategies and the influences on the implementation process reveals a number of barriers and facilitators that impacted on the engagement in the partnership and hence work stream involvement, as well as adoption and use of innovations. Table 6.1 summarises these barriers and facilitators. It presents ten different factors in implementation, describes the factor and evidence for its existence, whether its origin of influence was at the individual (micro), organisational (meso), or wider setting (macro). Barriers and facilitators reflected influences at all three (micro, meso, macro) levels which reflects the complex, interactional nature of the Project. There were three factors that both served as barriers and facilitators which have already been described: project manager, hospice leadership and perceived need/benefit. Also, there is some overlap between the factors, for example management is most likely tied to the Hospice leadership in the sense that the management structure came from the Hospice which created and designed the Project and it was perhaps their inexperience in complex programme management of a partnership that resulted in a loose management style. It is also interesting to note the different ways that Hospice leadership was perceived- with some stakeholders viewing it as lending the Project credibility, but others saw it as a sign of optional participation because of the lack of commissioning leadership.

Table 6.1 Barriers and facilitators in the implementation of the Project

Factor in implementation	Factor description/evidence	Influence level¹	Enabling characteristic
Communication	Lack of communication among partners in reporting progress and tasks; lack of communication about project to external organisations and professionals	Meso	Barrier
Management	Perfunctory, loose management style focused on meeting organisation rather than facilitation of tasks	Meso	Barrier
Project manager	Focused on EPaCCS implementation and not on project management; no authority among partners // When manager role ended, so too did project meetings; nothing produced after project manager left role	Meso	Barrier / Facilitator
Competing innovations	Blue System in competition with Red System which was monetarily incentivised; Navigation Centre (NC) in competition with 111 both acting as a single point of access	Macro	Barrier
Political change	NHS reforms stemming from political change impacted on structure of partner organisations	Macro	Barrier
Training	Focused on functional use of Blue System without changing beliefs of professionals in value of using new system	Micro	Barrier
Large, diverse partnership	Many partners each with different views on how to change care delivery; no 'stick' to hold partnership together	Meso	Barrier
Hospice leadership	Not taken seriously by all because lack of authority and power over partners; Project became more insular in second half when Hospice began funding it // Gave Project credibility because of expertise in end of life care	Meso/ Micro	Barrier / Facilitator

Perceived need/benefit	Ambulance service used the NC because it filled knowledge gap need; service users called NC for faster response to services // GPs did not use Blue System because perceived lack of need over Red system	Micro/ Meso	Facilitator / Barrier
Personal motivation	Partners who continued to engage in project had personal motivation or keen interest in end of life care, were determined to improve care	Micro	Facilitator

¹Influence refers to origin of factor

Macro: National, region-wide issue

Meso: Project group, organisation

Micro: Professional, individual, stakeholder

6.2 What implementation outcomes were achieved?

The Blue System EPaCCS was never fully implemented beyond the Hospice and was in fact abandoned by the end of the Project. However, in switching to the Red System, the organisations that could be counted as having implemented the register included GPs, the out-of-hours service, and the Hospice, though as many organisations had not implemented either system (the Hospital Trust, Community Health Trust, and social services). Importantly though, one stakeholder felt that the EPaCCS was not achieving its intended purpose of advance care planning which echoes the project manager's concerns:

I mean one of the big aims of the Project was to get an electronic palliative care record in place and that was never achieved, advance care planning which is you know something that I'm extremely keen on, was never moved forward [...] so I found that extremely frustrating, the fact that your two major parts of the Project, getting people to fill advance care plans in will help you then with palliative care records so I think that was a major shortfall. (Int Stakeholder 06)

It seems then that the education and training was insufficient for implementing the EPaCCS to its full intended effect, particularly when taking into account the competition posed by the Red System. On the other hand the Navigation Centre was established and was counted as an aspect of the Project that was implemented:

I think the main achievement is that the Navigation Centre did get up and running and stayed established and is still running. That's the one bit of the Project that is still completely doing what it said it would do, out of all the things that were kind of listed as would happen. (Int Stakeholder 06)

Like the EPaCCS though, implementation was not just about the tangible existence of the material resource, but whether it achieved its purpose, which was to help navigate patients around the system thereby reducing the duplication of work. In this capacity, it was felt that the Navigation Centre did not achieve its aim:

it's an excellent telephony service and definitely providing support, but in terms of navigating round the whole health and social care system that is not what's happening. (Int Hospice Director 14Q1-07)

While the perception from the stakeholder point of view was that this type of navigation was not happening consistently, there were some occasions where carers seemed to indicate that the

Navigation Centre did work as anticipated and with good acceptability from the carer point of view:

One night the patient had some considerable pain so the carer called the hospice as she didn't know what to do. The nurse called her back, then had to call the doctor for advice and then called her back again. So it was approximately 3 phone calls over a couple hours. They gave her advice which she found reassuring. It seems that if she had called the 111 then they would have sent a doctor out who wouldn't have known the patient and he would have given him an injection which she could do herself. (P27 carer telephone interview 3)

However, while this represents an example of the Navigation Centre working as intended, there were a number of carers who were entirely unaware of the Navigation Centre's existence suggesting either a lack of targeted communication to the intended service users, or a lack of absorption in remembering the availability of the service by patients and carers:

She says she called the hospice to let them know he was sick and she says they always phone her back. I asked if this was the [Care Navigation] service, she said it was just the hospice number that she was given. She didn't seem to know what I meant by [Care Navigation] service. (P25 carer telephone interview 1)

In either case, lack of awareness of the Navigation Centre services would likely threaten any sustained use of the service. There were other indications that while the service was used by carers and patients, it was sometimes used as a workaround to bypass existing channels of service access:

carer had phoned the [Navigation Centre] a few times during the patient's illness. Primarily he phoned out-of-hours as a way to enable quicker access to the district nursing service. The [Navigation Centre] would phone the district nurses who would then come out or phone and then visit. He said this worked well, but only used it out-of-hours as during hours he would have called the surgery directly. (P10 carer telephone interview 3)

While this indicates that the Navigation Centre did provide some benefit in terms of faster access, it was not actually providing a distinct service but rather duplicating a method of arranging a district nursing visit. The perspectives of patients and carers certainly add to understanding the implementation outcomes (*acceptability, appropriateness, adoption*) of those innovations for which they are co-creators in the care process.

In terms of work stream production, there was a modest amount of output in terms of developing the medicines pathway and the creation of patient pathway guidelines used by the Community Health Trust. Neither was in widespread use by the end of the study period so any impact is not reflected in the audit, but their creation in spite of major NHS changes is certainly a creditable outcome in a slow process of creating change at the service user level.

It was suggested that some of the implementation deficit may have been due to the management issues that the Project faced. One of the stakeholders felt that the Project “drifted” (*Int Stakeholder 09*) because there was a lack of clear timescales and partners were not held to account for their assignments. She compared her experience between two projects which had different management styles and felt the other project was more productive because of an authoritative manager:

I think they have a specific person who's driving the project, very motivated, very knowledgeable, she's there purely for that project and I think that it's at the 'lead of the helm' that brings people together and the communication is excellent, there's meeting minutes that follow more or less a few days afterwards. Badgered is not the right word but you are being badgered to read and attend to bring it forward, so I think it's just a different approach. (Int Stakeholder 09)

Using Proctor et al's (2011) taxonomy of implementation outcomes (outlined in Table 3.3), particularly those relating to the early stages of the implementation process as this was as far as the Project progressed, it might be concluded that the outcomes of *acceptability* (perception that the innovations were agreeable/ satisfactory), *adoption* (uptake of the innovations) and *appropriateness* (compatibility of the innovations with the organisation) varied by innovation and partner organisation. For patients and carers, of those who had experience with the Navigation Centre or were aware of the Blue System, the innovations appeared *acceptable* and *appropriate* to their needs, though clearly there were issues with widespread adoption. With regards to *fidelity*, no innovation was implemented entirely as planned: the patient records in the EPaCCS were often missing elements of advance care planning and the Navigation Centre was not used by non-hospice patients. Given the preceding chapter's discussion of implementation strategies, it seems likely that the 'dose' of the implementation strategies was not sufficient for the partnership approach within the context of the NHS reforms; i.e. not enough: project meetings, education, management, feedback from monitoring attempts, or communication. This is not to say that the Project produced poor implementation outcomes, but rather these outcomes reflect

a complex implementation process in which plans were tested by the external NHS changes which challenged the Project operation.

While the expected, measureable outcomes of the Project were perhaps limited, there were other outcomes with less tangible affect that could be attributed to the implementation process. Firstly, there was a greater awareness among stakeholders about the role of others in providing end of life care. One stakeholder described how he knew little about the Hospice prior to the Project:

the hospice is a lot bigger than I thought it was. I thought it was 'two man and a dog' but it's like 300 people and they have more beds than I thought so they have quite a lot of stuff that they want to analyse every week, and the way that works is fairly archaic. (Int Stakeholder 07)

Subsequently, this has led to closer working between the two organisations in helping to analyse data which is relevant to both. This demonstrates a sense of greater willingness to work together which was also evident from the care navigators' experience in dealing with the out-of-hours service:

2: I think there were a bit of obstacles put up at the start but now it's 'oh hello, the Hospice, oh what can we do?' and that's really improved an awful lot.

3: And some even say 'I'll mark it as urgent, it's a palliative care patient so thank you very much' (FG care navigators)

Greater willingness to work together could potentially lead to a more responsive service for patients. The awareness raised by simply getting stakeholders around the table and talking to each other was seen to be beneficial for creating a willingness to work together:

I think it also sort of just raised everybody's awareness of end of life issues and actually did engender some sort of joint working around end of life issues. (Int Stakeholder 02)

The partnership working which occurred as part of the Project may have also spurred on some unexpected and extracurricular activities related to the Project's goals. For example, during the project period the Hospice developed the role of their in-house social worker to become a trusted assessor, though it was questioned whether this outcome was actually a result of the Project or just from generally working closer together:

our social worker is now a trusted assessor, so I think probably as a result of... well is it as a result of the Project or just general sort of approaches to integrated working? We have now got a new arrangement so instead of when we need an [needs assessment] we don't have to get a [council] social worker to come in and do it, we can do it. (Int Hospice Director 13Q3-05)

Also, the Red System was developed during the Project to meet the needs of an EPaCCS. While this may have eventually happened as a result of national policy, it was thought that the Project may have forced this change to happen sooner:

I think that the [Blue System] initiative sort of forced them to respond and so [the Red System] really now does meet I think almost all of the requirements of an EPaCCS, the sort of national guidance about what should be included and I'm sure that work was stimulated by the competition in a way (Int Hospice Director 13Q3-06)

Following on from the partnership, the Hospital Trust and Hospice had started looking at ways that they could work together:

[X] is quite keen to look at how we might do some sort of shared posts or sort of job swaps between the hospice and the hospital so I think that you know we could potentially build on what's already done to look at whether or not we can achieve some of those sorts of outcomes. (Int Stakeholder 02)

These are unintended, positive benefits that stemmed from the Project and specifically the partnership approach in inviting all stakeholders to participate in the management groups and work streams. While not explicitly captured in Proctor et al's (2011) taxonomy of implementation outcomes, such peripheral outcomes do create a positive atmosphere which may be conducive to future project success.

6.3 How is implementation success judged?

Given the implementation outcomes of the Project and the various influences which shaped the implementation process, how might implementation success be judged? When asked to judge the success of the Project, stakeholders largely took an outcomes-based view citing the desire to see patient outcomes and service changes:

the patient outcomes are I think what we should measure on in the end. (Int Stakeholder 04)

it's no good having something that works really well on process if it's not delivering what it's supposed to deliver [...] in terms of what the patients feel is of benefit to them or the other users of the service (Int Stakeholder 05)

Indeed, a comment from one carer seemed to indicate that a lack of coordination was the norm suggesting little impact on improving her experience of coordinated care as expressed by the stakeholders:

I asked whether [the carer] felt the services they received were well coordinated or not. She said that they all come from different organisations, so she deals with them directly and they don't phone each other, though she didn't seem to indicate if this was good or bad, it's just how it is. (P15 carer telephone interview 6)

While patient and service outcomes were clearly the gold standard for judging success by stakeholders, this is not to say that they did not recognise important steps and processes that had to happen on the journey to creating improvements in patient care:

ultimately we should be assessing the success of any project by the outcomes that it delivers for patients but [...] I suppose it doesn't necessarily have to be judged just on what it has achieved for patients because I think it has achieved some things and we just need to make sure that we don't lose that. (Int Stakeholder 02)

While it was felt that the interpersonal processes of sharing experiences and raising awareness were a successful outcome because of the potential change that this might induce, it was felt that the basis of a project needed to be grounded in achieving improvements for patients:

you wouldn't describe the reasons for the Project starting as 'let's all just get to know each other a bit better because some good stuff will happen over the next five or ten years' but that's a perfectly reasonable outcome, but if you invited people together once a month for two years to say 'let's all get to know each other a bit better because some good stuff will probably happen', they wouldn't come because they would go 'well there's no deliverable' (Int Stakeholder 07)

The focus on achieving outcomes for patients aligns with an implementation science view which is about achieving significant outcomes. However, implementation science is focussed on establishing evidence-based interventions into practice, which the Project was not. Because so much of the Project's elements were untested, it required much more development and exploration to figure out what would work. This perhaps does not lend itself to judging success

based on patient outcomes, which might account for the seemingly negative view on the overall achievement of the Project.

Summary

This chapter has considered factors that influenced the shape of the implementation process which included elements internal and external to the Project. The internal features of the Project included the funding and resources available for delivering the Project and its distinctiveness to other ongoing pieces of work. The innovations in the Project met the needs of partners to varying degrees and faced competition from other similar innovations which was a barrier to adoption. However, the overwhelming influence on the Project was the changes to the NHS structure which created a sense of uncertainty and distracted key stakeholders who were perceived by some partners to hold the power to implement. Ultimately the complex process led to mixed implementation outcomes which varied by innovation and organisation, though overall partners suspected a lack of improvement at a patient level which they interpreted to mean that the Project did not achieve its aims.

7 Discussion

Introduction

This final chapter will consider the findings from this study in relation to the empirical and theoretical literature on implementation with particular reference to health and palliative care services. It will start with a brief summary of the key findings, followed by an in depth discussion of the prominent themes which will be structured around the research questions and consider their significance in relation to previous research. This is followed by a consideration of new insights this study contributes to theories of implementation and presentation of a reconstructed conceptual framework for analysing implementation of complex programmes as a process. Lastly, the strengths and weaknesses of the study will be considered before suggesting an agenda for future research.

7.1 Brief overview of empirical findings

This study aimed to address the questions of: what is the shape of implementation and what influences the implementation process; and how and to what effect were the strategies used to produce implementation outcomes?

The Project had characteristics of both programme planning and implementation and the two activities took place simultaneously during the project period, shifting back and forth. Seven implementation strategies were identified using constructs from the empirical and theoretical literature described in chapters two and three, but these strategies had limited effect on the overall process. Management structures and communication were the two most prominent strategies, yet these were threatened by the autonomy of individuals in the partnership which relied on individual motivation to participate in the Project and assumed power equality among stakeholders. Implementation of the Navigation Centre was characterised by trial and error and had mixed success in achieving its aims. The Blue System was either not adopted by partners, or among those who did adopt it, it was only sporadically used. Thus the shape of implementation depended on what element of the Project was being implemented, but overall implementation was characterised by competing interests and circular, adaptive progress in which implementation strategies seemed to feature very little in influencing individual stakeholder action in the face of external threats and implementation outcomes were inconsistent across the partnership.

The shape of the implementation process was found to be influenced by four elements: context, project resources, innovation characteristics, and the partnership approach. The NHS reforms

from the Health and Social Care Act 2012 and changes the NHS non-emergency telephone services in relation to the Navigation Centre proved to be a distraction and barrier for stakeholder participation. The Blue System was felt to increase the professional workload without adequately meeting the professional users' needs; coupled with competition from the existing Red System meant it was not widely adopted by a majority of GP practices. The involvement of a wide range of partners was meant to create regional system wide change, but given the NHS reforms, individuals had different priorities which they focused on. Poor attendance by some stakeholders, namely GP representatives, appeared to negatively affect decision making and it appeared that power was demonstrated through participation and engagement in that lack of stakeholder representation meant decisions could not be made. However, a number of stakeholders had a personal interest in palliative care and this was a real motivating factor in the face of loose project management. Despite these adverse circumstances, some stakeholders positively viewed the work that was achieved and it was recognised that the Project was a catalyst for improving information sharing and palliative care provision. Implementation outcomes were not highly rated by stakeholders for judging project success, but rather their interest was in impact on patient outcomes which they largely felt was minimal.

This study demonstrates how implementation strategies, programme characteristics, actors and context interact to shape the implementation process. This interaction is responsible for producing (or not) implementation outcomes which then have implications for patient and service outcomes.

7.2 Key themes and synthesis of findings with the empirical literature

This section synthesises the key findings from this study with the empirical literature regarding the shape of implementation, influences on the process, impact of implementation strategies on implementation outcomes, and barriers and facilitators.

7.2.1 The shape of implementation

The implementation process of the Project progressed in an interactional, overlapping process, with some tasks unfolding as planned and others such as the EPaCCS, redeveloped or incompletely established. This seems largely to have stemmed from the fact that adoption and implementation were taking place at the same time, whereas implementation usually assumes an adoption decision has been made prior to that process beginning (Linton, 2002). The empirical literature on health care innovation implementation suggests that this staged view of the process

(Rogers, 2003) is an idealized interpretation and that rather the implementation process is more often characterised by negotiation and adaptation among actors in reconciling new ways of working with existing practices and knowledge (Gabbay and le May, 2004; Raveis et al, 2014; May et al, 2007). In health care, practice is informed by both tacit and explicit knowledge (Gabbay and le May, 2004; McKinlay, 1981); the element of past experience informing future practice suggests that the implementation process is perhaps subject to less control than a rational model suggests. Experiential knowledge rather than empirical evidence was the basis for the design of the Project; innovations were selected or developed to suit a need rather than being selected for their empirical effectiveness. Given the range of different partners involved each with their own professional knowledge and experiences, it is unsurprising that there were different views on the various innovations incorporated in the project. For example, there were differing opinions over whether a functioning EPaCCS versus an agreed patient pathway was a more important first step. Reconciling these views through negotiation seems to be a feature of partnership working which implies a less rational and more adaptive approach to implementation.

As has been argued in previous chapters, programmes which have linear characteristics seem to reflect a planned, structured and controlled process in which the innovation clearly fits a need or does not require many changes or much involvement on the part of health professionals. This was most closely demonstrated by the Navigation Centre which was more readily used by health professionals than the Blue System EPaCCS. The only change required was for professionals to use a different telephone number (low behaviour change) for which they should have experienced a more proactive response from the Hospice (perceived benefit). However, there was some adaptation as the algorithms for call handling were abandoned during implementation. In contrast, it has been argued that non-linear implementation accords with practitioner-led, problem driven approaches. This was evidenced in the progression of the work streams in which development, planning and implementation all took place at once in an adaptive process. Implementation in health care is not just a series of steps, but rather a dynamic interaction of learning and adapting to find a path of change which fits an overarching aim and matches professional's needs for their work and what they see as patient needs (Raveis et al, 2014). While the theoretical literature suggests that implementation may be linear, the empirical literature suggests that it is more often a mix of negotiation and adaptation, though some elements may progress as planned giving a sense of linearity. The innovations in the Project demonstrate features of both shapes, though overall the implementation of the Project as a whole was messier with planning, re-planning, learning, negotiating, relenting, and adapting. The shape of

implementation appears to reflect characteristics of the innovation being introduced and the planning and management of the process which will be further described in the next sections.

The findings from this study of palliative care aligns with these findings of innovation implementation in health care more widely; that it is an interactional process characterised by uncertainty and negotiation, though at times it can have the appearance of following a rational model of implementation. In the debate over linear vs non-linear, this study concludes that programmes which feature professionals from different health care arenas (as in coordinated or integrated care provision), implementation will be best characterised by messy, non-linear features. Retrospective analyses of the process might suggest more linearity (as discussed in chapter two), but a prospective analysis of process suggests that even in seemingly straightforward implementations there are nuanced elements of negotiation and testing that suggest a more interactive, less proscriptive process.

Type of innovation

The characteristics of the innovation itself appears to shape the implementation process because its features influence what type of strategies are used for implementation and how professionals respond. Denis and colleagues (2002) describes these features as the 'hard core' in that they are irreducible and immovable and the softer, more flexible aspects of the Project, such as implementation strategies, are determined by these hard elements. As was defined in chapter two, innovation can refer to policies, products, practices or processes, and in the case of the Project, the programme encompassed all four to varying degrees and was itself an innovative and ambitious approach to improving health services. Compounding this complexity was the fact that the Project encompassed both innovation generation (e.g. the Patient Pathway) and innovation adoption (e.g. the readymade Blue System EPaCCS) (Damanpour and Gopalakrishnan, 1998). While the Blue System and Navigation Centre comprised the 'hard core', the work streams were largely tasked with generating new ideas to change end of life care in the regional health and social care system. Therefore the Project team had to undertake two separate types of processes – *adapting* processes to assimilate an innovation into working practice and *creating* processes to develop something new. These two processes are generally treated as two separate areas of inquiry with distinct bodies of literature in organisational and social science. Whether innovations are home-grown or taken off the shelf, it seems that there are likely to be common features of what makes innovations more or less implementable. The standard attributes that influence innovation implementability have been well-studied and include: *relative advantage*, *compatibility*, *complexity*, *trialability*, *observability*, and *re-invention* (Greenhalgh et al, 2004b).

The literature indicates that implementation is perhaps easier to achieve when the focus is on redesign of existing services (*re-invention*) rather than procurement of a new innovation or service (Connor and Kissen, 2010). In the case of the Navigation Centre, it involved both a redesign in that the existing telephone advisory service was extended to 24 hours and an advising structure within the Hospice was formalised, but this change also required the procurement of more staff and a telephone system to support care navigation. Overall the concept of an advising service in the Hospice was not new and was generally well received among service users and professionals. This approach to maximising an existing or established service proved to be a successful feature in the study of the Palliative Care Integration Project in Canada (Dudgeon et al, 2009). Such an approach may be particularly prudent in palliative care in which it can be difficult to integrate a specialist approach into generalist care (Mirando et al, 2005). This introduces a distinction between different types of innovations – those that are simple and those that are complex. While *complexity* – that is how difficult an innovation is to understand and use – is not conclusively linked to implementation (Rogers, 2003), it may be that complexity is linked to the sense-making process that professionals go through to internalise new work (May and Finch, 2009). More complex interventions perhaps require more intensive strategies at the individual level to help professionals relate them to their work. This may be why the Navigation Centre was adopted by professionals because the change was relatively simple, whereas learning and understanding how to incorporate the Blue System into usual work was more complex.

In health care there is a growing trend, or indeed imperative, to ensure that practice reflects the best available evidence (McKinlay, 1981; Rycroft-Malone et al, 2004). In some cases evidence as demonstrated in a randomised trial can be an important factor in helping innovations to spread and be adopted (Della Penna et al, 2009). One reason for this is because it makes the innovation seem less risky, which is an additional implementation attribute identified in Greenhalgh and colleague's framework (2004a). However, not all changes being made in the health service are evidence-based or have some proven efficacy – indeed practices are often reinforced or developed through experiential knowledge (Gabbay and le May, 2004), as was the case with the Navigation Centre which was not evidence-based, though this did not seem to concern stakeholders. The collective local experience among the partners reiterated the need for improving end of life care through better coordination, hence the initial buy-in to the aims and principles of the Project, but there was some scepticism to the specific details for achieving this change. The need for the Navigation Centre and EPaCCS were clearly not perceived equally across the partnership and this perception was linked to the type of work that the partners were engaged in. For example, the ambulance service, which by its very nature is generally called to

situations where it has no prior information, found the introduction of the Navigation Centre to be useful in filling an information gap; it was *compatible* with and *advantageous* to their work. In contrast, GPs who engage with end of life patients less frequently saw little *relative advantage* in using the new Blue System over the existing Red System and therefore they largely did not engage with it. The Blue System EPaCCS did not fit seamlessly into existing working practices, nor did it offer a perceptible benefit to GPs over the Red System. This lack of fit within existing working practices was the reason why the Blue System was abandoned. The perceived need for change seemed to drive the uptake of the innovations on offer. This confirms the conclusions drawn by Cresswell et al (2012) which found that the most important factor in whether staff engage with a software package is whether it is perceived to meet a need; if it did not improve their individual working practices then the staff used workarounds.

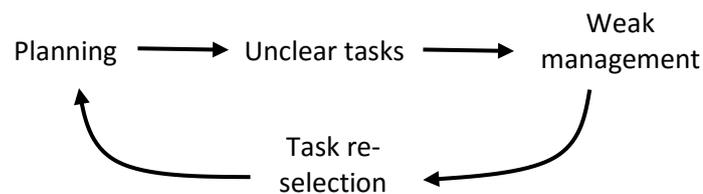
This study demonstrates that innovations struggle to be implemented where they are perceived to have no advantage (as with the Blue System) and are implemented more easily when they are simple and compatible with needs (as with the Navigation Centre). Therefore the shape of the implementation process seems to depend largely on what is being implemented and where. In this study the characteristics of the innovation seemed to be the starting point from which actions then followed, whereas elsewhere the type of innovation being implemented was not as important as other elements of the process (Spyridonidis, 2010). For example, the simplicity of calling the Navigation Centre for accessing or relaying patient information meant it was easily adopted professionals, such as the ambulance service, who rely on quick access to information. The Blue System was less well used because neither the computer system nor the practice of having and inputting difficult end of life discussions onto a new system integrated as easily into the existing working practices of professionals. The characteristics of the innovation appear important insofar as how professionals perceive that it will impact on their work – whether it will reduce their workload, improve the quality of their work or patient care to a point that additional work is worthwhile. However, new technologies and services rarely emerge fully formed but rather are developed and adapted to suit the clinical and organisational context (Gelijns and Rosenberg, 1994). The innovations in the Project were not in situ long enough during this study to determine how they would change as they settled into daily practice.

Planning and managing the change process

Damschroder et al (2009) conceptualises planning as the start of the implementation process in that organising large scale change requires a plan and directions. For example, Dudgeon et al (2009) describe a project with clear phases proceeding one after another with little overlap in a seemingly structured, linear process: development, a pre-implementation organisational impact

assessment, implementation comprised of training, continuous education and dissemination support, and a final evaluation. The authors argued that all-encompassing planning including infrastructure and resources would lead to “unquestionable implementation” (Dudgeon et al, 2009, pp. 484), which is essentially a statement that implementation would progress as planned. In contrast, such all-encompassing planning is more difficult when innovations are untested or developed from the ground up. This was clearly the case in the Project, particularly with regards to the work streams such as the Pharmacy & Drugs group which had insufficient time to develop the medicines pathway and implement it during the Project period. While there was a project initiation document for the Project, some stakeholders felt that this lacked clarity and detail such that it did not give a clear plan of how change would be achieved. Subsequently, the project manager was unable to articulate and facilitate the expected change process in a meaningful way. Thus there seemed to be a cyclical process (depicted in Figure 7.1) in which tasks, such as developing the patient pathway or training for the Blue System, were revised and re-planned.

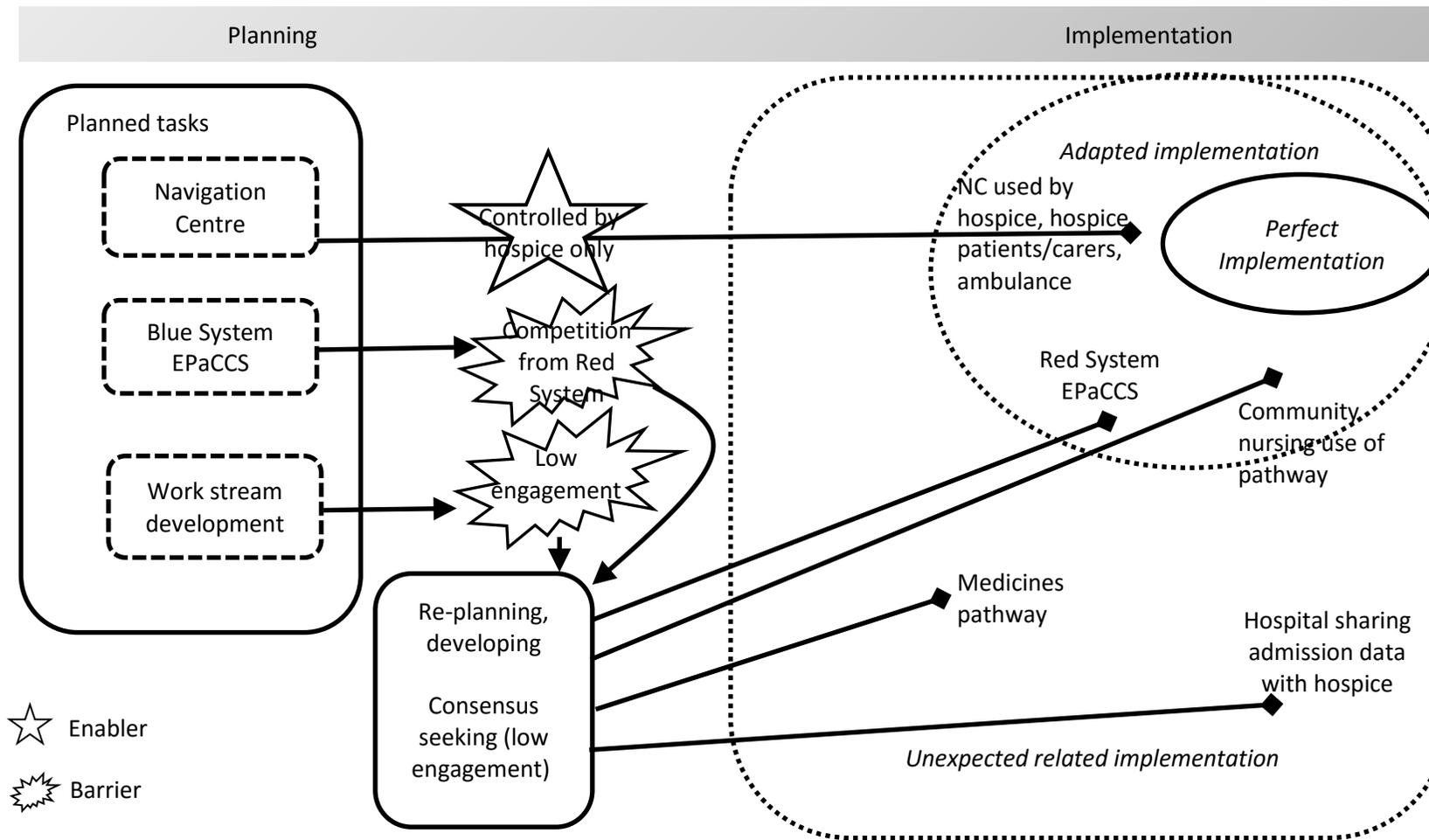
Figure 7.1 Cycle of planning, task selection and weak management in the Project



Though the project planning process itself was not explored in the study because it took place prior to the start, planning can itself be a lengthy process subject to the same learning and adapting as implementation as indicated by a report by Connor and Kissen (2010) who describe a process taking several years involving numerous consensus activities in order to create plans for regional change. While planning seems to take place in an effort to streamline the implementation process, it clearly does not always produce a linear process because it must then be managed. Lack of distinctive planning and management resulted in the Project as a whole “drifting”, as one stakeholder put it. Figure 7.2 depicts the planned tasks (installing the Navigation Centre, implementing the EPaCCS, producing outputs from the work streams), the influence of barriers and enablers on task progress, and subsequently how close each task came to being implemented as planned, i.e. ‘perfect’ implementation. For example, the work streams were tasked with delivering a number of outputs for implementation, but poor attendance at meetings and overall low engagement was a barrier which led to the project management team re-planning how the work streams would deliver their tasks. Subsequently, the outputs from the

work streams were less than expected. Planning may set the expectations for how tasks will be completed, but as barriers arise the role of project management is clearly influential in what implementation outcomes are achieved as a result of re-planning.

Figure 7.2 The influence of barriers and enablers on implementation outcomes and proximity to 'perfect' implementation



7.2.2 Influences on the implementation process

While the previous section considered core elements of the programme which are the starting point in determining the shape of the process, this section considers the external and somewhat unpredictable elements that influence and shape the process.

Context – an uncertain force

Context, to a large degree, determined the fate of implementation in the Project, yet is often poorly understood as a mediator of change (Dopson et al, 2008). Empirical studies reporting on implementation processes rarely provide much detail about the environmental, social, political and economic setting. This is possibly because context is hard to define because it is limitless or that it is treated as a passive backdrop (Dopson et al, 2008). Despite a lack of research into context, it is often cited as an important influence on implementation (Dogherty et al, 2012; Tolson et al, 2007). What happened in the two years while the Project was ongoing demonstrates that context is not static, but is constantly evolving, uncertain and unpredictable. While it may seem that planning is a futile exercise since planners cannot know what the future will hold, plans do give a sense of direction though invariably they will be influenced by external pressures. Between 2012 and 2014 there was a major shift in health policy and legislation as was described in chapter one. The Health and Social Care Act 2012 disbanded PCTs and shifted commissioning responsibility to GPs which meant commissioning priorities became uncertain. Also, the End of Life Care Programme came to an end in 2013 with no replacement specifically focussed on facilitating the improvement of end of life care. This, along with the negative press coverage of the Liverpool Care Pathway and ultimate proposal to end it meant that end of life care as a priority area was perhaps overshadowed.

What this study demonstrates is how influential the wider political and regional context (macro level) can be on professionals and their actions (micro level). The engagement of stakeholders which impacted on the management's view of the success of the Project was influenced by the NHS reforms and the uncertain political and economic climate within public services in the UK between 2012 and 2014. The reforms and subsequent uncertainty appeared to lead to a lack of openness to innovate among those stakeholders and organisations most heavily affected – primary and social care. The CCGs' lack of experience and maturity as organisations may have led them to act cautiously and therefore not engage with the changes proposed in the Project. The hospice and hospital were both relatively unaffected by the reforms and maintained a continuous presence throughout the Project, though because of the structure of the Project they were dependent on other partners to produce outcomes and were therefore caught up in the wake of the changes nonetheless. Some stakeholders were more concerned with their role in the

new landscape and therefore the Project lost a number of influential people. Indeed threats to job security stemming from organisational and system change have been identified in other studies as being a barrier to implementation (Devlin et al, 2015; Jackson, 2000). Jackson (2000) concluded in her study in Canada that: “staff’s innate desire for job security in this time of organisational change has a negative effect on the implementation of the model” (pp. 174). Whether stemming from national policy changes or organisational restructuring, concerns for job security at the individual level clearly takes precedence over project activity.

Within the context of major system change, it is perhaps unsurprising that projects and programmes (even if funded) are moved down the priority list by professionals when they are also pressured to meet targets and minimum service requirements. Indeed, a study by Gollop et al (2004) found that meeting performance targets often took precedence over implementing service improvements. Such prioritisation was seen to contribute to staff scepticism to implement improvement programmes. Improvement programmes such as the Project do not seem to be viewed as essential and therefore seem to suffer more acutely from external political, social or possibly economic threats. It might therefore be considered that the partnership held together reasonably well given the intense NHS changes that were ongoing at the time with little more than personal motivation and organisational commitment to keep people engaged.

Unintentionally, this study has demonstrated the impact of the NHS reforms on a multi-organisational programme. The NHS reforms were largely blamed for the partnership dissolving, but it should be considered that people tend to “attribute success to internal factors within their control and to blame failures on uncontrollable environmental forces” (Van de Ven and Polley, 1992, pp. 97). There will always be external factors that threaten the progress of projects, but the resiliency of the project (people, strategies and resources) to adapt to change is an internal attribute and perhaps is something that needs to be developed to improve the chances of project success and sustainability. A study by Devlin et al (2015) investigated the implementation process of digital health systems on a national scale during the same period as this project while the NHS was undergoing structural change. The findings with regard to impact on organisations and individuals were strikingly similar; the externally imposed NHS changes impacted on the internal organisational working and the fear of role redundancy as a consequence restricted stakeholder engagement. They concluded that there was a “need for resilience in the face of challenging socio-political and economic factors in the external environment” (pp. 5); however it is not specified how such resilience would be achieved. Where does resiliency come from and how can programme resiliency be generated? Resiliency can be viewed as “a process that leads to adaptation and superior outcomes” (Brodsky et al, 2011). How to operationalise resiliency is still

debatable (Pangallo et al, 2015; McManus et al, 2008), but at a project or programme level will perhaps combine features of both personal and organisational resilience; that is: a positive outlook, awareness of dependency on other parties, anticipation of possible threats, and perhaps most importantly, slack resources (Vogus and Sutcliffe, 2007; McManus et al, 2008). No definition of 'programme or project resilience' was found in the literature, but an emerging conceptualisation from this study is proposed here.

Resiliency within the implementation process is similar to the concept of adaptability, though the latter is more often considered as a feature of the innovation itself in terms of adapting it to suit the setting of installation or the organisation adapting to change (Damschroder et al, 2009; Durlak and DuPre, 2008; Rogers, 2003); it is subtly related to the material aspects of implementation. In contrast, project resiliency is aligned more to the human aspects of implementation and describes the agility of the actors to adapt the project's resources and re-orientate strategies to effectively deal with barriers and threats stemming from the context. This is also similar to sustainability, but whereas sustainability presupposes implementation (Greenhalgh et al, 2004b), resiliency describes the attributes of the project that facilitate and maintain momentum in the implementation process towards sustaining change. Project resiliency seems likely to be the accumulation of implementation strategies, such as project management, the independence of individual project elements, and monitoring activities which might indicate where the strengths and weaknesses of the project lie. It is also likely linked to project resources in having flexibility to alter the strategies used and reallocate as necessary. This suggests that it is not situated at just an individual, project or organisational level, but rather reflects an ongoing reciprocal process between all three layers. A similar conclusion was drawn in a different field by Brodsky et al (2011) looking at an Afghan women's underground resistance organisation who found that individual and organisational resiliency interacts such that "individual resilience comes before and is essential to building and maintaining organisational level resilience but is also nurtured, augmented, and in some cases created by the organisational resilience" (pp. 220). This back and forth relationship is likely to be relevant in partnership project implementation in which there is movement between the project and organisation via stakeholders.

The project demonstrated some features of resiliency, such as with redirecting management resources to implement the Blue System EPaCCS when GPs were slow to take up the system, yet at the same time there were not additional resources available to ensure that GPs could be given more one to one support without the overall project management slipping. Such resiliency or flexibility in the face of contextual challenges which almost always present themselves during the

implementation process does not seem to appear as a construct in implementation frameworks (e.g. Damschroder et al, 2009; Greenhalgh et al, 2004b), but rather likely reflects the interaction of a number of constructs. This concept fits a non-linear implementation model in which negotiation and interaction are highly likely to feature, such as in this case with coordinated, multi-organisational, multi-professional models of care. The concept of resilience in programme work may begin to emerge more commonly in future studies for two reasons. First, as partnership working at scale becomes increasingly common because of the political agenda which pushes for more coordination and integration (DH, 2006 & 2010; HM Government, 2012) change will depend more on work at a group level. Delivery of health services will be less about single organisations delivering change and will depend more on multi-sectoral agreement to deliver patient-centred change which means resilience within the partnership and not just the organisation will become relevant. Secondly, as studies begin to publish their findings of implementations which were ongoing during the NHS restructuring, such as the example published by Devlin and colleagues (2015), these changes are likely to have been viewed as a threat to implementation and it will be interesting to see how implementers responded and what helped to overcome threats stemming from the structural reforms.

Autonomous actors and engagement

The professional people (or actors) involved in the Project included managers, executives and frontline staff. The literature review indicated that the facilitator role is essential in implementation in order to align the work of these various actors at different levels (McConnell et al, 2013; Mirando et al, 2005; Dudgeon et al, 2009; Vahedi Nikbakht-Van de Sande et al, 2014). It seems evident that a dispersed and diverse group of people need managing, as was stated by one of the stakeholders. If implementation requires planning, then it reasons to follow that someone must direct people in how to follow this plan. Self-implementation, though possible, does not necessarily lead to sustainment, as evidenced by Di Leo et al's (2014) study in which three of the seven self-implementing hospices ceased using the Liverpool Care Pathway at the end of the study period. Project organisation provided by the manager is one element, the other is the enthusiasm and knowledge that he or she imparts on professionals and motivates them to engage with change (Davis et al, 2006; McConnell et al, 2013; Dudgeon et al, 2009; Tolson et al, 2007). Thus the changes that facilitators create happen at an individual level. However, the project manager role in the Project was focused on managing the organisation of the Project rather than facilitating tasks and professional understanding, but the stakeholders indicated that they would have liked more facilitation.

The interaction of stakeholders and professionals in the partnership should also be considered when thinking about how actors make sense of new work and what influences their decision to adopt and sustain the use of an innovation. It should be considered that each of the stakeholders came from different clinical traditions with different organisational priorities in relation to end of life care. Therefore the risks and benefits of participating in the Project were unevenly distributed (Denis et al, 2002). In particular the GPs seemed to be a difficult group to mobilise and influence, and this has been reflected in other studies (Dopson et al, 2008). This is not to say that GPs were a homogenous group as some GPs welcomed the proposed changes, but there was a large, immovable cohort of GPs who resisted change. This begs the question of 'what is it about their work that makes GPs lack receptivity to change?' While there may be a number of reasons, such as financial imperatives or specialist interests, projects such as this require GPs to prioritise and make changes regarding a specific patient group – for end of life care this equates to only 0.75% of the GP caseload per year (Blackmore et al, 2011). This perhaps creates a sense of 'change fatigue' and a subsequent scepticism towards innovation (Gollop et al, 2004). The reluctance to change (which was also in part due to the NHS reforms) in turn seems to have affected the views of the other stakeholders who took the disengagement by the GPs negatively. But whereas the Health and Social Care Act 2012 shifted control to GPs, GPs within the Project were treated as any other partner, and thus as with other organisations, engagement relied on individual or organisational commitment. Studies which have demonstrated successful implementation cite the enthusiasm of key people as crucial in the implementation process (Dudgeon et al, 2009; Mirando et al, 2005); it seems evident that GPs were a key group as their mixed enthusiasm was influential on the views of others. This suggests that individual attributes are essential in implementation as this might contribute to the project's resiliency and flexibility. Key personality traits would likely include resilience, perseverance and commitment to the cause. However, programmes cannot be implemented by individuals alone but are the result of collective action (May and Finch, 2009), which requires facilitation. This seems to demonstrate that relationships are more important than structures; it is the interpersonal connection, collective vision and commitment from stakeholders that is reinforcing in implementation (Connor and Kissen, 2010). The way in which individuals coalesce as a group will inform the progress of implementation. In the Project where engagement was unified, such as in the Pharmacy & Drugs work stream, tasks progressed largely to plan. Where engagement lacked cohesion, as in the Patient Pathway group, progress became more circular.

Was the poor engagement by stakeholders something that could have been improved through better management arrangements and facilitation, or was the cause of the patchy engagement

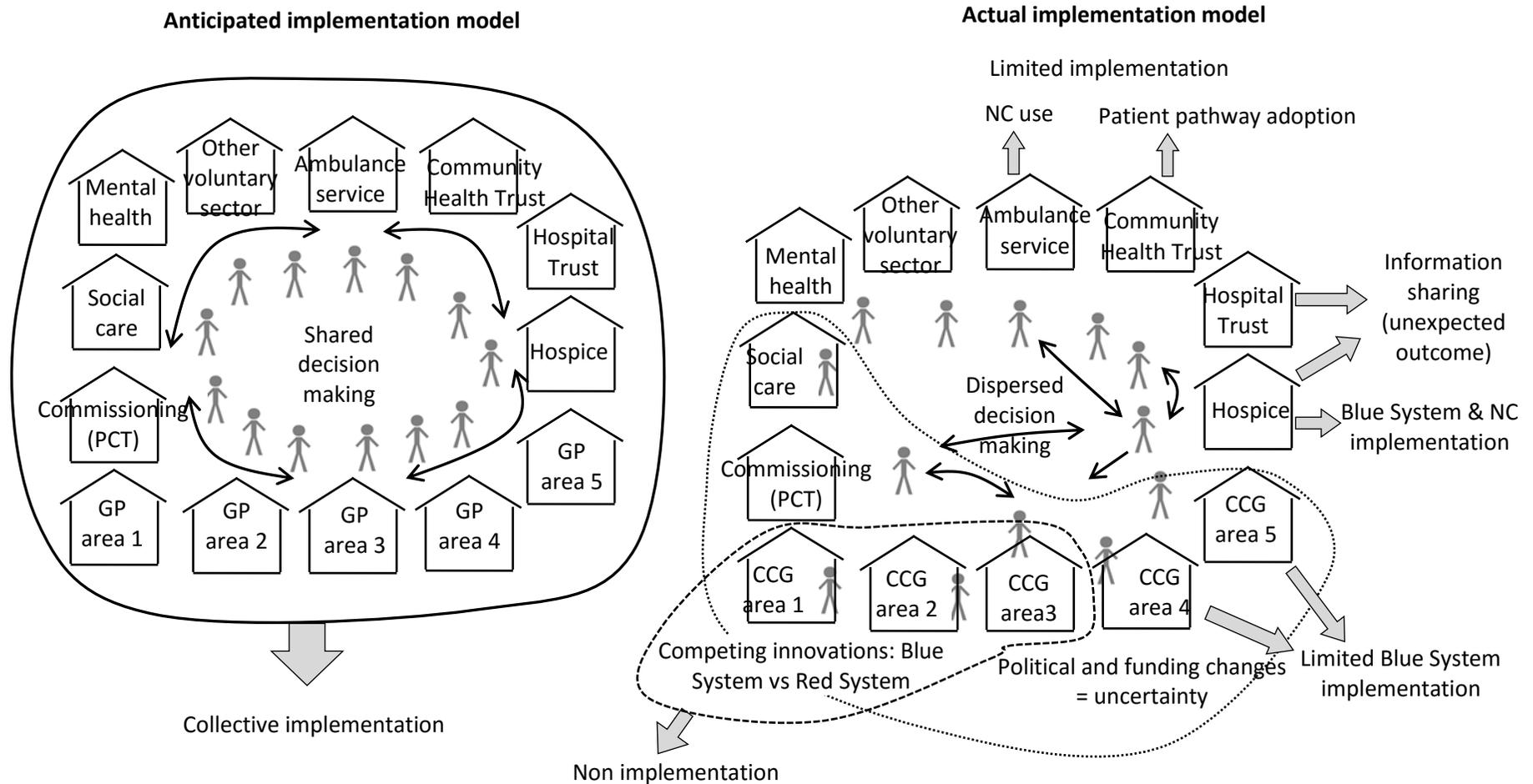
the result of the loose connection between organisations which was easily threatened by the NHS structural changes? The Project was a partnership based on a common local ideal of improving care and reducing costs – there were no contracts or other binding arrangements between stakeholders. This is essentially a difference between *commitment* which is aspirational and focussed on collective goals, and *adherence* which is based on hierarchy, threats and minimum standards. There was a lack of consistency in how stakeholders viewed their commitment to the project; some felt that it was something good to do so attended because of their personal motivation, whereas others stated that there was a decision made higher up in their respective organisation so were obliged to participate. Fixsen et al (2005) argues that ‘buy-in’ is an essential starting point for implementation, but it appears here that buy-in can be at either an individual or organisational level, and while organisational buy-in may be necessary it is not sufficient. Stakeholders responsible for management activities in the project were concerned that there was a lack of commissioner buy-in, though this did not seem to be a motivational or sustaining factor for the engagement of other stakeholders. The lack of governance and change of commissioners was perhaps most influential in terms of its distraction for management because progress was made on some pieces of work within the work streams, such as in creating a medicines pathway, which were further removed from the management hierarchy, though needed approval by management. It seems perhaps that there could have been more work in helping to create a unified vision for stakeholders which could facilitate implementation by increasing awareness of other’s needs resulting in more responsive actions (Hartgerink et al, 2013).

It has been suggested that the needed ‘pull’ for implementation can either be an existing characteristic of professionals in a desire to change or it can be cultivated by a facilitator through activities that help professionals identify deficits in current practice. As stated, this is often part of facilitation (Dogherty et al, 2012). But there are frequently other important roles in implementation which do not necessarily stem from a management approach but are perhaps more spontaneous in origin, such as champions, boundary spanners, opinion leaders, and knowledge brokers. Indeed, Gabbay and le May (2004) found that professionals develop their knowledge from multiple sources including trustworthy others through ‘communities of practice’. There were not any obvious examples of these roles emanating from within the Project that could have been identified through the data collected. It was difficult to identify these roles in the Project because of the nature of the partnership in which each stakeholder occupied senior positions within their organisation and each was expected to champion the Project within their respective organisations, share their knowledge, and help to break down boundaries between

and within organisations. Some of these roles may have been evident within each of the organisations, but data was not collected beyond the project level.

Figure 7.3 combines the preceding discussion on context and engagement to illustrate the anticipated model of implementation versus what unfolded. The anticipated model on the left, which builds on Figure 5.2, demonstrates that the equal engagement of stakeholders from each organisation in the partnership model was expected to result in shared decision making (illustrated by the circle of people figures) and lead to collective implementation of all the innovations (encircled by a solid line). In reality the political and funding changes stemming from the Health and Social Care Act 2012 created a sense of uncertainty within primary and social care resulting in some of these stakeholders pulling back from the group process to focus more on internal organisational concerns (illustrated by the dispersed positioning of the people figures). Without a cohesive group, some of the discussions and decision making were carried out between only a few partners, such as the Hospital Trust and the Hospice and therefore implementation, where it occurred, seemed to take place in isolation in a sort of 'pick and choose' process resulting in various adoption rates. Additionally, some of the CCG areas felt strongly that the existing Red System was sufficient, so the Blue System was not implemented in these areas (encircled by a dashed line) and only had limited implementation across primary care as a whole (encircled by a larger dotted line). This illustration demonstrates that the expectation of collective implementation in a partnership cannot take place if there are differing priorities and inconsistent engagement to lead to shared decision making and subsequent unified action.

Figure 7.3 Explanatory model of the influence of context, engagement, and decision making on implementation outcomes in a partnership



In terms of Rogers' (2003) adopter categories within Figure 7.3, the Hospice might be considered an 'innovator' with regards to both the Blue System and Navigation Centre as they led the Project, made decisions about how the innovations would look and were the first to integrate them into practice. This was followed by four GP practices which were early adopters as part of the pilot in CCG area 5 driven by strong leadership from the end of life lead within that locality, followed by three GP practices in area 4. However, at this point the adoption process slowed within GP practices and instead a non-adoption movement seemed to arise in which some GP practices resisted implementation in areas 5 and 1 which then seemed to create a barrier to stall implementation of the Blue System elsewhere. So instead of viewing these practices as 'laggards', their influence as opinion leaders in pushing for the Red System over the Blue System does not seem to fit within Rogers' diffusion model for adopter types as it does not seem to account for what happens when multiple innovations are competing for the same position. Additionally, while 24 practices adopted the Blue System, only two new patients were added on to the system, which seems to indicate that most practices only adopted the system in name and not in practice. With regards to the Navigation Centre, after the Hospice's adoption, the only other service to consistently adopt its use into practice was the ambulance service. The patient pathway was adopted by the Community Health Trust as a leader within the organisation was involved with the development of the pathway and therefore was in a position to communicate and support its use within the organisation, whereas there seemed to be a lack of awareness of its existence by other stakeholders. It is possible that the Navigation Centre and patient pathway may have been adopted by other organisations over time, but this diffusion process did not happen within the study time period.

7.2.3 Influence of strategies on implementation outcomes

Implementation strategies are not often well described in the palliative care literature; they are usually briefly described without specifics or are not easily differentiated from the intervention itself, especially if they have multiple components (Della Penna et al, 2009; Tolson et al, 2007; Hall et al, 2012; Smith et al, 2012; Teunissen et al, 2007). It may be that implementation is often assumed to take place following an adoption decision in what has been characterised as 'implementation as usual' (Powell et al, 2013). There was no explicit statement of implementation strategies in the Project documentation, but rather for the purposes of this study they were identified using the *a priori* framework presented in chapter three. This then leads to the question of whether implementation strategies are always understood as such or whether they are more often simply implied though not strategically matched to the innovation characteristics (Leonard-Barton, 1988). Implied strategies seem to suit the 'implementation as

usual' model and perhaps explain why they are often not described in detail and are not easily distinguished from the intervention themselves.

A common purpose of implementation strategies is to get professionals to internalise and enact change. May's work with colleagues on Normalisation Process Theory (NPT) proposes that there are four mechanisms for routinizing new work (May and Finch, 2009; May, 2006; May et al, 2009). These include: coherence (relating and making sense of a new practice to existing work); cognitive participation (initiating and preparing for work); collective action (engaging in the new work); and reflexive monitoring (appraisal of new work). What appears to have been missing from the Project were coherence type activities in which stakeholders were enabled to make sense of how proposed changes would impact on their organisation and professional duties, which is arguably a first step in individual implementation. The project plans and design seem to have been predicated on the assumption that the organisations which had agreed to participate in the Project were accepting of the proposed changes – essentially they had made sense of how they would fit within the organisation. But the work streams were tasked with developing new pathways for work which could not have been agreed prior to the start of the Project. A review by Mair et al (2012) on the implementation of e-health systems using NPT as a coding framework (i.e. using constructs in the model to code the literature) found that coherence work was generally part of project preparation, but that it is not often the focus of studies of implementation. They found that most often the focus of implementation evaluation is on collective action, or the actual work involved in the new programme or innovation. The literature search confirms this – there is very little information about the processes that surround the enactment of a new programme. A systematic review by Antunes et al (2014) highlights the importance of recognising the cognitive and emotional processes in actors that contribute to the way they perform. They state that education should be seen as a key component of implementation in order to help actors to make the leap towards behaviour through changing cognition and emotions. This indicates the need for proactive background work in helping actors to come to a cognitive and emotional state whereby they are ready, or perhaps even eager to engage in change. Consensus type work during planning phases, particularly where multiple stakeholder organisations are involved may help towards increasing individual readiness, but only if all professionals in the organisation are included (Connor and Kissen, 2010).

Looking at implementation outcomes, as opposed to patient or service outcomes, means looking at whether the programme was done as expected (Fixsen et al, 2005). Did the strategies produce the expected project? While a number of strategies were identified in the planning

documentation, only four featured saliently during the process: management, education and training, division of work and monitoring.

Management – project management vs change management

While planning might create a foundation for the implementation process, management gives direction during the process. Project managers, facilitators and coordinators are terms which have slightly different connotations, but largely refer to someone who has the role of organising project activities and encouraging actors to participate. The partnership approach of the Project relied on strong management and organisation, yet the management arrangements for the Project were claimed to be weak in not holding partners to account or giving direction and ensuring that tasks were completed as required. However, those responsible for project management felt the Project lacked authority and legitimacy without having the underlying project governance in place that dissolved with the PCT. The differing viewpoints about the underlying cause of poor management (i.e. individual characteristics vs governance structures) shows a discord between management and stakeholders about the source of authority to lead the Project. Those managing the Project perceived the commissioning changes to negatively impact on the Project and became disempowered by the subsequent lack of engagement, which perhaps then led to a negative outlook and weakened managing behaviour. However, other stakeholders felt that hospice leadership was a strength because of their expertise in end of life care and that gave the Project credibility. Yet individual stakeholder engagement was patchy for a number of reasons which contributed to a negative cycle of loose management and low engagement.

It seems that the manager was focused on project management alone, as per the job title, rather than change management (Change First, 2011). However, it seems that some of the expectations around the manager's role were to facilitate change as well. Indeed, the most effective managers and coordinators in the literature were those who were described as "having drive, personality, motivation, enthusiasm" (Mirando et al, 2005, pp. 38) and "a member of all expert working groups, and therefore, provided continuity" (Dudgeon et al, 2009, pp. 493). These descriptions characterise a role that is more people focused than task orientated. In terms of leadership styles, a more task-orientated approach is linked to a transactional style whereas more charismatic, people-orientated approaches are indicative of transformational leadership (Turner and Müller, 2005). Yet in this case, neither style seemed apparent within the overall project management which tended more towards a laissez-faire approach. This is perhaps a consequence of the partnership design and the subsequent lack of a sense of authority over equal partners from those managing the decision making. Instead, project management was focused on

organisation, rather than leadership of the group as a whole. While project management may be essential for organising a project, clearly people need to be helped to make changes. Indeed, the role of facilitation is to help make the implementation of innovations into practice easier (Rycroft-Malone, 2004). When allocating human resources to programmes, it must be considered that it is individuals within an organisation that are involved in implementation and thus resources for facilitation should be allocated per person rather than per organisation.

Additionally, perhaps greater attention should have been paid to the selection of those given leadership positions within the work streams and wider project management as it has been suggested that leadership style and competence are tied to project success (Turner and Muller, 2005). In terms of the impact of management as a strategy on implementation outcomes, the lack of focus on managing change either in the manager role or at the Executive Project Board level meant that it was ineffective in producing the required change in professional-level work.

Education and training – awareness in end of life care

Nearly all instances of implementation of a new innovation or programme requires some degree of learning. Sometimes this is achieved purely through dissemination and then self-learning, but many palliative care programmes propose a facilitated education or training session (Davis et al, 2006; Di Leo et al, 2014; McConnell et al, 2013). In some cases education might be considered a part of the innovation, but it is treated as an implementation strategy here as it is one way to create the desired change in behaviour, i.e. using the EPaCCS. Education and training might be particularly important in end of life care given the tension that clinicians can experience with needing to engage patients in decision making while navigating the uncomfortable nature of discussing death (Zimmerman and Rodin, 2004). Indeed McConnell and colleagues (2013) found that “education created more confidence and openness in staff to discuss death and dying” (pp. 231).

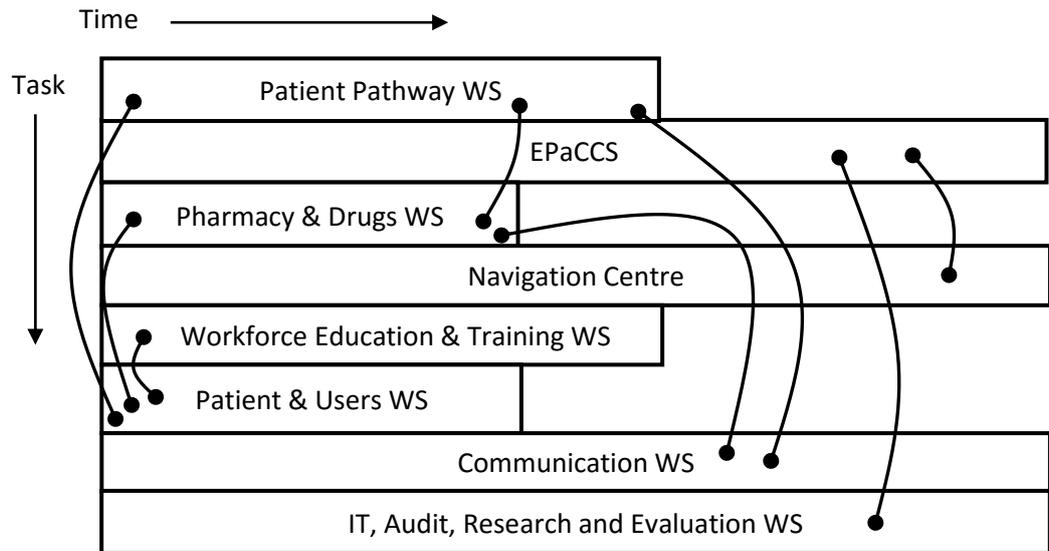
A lack of resource for training GPs in how to use the Blue System and in how to do advance care planning in general was cited as a problem by the project manager and a stakeholder and is reflected in the low usage of the Blue System. There seemed to be an underlying assumption made by the Project team that all frontline professionals perceived an information deficit which could be filled by the Blue System and Navigation Centre and therefore little training or education was required. It may be that the minimal training that was on offer was insufficient to raise awareness and address individual beliefs that might be required to create sustained change (May, 2006) as even those who received training did not use the Blue System regularly. Training using a ‘train the trainer’ model was insufficient in this case to create sustained change in practice, especially when considering the competition from the existing Red System which meant

that professionals would have needed to be convinced to switch systems. This is somewhat unsurprising given the previous discussion of how change is best created through enthusiastic and knowledgeable individual contact to facilitate adoption (Rycroft-Malone, 2004). The train the trainer model for the EPaCCS, in the context of the competition from the Red System, seems to have led to limited implementation and non-adoption of the Blue System.

Division of work

Division of work refers to the ability of breaking down the programme or innovation into smaller parts for implementation and is similar to the concept of 'divisibility' within the literature (Leonard-Barton, 1988; Greenhalgh et al, 2004b). The tasks for completion in the Project were divided into six work streams, the Navigation Centre and the Blue System EPaCCS. Divisibility is meant to allow organisations to adopt innovations in a piecemeal manner, such that either implementing only part of the innovation or adoption by only a few individuals within the organisations will still have benefits (Leonard-Barton, 1988). However, in this case, dividing work was meant to allow the installation and development of tasks to proceed at pace. However, this was a somewhat flawed approach in the Project as some of the work streams were in fact not sufficiently differentiated from the other parts, for example the medicines pathway stemming from the Pharmacy & Drugs work stream was dependent on the outputs from the Patient Pathway work stream, and the Navigation Centre was dependent on EPaCCS implementation to navigate non-hospice patients. These connections are indicated by the lines connecting the boxes in Figure 7.4; the size of the boxes indicate how long into the Project each task was expected to last. In this case this strategy did not have the desired effect of making tasks more manageable and thus impacted on their completion.

Figure 7.4 Division of work within the Project



Dividing work was successful in producing implementation outcomes in some ways, but failed in others. It was successful for establishing the Navigation Centre with sole ownership from the Hospice and allowed the Pharmacy & Drugs work stream to develop the medicines pathway. However, it failed where there was overlap in work between the divided parts.

Monitoring

Monitoring activities encompassing audit, evaluation and *ad hoc* reflection are often presented as an integral and formative part of the implementation process (Di Leo et al, 2014; Dudgeon et al, 2009; Tolson et al, 2007). In the study by Tolson et al (2007) the evaluation was viewed as a part of the implementation process and connected to the intervention itself. Regular feedback cycles were part of the process and were used to inform subsequent changes to the process and intervention. This is a more proactive approach to monitoring when compared to the Project in which monitoring activities, largely due to timing issues with the access to data, became more of a peripheral or *ad hoc* activity. When data was available it was not always interpreted or fed back into the Project in a structured or observable way in order to learn and adapt, except in the case of the Navigation Centre algorithms used for assessing calls which were abandoned based on call audit data. Monitoring activities can help implementers to see where the gaps in care are and the impact of change which would thus act to reinforce practice, or help professionals make informed decisions about abandoning a new practice, as was the case here.

Monitoring progress during implementation might contribute to a more adaptive, non-linear implementation process as changes can be made to overcome any obstacles. Alternatively, the planning process might encompass an audit of current practice as a foundation to attempt to

make the implementation process smoother. For example, a pre-implementation audit can highlight deficits in current practice and scope for improvement which creates tension for change (McConnell et al, 2013). In the case of the Project, most stakeholders already perceived there to be a deficit in the regional system for the care of the dying, though possibly each held different views on the relative severity of the blockages. A pre-implementation audit was not taken prior to the Project which potentially could have helped to create a unifying vision for all stakeholders and a stronger 'pull' for implementation which might have led to the Project progressing as planned.

Monitoring may be a useful strategy particularly in the area of health care where professionals judge project success based on improvements in patient or service outcomes. It may be unrealistic to expect to see improvements during the implementation process, but reviewing patient level data may reinforce a need to change which might help to sustain engagement, though that did not happen here. The telephone interviews with carers indicated that while only a small proportion of carers and patients used the Navigation Centre, those that did found it helpful. This pattern of usage perhaps indicates that the need for the service was low or that its existence was not widely known. In health care services, implementation by professionals accounts for only part of how a service operates, the other part is the response and actions by patients and carers. Indeed, care navigation in particular has been found to be a bi-directional activity in that it is reliant on callers to provide relevant information and care navigators to assess and make sense of the information (Fillion et al, 2012). In this case, the collection of data from carers indicated that the Navigation Centre was one of a number of resources being used rather than fulfilling the role of a single point of access. Only by asking service users can it be known whether the service was implemented as intended.

In summary, the influence of implementation strategies on outcomes was limited because most of the strategies depended on stakeholder engagement which was lacking. The four which did have some impact described here had mixed effect because of their execution. Management needed more elements of facilitation within the work streams and not just for the EPaCCS, education and training had limited reach, some project elements were interdependent, and some monitoring activities were effective but some took place too late in the process. However, these strategies were also influenced by a number of barriers and facilitators.

7.2.4 Barriers and facilitators

The influence of barriers and facilitators is a common point of discussion in the implementation literature (McGinn et al, 2011; Vahedi Nikbakht-Van de Sande et al, 2014; Miake-Lye et al, 2011;

Davis et al, 2006; Goepp et al, 2008) and while the previous chapter outlined the barriers and facilitators within the implementation of the Project, it is worth highlighting a few of the most salient factors as they relate to the existing empirical literature. Some factors in the Project had both enabling and barring influences and that rather than being either present or not, the factor seemed to exist along a continuum which at times was mediated by other influencing factors. For example, the role of the project manager could be seen as both a facilitator in the sense that once this role ended, project activity appeared to cease. On the other hand, the project manager was felt to be somewhat ineffective which was why the role was terminated. But the role of the project manager was situated within a wider management structure which was another factor that impacted on the scope of the role.

The *funding* allocated for the Project enabled many of the facilitative factors discussed here to exist, such as the project manager and data analyst roles, and the purchase of the EPaCCS. However, the funding was allocated for two years which was insufficient time for both the developmental aspects of the Project (i.e. the work streams) and implementation activities particularly given the NHS changes which setback the timescales for the Project. The empirical literature demonstrates the salience of *management* during the change process (Dudgeon et al, 2009; Miranda et al, 2005; Vahedi Nikbakht-Van de Sande et al, 2014). Much of the virtue of management seems to stem from a type of management which is focused on a more facilitative style (Rycroft-Malone, 2004). *Facilitation* itself encompasses three central tenets: knowledge and data management, project management, and administrative and project-specific support (Dogherty et al, 2012). The facilitator or project manager role is often cited as an essential part of the implementation process (Tolson et al, 2007; Miranda et al, 2005; Antunes et al, 2014; McConnell et al, 2013; Dudgeon et al, 2009). However, the management structure was more focused on the practicalities of organising the numerous organisational and professional partners in terms of meeting attendance and working arrangements. This approach did not seem to be effective in holding together a diverse, voluntary partnership. There seems to be a distinction then between functional management (as evident in the Project) and facilitation, something which is not clearly delineated across the empirical implementation literature. Facilitation is perhaps particularly important in the area of palliative care as it is not a core activity of many health care disciplines so non-specialist professionals perhaps need more supportive guidance in relating it to their work.

Given the lack of management structure or other incentives to hold partners to account, the *perceived need* for the Project and innovations was relied on as a facilitator for the project. For some, this proved a driving force, such as the ambulance service which needed information on

the patients they were seeing, and the community nursing service which experienced a gap with the change in guidance on using the Liverpool Care Pathway. These stakeholders were particularly keen to engage in the Project because for them it would fill a gap in their practice. However, for others such as the GPs, the Blue System did not appear to fill a real need and therefore a lack of perceived need was a barrier. *Perception of need* or *benefit* seems to be masked in the empirical literature, generally manifesting in hidden language, such as “physicians were increasingly concerned” (Santa-Emma et al, 2002, pp. 97) (*need*) or “physicians and the community nurses [...] felt more confident and capable” (Marshall et al, 2008, pp. 1703e5) (*benefit*). The relative importance of the perception of need is sometimes not further reflected upon in empirical studies such as these. The findings from this study suggest that generating a sense of a *need for change*, or ensuring that innovations do meet a need, should be the focus of strategies to facilitate the cognitive processes necessary for adoption and implementation.

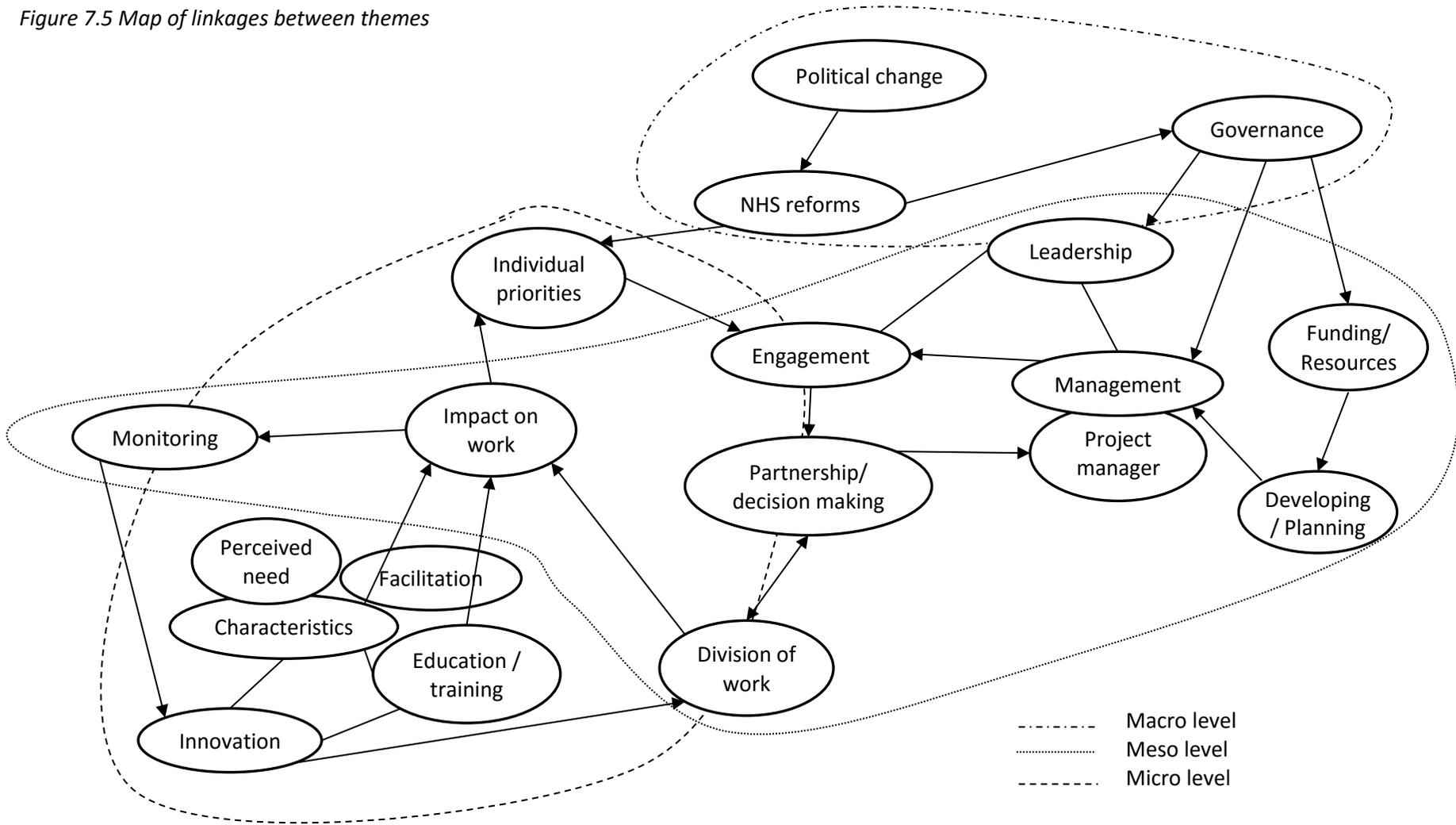
The last key influence which proved to be a significant barrier was the *political change* that was ongoing external to the project at a national level but which became an overwhelming force on a local level. The subsequent NHS reforms and organisational changes which threatened job security were beyond the scope of project management to handle. The impact of the changes on some of the NHS partners seemed to highlight in particular that palliative care is not a core concern of NHS primary and acute sectors which seemed to shift focus away from the Project, and even once there were new commissioning arrangements other areas of care seemed to take priority. The empirical literature does not often reflect the impact of external political forces on the implementation process, but then it is not that often that the structure of the health system undergoes radical transformation while a prospective study of implementation is taking place. In the next few years, more studies like this and Devlin et al (2015) which have evaluated implementation processes during the NHS reforms will report findings which will provide a larger picture of the influence of the changes. This study demonstrates a downstream trend in which system level obstacles (e.g. changes in commissioning powers) and incentives (End of Life Care Programme funding for the Project) influence local agendas and priorities. The Project took place whilst system level changes were being decided and introduced, which meant that some stakeholders ‘were on hold’ because they knew there would be local changes stemming from the national changes, but they were not certain what these changes would look like. Therefore even the prospect of change creates uncertainty and a lack of willingness to innovate in case such work is undone by future changes.

While it does not seem likely that changing one or two barriers to facilitators might make the achievement of implementation outcomes more likely, the interlinked nature of the barriers and

facilitators described in this study does suggest that changing one would have a knock-on effect on others. For example, had the *perceived need* been greater among all partners, would engagement have been higher, and therefore would the *management* structure have been more effective? The what-if scenarios are endless and perhaps implementation science will determine what the most successful strategies are to ensure the process has more facilitators than barriers.

Figure 7.5 visually presents a map of the relationship between key themes, implementation strategies and barriers and facilitators which have thus far been discussed. Lines with arrows indicate directionality between concepts, whereas lines without arrows indicate that they are connected, but not in a particular direction.

Figure 7.5 Map of linkages between themes



7.3 Implications for theory

The Project implementation process demonstrated characteristics of both a linear, staged process and one of re-planning and adapting as part of an interactive, negotiated process. The impetus for implementation was managerial and to some extent policy led in that Project partners, who held management roles within their respective organisations, were responding to national policy imperatives. The Project was constructed, organised and planned by managers, but the actual implementation process was more passive than the initial Project planning documents implied. On the diffusion and implementation spectrum in which diffusion implies a passive spread of ideas and implementation is a structured approach of putting evidence into practice (Greenhalgh et al, 2004a), the Project approach lies somewhere in the middle. There was a managerial attempt to facilitate the process using group work and tasks. However, the tasks then needed to be implemented by the partner organisations for which there was no distinct structure for how this would happen, but instead seemed to rely on a more diffusive process in which professionals within the partner organisations would come to accept and adopt the Project innovations in their own way. This is illustrated in Figure 7.3 in which under the 'Actual Implementation Model' there are separate arrows indicating different implementation outcomes for the various organisations because each organisation responded individually to the Project. The integrated and multi-layered nature of the Project meant that failure, and indeed success, was interdependent meaning that while some activity was sequential in nature, overall the Project was continually adapting in a more non-linear, interactional process. This perhaps stems from the fact that the Project drew on a 'pluralist' view of evidence (Billings, 2013); that is change is informed from multiple sources including traditional research, tacit knowledge of 'best practice' and policy imperatives. Such an approach to service design is likely to imply an interactive implementation process as people make sense of the service changes in their own way.

While the actual implementation process progressed non-linearly, the implementation of programmes also challenges the notion that implementation is a distinct phase from development and evaluation as has been argued elsewhere (Fixsen et al, 2005). Rather, the Project demonstrates that programmes which encompass innovations and service development are situated within a context where work exists and will continue after the project has finished; essentially that there is no void into which a programme or innovation is installed. While there was a start and end date to the Project, the work that it involved had in fact followed on from previous discussions between

organisations and following the end of the Project, strands of related work, such as the hospital sharing admission data with the Hospice, continued to develop. Health services are continually developing and evolving and in this sense programmes perhaps represent a timely coalescence of activity or critical mass towards the adoption of change rather than the installation of something entirely new.

Rogers (2003) proposed that the rate of adoption of new innovations is related to adopter characteristics, and this study demonstrates the centrality of individual actors to the implementation process, even within a group approach. Even though stakeholders represent organisations at a project level, they are still acting as individuals and therefore their actions shape the way their organisation engages with the project. Likewise, stakeholders do not act in isolation but reflect the organisations they represent which is observed in their capacity to participate and interest. The Project demonstrated that individuals are the gatekeepers to their organisations and they control how the Project is introduced to their organisation. While some of those attending on a daily basis may not have had the executive authority to start or stop adoption, they certainly had the power to slow or speed up the rate at which adoption and diffusion takes in the extent to which they promoted the changes in their organisation (Rogers, 2003). Indeed, some GPs within one area were quick to take up the Blue System and could be characterised as early adopters, whereas GPs in other areas were slower to adopt the system or indeed were non-adopters, preferring instead to stick with the Red System. In a programme or project context, the organisation's uptake of the innovation depends on the individual's knowledge and beliefs about the intervention which is mediated by their responsibility to the organisation. The Consolidated Framework for Implementation Research (CFIR) suggests that an individuals' identification with their organisation will affect their willingness to adopt an innovation (Damschroder et al, 2009). Data was not collected on individuals within organisations (beyond the stakeholder level) so this cannot be confirmed or refuted. However, the UK context may be unique because almost all stakeholders were from NHS institutions so it makes it difficult to tease out organisational fidelity as essentially they all fit under one umbrella.

While the characteristics of professionals as innovation users and implementers are often described in the literature (Rogers, 2003), the role of patients and carers as service users in affecting the implementation process has been given less attention. The dual purpose design of the Navigation Centre in targeting both professionals and service users demonstrates that the interaction between service users, innovations and

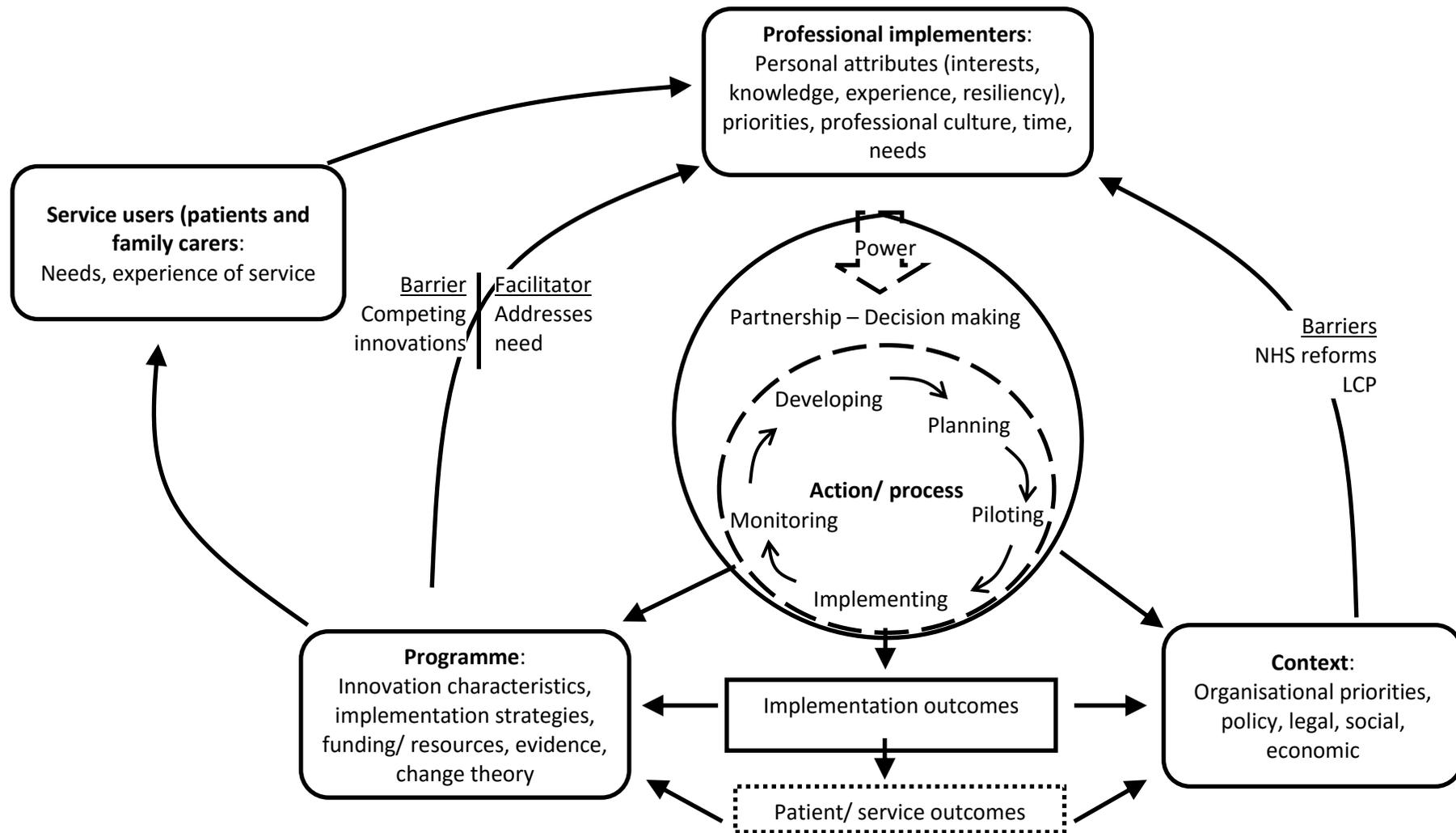
professionals can influence implementation outcomes. In health care, implementation depends in part on the response of service users and not just professionals. This is demonstrated most clearly with medicines; a doctor may prescribe a new medicine, but it is up to the patient to take it as directed. In the Project, service users had to make a decision whether or not to phone the Navigation Centre; thus its implementation and indeed efficacy for keeping patients out of hospital depended on the engagement of service users. Perhaps the role of service users is not often considered because they are often conceptualised in terms of service outcomes and not implementation outcomes, though in this case the number of phone calls to the Navigation Centre might be considered an implementation outcome, and the care that patients receive might then be considered the service or patient outcome.

What seems evident from this discussion and the foregoing chapters is that implementation of programmes is characterised by interaction, and project success depends on features of resiliency to cope with various challenges that arise as the result of multiple moving parts that are characteristic of complex and integrated care programmes. *Process* has been conceptualised as a distinct area of study in implementation (Moullin et al, 2015), but the process is quite clearly influenced by other concepts within implementation theory, such as barriers and facilitators and the domains or determinants which have been characterised as ‘influences’ in this study. While these concepts may be described independently, they are interactive in shaping the implementation process. Adding to this complexity is the fact that implementation strategies are not often clearly defined and are often closely tied to the innovation itself. Perhaps it is more relevant to consider the innovation, activities and context as a package and focus on understanding how they interact to produce implementation outcomes and what aspects contribute to project resiliency. However, within health care there is flexibility in the definition of implementation outcomes and patient/service outcomes. It may be possible to conceptualise them independently, but in reality, what is classed as each is likely to be innovation and context specific which makes generalisation of implementation constructs across fields difficult. Given that understanding the implementation process seems to be case specific, what may be most important for the study of implementation is to be explicit about the definition of each of the elements relevant in the implementation process within a particular case so that authors can make their own judgements in relation to their own work.

7.3.1 Conceptual framework – reconstructed

The conceptual framework presented in chapter three was intentionally loose and generic in order to encompass the range of possible concepts important to the implementation process and give some indication as to how they may interact without being overly prescriptive given the novelty of the programme and methodological perspective of the study. The framework presented implementation strategies as the central component as to how change would be achieved during the implementation process. The framework has been reconstructed (Figure 7.6) based on the findings from the study and more specifically indicates the relationship between concepts which were loosely mapped out in Figure 7.5. There are several key changes: the separation of actions from actors, the separation of service users from professional implementers (formerly conceptualised jointly under actors), the centrality of actions and process, and the inclusion of outcomes as these then influence the context and programme.

Figure 7.6 Reconstructed conceptual framework of the implementation process and influences of the Project



Whereas the first model conceptualised implementation strategies as the primary source of change, in the reconstructed model they are incorporated in the 'programme' box because of the interlinked nature of strategies and the innovations themselves. The features of the programme encompass: the innovation characteristics, the implementation strategies which are developed based on those characteristics, the funding and human resource available, any evidence for or against the innovation, and how the programme will create the desired impact of change (change theory). These attributes then influence the response of service users. For example, the Navigation Centre was available 24 hours a day where some carers used to get advice about pain management, but because awareness of the Navigation Centre relied on word of mouth from hospice staff as the communication strategy and phone calls to the Navigation Centre were not clearly distinguished from other hospice calls, the number of service users phoning the Navigation Centre was perhaps limited. In the reconstructed model, implementation strategies are a part of the 'programme' package and sphere of influence on the process because mediating their influence is the actions of 'service users' and 'professional implementers.'

The 'actions' which make up the implementation process and which are central in the framework, come from 'professional implementers.' Like the Consolidated Framework for Implementation Research (CFIR), the actors and their subsequent actions are given prominence because "organisational change starts with individual behaviour change" (Damschroder et al, 2009, pp. 9). Implementation as a process is comprised of different actions and behaviours such as learning, adopting, acting, and sustaining. Professional implementers' actions are informed by their interests, knowledge, priorities, professional background, time available to give to the project, and what conditions they need to do their job. Part of what forms these attributes is their prior experience in dealing with service users, as indicated by the arrow connecting them. For example, one of the hospital stakeholders reported an increase in the number of patients attending A&E on the advice of the Navigation Centre and leading her to question its utility and perhaps contributing to the reconsideration of whether the Navigation Centre needed to be a distinct operation to the 111 service. These various thoughts take place at an individual level and may affect subsequent actions. In this sense implementation is more of a cognitive process – the leap from adopting and learning to making it a part of usual practice. Therefore in studying the implementation process from a subtle realist perspective (Hammersley, 1992) we can observe the events that occur and surmise that these cognitive processes have taken place.

This example also illustrates how professional implementers are influenced by the context in which they are working. In this case, the stakeholder was weighing up the Navigation Centre to the 111 service (a barrier as a competing innovation) against her organisational priorities to

reduce hospital admissions. The programme characteristics, experience with service users and the context in which they work all impact on the professional implementer's decision making which also draws on those individual attributes. This balance between the programme and context reflects Greenhalgh et al's (2004b) conclusion that "it is not fixed attributes of either the innovation or the organisation that matter, but the fit between them" (pp. 139). The actions that result from this individual decision making are magnified by the individual's power to influence others in the subsequent processes that take place. The implementation process appeared to be a continuous cycle of developing and testing changes, planning for change, implementing more widely, monitoring the process and then re-developing and re-planning as in the case with the EPaCCS if obstacles were not overcome. Because the programme was layered with innovations at various stages, each of these types of actions were taking place simultaneously.

The process then culminated in implementation outcomes and patient and service outcomes. Each of these outcomes then influenced the Project, such as the low uptake of the Blue System EPaCCS led to a switch to the Red System, and the context, for example patients using both the 111 service and the Navigation Centre which ultimately may affect future commissioning decisions. Thus the loop is complete and the circular nature reflects the concept that service development, particularly across organisations in health care, is a continuous process.

With regards to explanatory power, the above example can be followed with the Navigation Centre, EPaCCS and work streams around from development, impact on service users, what barriers and facilitators were faced, how they were situated within the local context and how the combination of characteristics and context then impacted on the cognitive processes of professional implementers and their power to produce actions which characterise the implementation process to produce outcomes. The framework presented here may be suitable for analysing similar programmes which feature multiple, interacting innovations at varying stages of development or a partnership approach drawing on a multidisciplinary group of stakeholders in health and social care as it features all relevant concepts to the process including the influence of service users which are not featured in other more generic frameworks (Moullin et al, 2015).

7.3.2 Power conceptualised

The partnership approach in which stakeholders from different organisations participated in group meetings and then individually led change within their respective organisations suggested that power might be evident primarily in the group decision-making process reflective of a partnership approach. Because participation in the Project was based on the desire to achieve

benefits for patients and service improvement, it was thought that power might be shared pluralistically because it was presumed that the aim of the group would be to achieve consensus (Dahl, 1958), or if not, that coalitions of powerful professional groups would form to dominate the group (Addicott and Ferlie, 2007). However, project meetings were characterised by a lack of engagement from primary and social care and, as might be expected, not all stakeholders were able to attend every meeting. Because many of the major decisions in the project required group discussion, very few expressed decisions regarding implementation or the direction of the project were made because of low attendance at meetings. Instead there was evidence of underlying tension and conflict in deciding the direction of the project which suggests that there was a lack of overall domination of one group of stakeholders. The expression of power was more subtle and indirect than a basic pluralist view would suggest.

With regards to decisions that were made, there were two key decisions both in relation to the use of the Blue System as the EPaCCS. The selection of the Blue System was made at the start of the Project and the selection process was led primarily by the Hospice. Though there was hesitation by some of the group members in whether this would be acceptable to GPs, most partners were persuaded to accept this decision because the Hospice stakeholders were experts in end of life care planning. Thus from the beginning of the Project there appeared to be an asymmetry in the power relationship in the partnership towards the Hospice because of their expertise which provided a soft base of power (Pierro et al, 2013). However, this decision was not sustained because of lack of action. When it came time for action to follow decision, some GPs acted by implementing the software, some refused to implement, and others kept delaying implementation in what could be interpreted as a passive form of conflict. If consensus had truly been achieved amongst the partnership, then the GPs would have followed through with the decision made. However, it could be concluded that whereas the Hospice's expertise on the issue was sufficient to influence some of the stakeholders (Kudisch et al, 1995), it was insufficient to persuade a large group of GPs who found it contrary to their interests to adopt it.

Subsequently, the Hospice perceived this reluctance by the GPs as a defeat of their agenda for the EPaCCS and therefore a second decision was made towards the end of the Project to switch from the Blue System to the Red System. This decision was largely driven by the GP agenda and the Hospice's desire to implement a workable EPaCCS. However, in the time between the two decisions, the Red System was upgraded which was deemed acceptable by the Hospice stakeholders so it is unclear whether the Hospice would have capitulated to the GPs had these changes not been made. The nearly 18 months between the two decisions was characterised by overt and covert conflict (Bachrach and Baratz, 1962) in the form of vocal opposition and

delaying implementation over the selection of the EPaCCS which resulted in a lack of progress in implementation. Clearly the Hospice did not dominate the first decision and because the second decision was made at the end of the Project, it is unclear how this decision would have been implemented by the other partners because they were largely silent in the decision-making process. The EPaCCS discussion was dominated by the Hospice and GPs in a form of bounded pluralism, though the negotiation was not necessarily favourable to each party as suggested by Addicott and Ferlie (2007), but rather the Hospice and GPs battled among themselves with little evidence of other stakeholders contributing. Though the Hospice's and GPs' concerns seemed to dominate the agenda with regards to the EPaCCS, overall neither group seemed to dominate the partnership. Indeed, Derkzen et al (2008) argues that it is not possible to have total domination in a partnership because of the nature of the partnership is to question the actions of other members which means there is rarely likely to be passive compliance with a decision. Thus conflict, either overt or covert, seems an innate feature of partnership working.

Similar to the study by Derkzen et al (2008) in which they identified a 'stalemate' in the decision-making process, progress in the Patient Pathway work stream and in implementing the Blue System were slowed by bottlenecks in decision making. This was the product of low attendance at meetings and overall disjointed engagement by partners. Low attendance meant that the meetings were characterised by deferred decision making; i.e. waiting to make decisions until key people could be involved. This is indicative of a democratic leadership process which can suffer from few decisions being made because of the desire to be inclusive of the entire group (Turner and Müller, 2005). This is different to non-decision making described by Bachrach and Baratz (1962) in which certain topics are prevented from being discussed. The GPs absence from meetings in which implementation in primary care was to be discussed was conspicuous as their absence prevented decisions being made. Their self-exclusion was not necessarily a malicious intent to slow the Project, but more likely the result of having had other priorities stemming from the NHS reforms. However, it does not necessarily have to have been the GPs intentions to thwart the process that expresses their power, but simply was the result of their intentional or unintentional actions (Lukes, 1974; Digeser, 1992). As some stakeholders were continually absent from meetings and therefore few decisions could be made, the individual stakeholders began to make decisions independently for their organisation and some stakeholders agreed to work together on small off-shoot projects, which demonstrates the diffusive nature of the Project described in a previous section. For example, the Community Health Trust decided to proceed with a version of the patient pathway, and the group decided to bypass the implementation of the Blue System in GP practices and instead focus on how it might be rolled out in hospital.

Decision making was therefore dispersed because group consensus could not be reached which does not seem to indicate a pluralistic sharing of power within the partnership at large as decisions did not affect the group as a whole.

It could be argued one step further that this prolonged lack of engagement from some partners led other stakeholders to reflect more negatively on aspects of the Project. This is perhaps evidenced in decreased engagement over time by other stakeholders and the negative outlook expressed by the project manager. In this sense absent stakeholders not only delayed decision making, but their actions may have influenced the views of others. The continued lack of progress with the GPs may have created a feeling of powerlessness (Gaventa, 1980) which is indicated in some of the comments from the project manager and hospice stakeholders and which was reinforced through sustained lack of progress and ultimately succumbing to the GP-led agenda to implement the Red System. The sense of lack of power among hospice stakeholders might also have stemmed from coercive and reward power that GPs were perceived to have had because of their newly created commissioning powers. According to Lukes (1974), this feeling would be internalised and ultimately affect the decisions the Hospice stakeholders put on the table, which is indicative of the third dimension of power. Evidence of this dimension within project decisions is limited, but in an interview a hospice stakeholder did state that they would not take the lead in this type of project again which suggests that the experience with the GPs has changed their view of the power of the Hospice within the health care landscape. This statement seems to indicate that there was a sense that power was not shared and instead that the Hospice was over-powered in their decision making. Power sharing has been linked to implementation effectiveness and group commitment (Foster-Fishman et al, 2001). While it has been argued that implementation success can be improved by building capacity for power-sharing (Foster-Fishman et al, 2001), power can only be shared by those who have it.

An assumption was made at the start that power would be overt in a group because of an assumed conflict-resolution process inherent in a pluralistic power relationship, but actually, there was little observation of overt power in decision making. Instead, meeting absences or delaying decision making which were the 'actions' that formed the core of implementation is perhaps suggestive of more indirect power relationships, as in what Gaventa (1980) refers to as "decisionless decisions" (pp. 15) which are not readily observable exertions of power, but are more covert in nature because they are essentially non-events. It is difficult to prove such a power relationship as it is hard to find evidence of purposeful inaction, but certainly the inaction appeared to be indicative of some sort of power relationship. Power relationships within the partnership were not straightforward, but they do appear related to decision making in either

the making or delaying of decisions. No one stakeholder group seemed to dominate the partnership as a whole, but rather dominant groups emerged over particular issues and the perception of power seemed to be related to the values or priorities of the individual stakeholder. For some stakeholders, the Hospice's expertise was a source of power, for others, they were more concerned with legitimate or punitive influence which stemmed largely from commissioning powers. Where no obvious hierarchy exists, as in a partnership, people may still perceive others to occupy a higher status thus creating a hierarchical structure (Gordon, 2002). This may be particularly so in the health and social care setting in which there is a hierarchy within the health professions with doctors occupying the top spot (Goodwin, 2000). This imposed hierarchy seemed to span all stakeholder groups as it appeared that some decisions were not viewed as valid unless they included the GPs; in contrast there was little consideration as to the concerns of social care even though they were not represented at meetings. This suggests that some sort of order or leadership structure is 'naturally' created even when there is meant to be equity among members. There were clearly multiple bases of power at play which begs the question of what is the most important base for power and leadership in partnership working? Expertise seemed to lend credibility to the Project, though it was insufficient to ensure commitment from all stakeholders. Some stakeholders suggested that more coercive power was necessary which could support Shortell and colleagues (2002) conclusions that strong governance is needed for a successful partnership. This is likely because governance provides a clear authoritative structure which can be missing from partnerships which strive for consensus and equality.

What this study demonstrates is that implementation in a partnership is difficult to achieve when there is a lack of real consensus and when people respond to competing power bases. How people respond to different types of power then influences their actions in implementation. The interactional nature of implementation of complex programmes and through partnership approaches means that there might always exist competing bases of power.

7.4 Study strengths and weaknesses

The key points which this study has addressed will be summarised briefly before discussing the strengths and weaknesses. This study of a single project demonstrates the complexity of the implementation process and particularly the interconnected nature of implementation strategies, innovations, context and actors. The influence of implementation strategies on outcomes was mixed, largely because they were underpinned by the partnership approach which had less than optimal participation due to the concurrent NHS restructuring which shifted actor and organisational priorities. Priorities are informed by tacit and explicit knowledge; this is

particularly relevant in palliative care related innovations which can involve a mix of professionals and each may have a different perception of need. Yet at the same time it was the professional level dedication to improve services and the care of patients which seemed to drive success in the face of challenges and contributed to project resiliency. Barriers to implementation included: the NHS reforms, lack of robust project management, interconnected project elements, and competition from similar innovations. Facilitating factors included: leadership by the Hospice as experts in end of life care, benefit on work, individual motivation, and sole ownership and management over implementation. This accumulation of factors led to a non-linear, interactional, negotiated implementation process in which planning, development, implementation and adaptation of the various innovations proceeded simultaneously.

A strength of this study is its explicit focus on the process in order to build a detailed picture of how the various implementation strategies worked in a specific context among a diverse group of actors to establish a complex coordinated care programme. The literature review revealed that there are relatively few examples of research into the implementation process of complex health programmes (Greenhalgh et al, 2004b) and fewer still in palliative care, with more attention given to the outcomes of such programmes and therefore this study contributes to an under-researched area. Thus far research in palliative care implementation has been focused on the uptake of tools (Di Leo et al, 2014) or introducing palliative care practices into a new organisational or departmental setting (Hogan et al, 2011; Santa-Emma et al, 2002). While some studies have described the implementation process, reports often read like an ingredient list of activities or people involved (e.g. Dudgeon et al, 2009), rather than providing explanation as to how and why different strategies worked together with the intervention or did not. More often studies of implementation focus on the reach or uptake of new programmes or tools (e.g. Santa-Emma et al, 2002), but without consideration of the individual and group processes that led to their uptake. Such studies make assumptions about the implementation process occurring as planned. The authors of a systematic realist review of the key factors affecting the successful implementation and sustainability of the Liverpool Care Pathway concluded that “the underlying complexity of factors influencing implementation is rarely explicitly investigated” (McConnell et al, 2013, pp.232). This study aimed to unpick some of these complex factors that occur when multiple health and social care providers aim to coordinate care.

This study introduced the concept of resiliency to project implementation and has suggested that it may be a useful construct for exploring how the innovation and implementers interact and adapt to external project threats. Resiliency may be particularly relevant in studying service development delivered in a partnership approach where there may be competing power bases

which pull stakeholders in different ways in addition to the inevitable external threats that come with lengthy service implementation. Further exploration of what contributes to project resiliency may be a pragmatic approach to implementation theory development.

The prospective design of the study reduced the chance of a pro-innovation bias which is common to retrospective studies that start from the point of an innovation being adopted and work backward (Greenhalgh et al, 2004b). The Project ended in what might be considered mid-implementation with some elements still being developed or abandoned (medicines and patient pathway), others in the process of being adopted (Red System EPaCCS), and the use of others being refined through practice (Navigation Centre). In comparison to previous research, one might question whether such an ending would have led to a retrospective evaluation of implementation or whether it would have just been cast off as a failed project as it did not achieve its aims. The prospective design means that such a bias was averted and important lessons were learned.

The pragmatic methodology adopted was appropriate given the uncertainty of the process in the overlapping of innovation generation, adoption and implementation. However, the study was originally envisaged as a realist evaluation following Pawson and Tilley's (1997) methodology. Realistic evaluation was initially chosen because it attempts to theorize what 'mechanisms' lead to implementation and are couched in a way that works toward knowledge accumulation thereby contributing to our understanding of implementation in a structured way. Indeed realist evaluation has been argued as a good way for studying implementation (Greenhalgh et al, 2004b), though many researchers have found it difficult to use because of the confusion that can arise regarding what is a context and what is a mechanism (Byng et al, 2008; Marchal et al, 2012; McConnell et al, 2013). McConnell and colleagues (2013) found that the method was only workable through group discussion and consensus. Given that this study was conducted by a lone researcher, refinement of the context-mechanism-outcome configurations was very difficult and at times seemed as though the data was being forced to fit a predetermined framework rather than looking for emerging patterns. The method was therefore abandoned after the first six months of data collection with the conclusion being that while realist evaluation is intuitively appealing, the practical application of the method is best suited to a group (preferably with at least one researcher experienced in the method) in which the analytical process can be refined and confirmed through group consensus. Changing the method part way through may be seen to be a weakness, but the realist foundations and data collection methods remained the same and therefore abandoning the realist evaluation which was felt to be leading to artificial findings was a strength.

The pluralist approach to data collection using primarily ethnographic methods was a strength in that evidence from observations, interviews, focus group and document review could be compared to triangulate findings (Lewis and Ritchie, 2003). For example, the observations of the meetings provided insight into the weak decision-making process and individual attributes which were merely described as 'poor management' by the stakeholders. Without the observations, a statement of poor management could have been interpreted broadly, but the observations provided more detail into what particularly had been lacking and that context and set up of the project affected the way management could act.

As with all studies, there were a number of weaknesses. Firstly, the study only captured project level data and not data on how the Project was taken up within the partner organisations except for the feedback which was given by the stakeholders. It might have been useful to track the progress of the Project through each of the organisations and services to gain insight into how it was prioritised and resourced, particularly given the NHS reforms. A multi-organisational project requires all organisations to be equally engaged and such organisational level data may have better indicated the degree of equity among partners which may have influenced decision making. Studying the implementation of a project which spans organisations is difficult, if not impossible for one person alone to capture. The design of this study aimed to capture key points of decision making and progress reporting, though some decisions about the Project were made outside of project meetings.

By only capturing project level data, there is little first-hand data regarding GPs, out-of-hours care and social care, particularly the latter two as they did not engage with the Project. Any data regarding their involvement was provided second-hand by other professionals who did attend meetings. While some data is missing regarding those who did not participate, data from the Hospice may have been over-represented because the project manager was a key informant, but was also based in the Hospice so the two views may have been conflated, particularly when the Hospice director took over from the project manager. As was described in the methods chapter, the researcher had previously worked with the Hospice, and while this may have been a strength because it possibly enabled greater access because of an established relationship, it also meant that the researcher had existing knowledge and insights about the staff and activities in the Hospice where she would have had none regarding the working practices of the other providers.

It was only possible for the researcher to study the implementation of the one project due to time and resource constraints. Had multiple cases been compared, then some of the observations regarding the impact of the NHS reforms on the implementation process could have

been explored further, particularly with regards to the influence on management strategies. Using multiple cases in future would also be particularly useful for further exploring the concept of 'project resiliency' and identifying which features contribute towards project resiliency.

7.5 Main conclusions and an agenda for future research

There are five main conclusions to be drawn from this study about project implementation within health services and end of life care. Firstly, in health care, the implementation process is not limited to the actions of professionals and organisations, but also depends on service user engagement and how they interact with service changes. Implementation frameworks (e.g. the CFIR, Greenhalgh et al's, (2004a) framework, Moullin et al's (2015) generic framework) do not all conceptualise the role of patients in contributing to implementation outcomes but rather the focus is on patient and service outcomes. But, as seen with the Navigation Centre, interaction with service users clearly affects whether the service is implemented as planned. It may not be appropriate for all types of services, but where service users are co-creators in their care, they should be considered within implementation frameworks to understand their impact on implementation outcomes. Therefore, how should service users be conceptualised within implementation frameworks so that their influence on implementation outcomes (e.g. reach, fidelity) can be distinct from patient outcomes (e.g. patient experience)?

Second, the implementation of the programme was characterised by multi-level interaction which is also apparent in previous studies of the implementation process: implementation strategies can overlap with innovation characteristics; process is not easily distinguished from other implementation constructs; and implementation outcomes can be conflated with patient and service outcomes. As implementation is now a distinct 'science', the literature is increasing and becoming more diverse with greater overlap between constructs and terms. A framework for organising the literature conceptually and methodologically would be useful to start accumulating knowledge. There are a number of strands of inquiry arising in the implementation literature, from describing examples of implementation as was done here, to experimental testing of the impact of implementation strategies. These different strands of work seem to have also increased the variety of terminology in the implementation literature which was a major hindrance in the search for previous work investigating the implementation process. The term 'implementation' encompasses all manner of activity in the literature, from adoption to sustainment. There have been some attempts towards common terminology (e.g. Rabin et al, 2008), but further work is needed to cover all instances of implementation. Can the relationship of these strands of work be consolidated into reporting guidelines for knowledge accumulation and generalisation?

Third, it is widely understood that the provision of evidence alone does not translate into changes in practice (Rycroft-Malone, 2004). Implementation science is about filling the knowledge-practice gap, but as was the case here, not all service developments are based on research evidence alone but rather reflect a pluralistic consolidation of knowledge. Therefore what is the role of 'evidence' in relation to service development if it is not used to inform development? This begs the question of whether research is filling a practice need and whether researchers are paying enough attention to service development implementation. Perhaps there are lessons to be learned from 'implementation as usual' which occur all the time and can better help to uncover the social processes that result in change (Powell et al, 2013).

Fourth, this study suggested that project resiliency is particularly important for complex programmes which are implemented over a long time because of the variety of external threats to projects. It was suggested that resiliency is a product of implementation strategies, innovation adaptiveness and implementer characteristics. Resiliency as a construct described in this way was not found in the implementation literature, but seems to encompass a number of implementation concepts to succinctly describe how projects react to unplanned events. Can the concept of resiliency be used to better explain the relationship of implementation strategies to contextual influences on implementation? How can projects develop resilient factors to ensure their success?

Lastly, though the categories of the conceptual framework are broad enough for analytical generalisation, the focus on end of life and palliative care could be seen as a special area in health care because the topic of death can be difficult for professionals to navigate (Zimmerman and Rodin, 2004). This perhaps limits the transferability of some of the findings to within palliative care, or perhaps to other social pariahs in health care, such as sexual or mental health which struggle for traction among care professionals and resource allocation. How relevant are the lessons learned in a palliative care setting to health care generally or to other speciality areas? Implementation of palliative care initiatives into general health care is difficult because general practitioners are not specialised in palliative care and care for a variety of people (Raijmakers et al, 2014). Do these characteristics preclude generalisation to health care as a whole or simply highlight the importance of innovation fit to organisations (Greenhalgh et al, 2004b)? Palliative care represents a true integration of care and therefore perhaps will have wide applicability as health and social care systems are increasingly aligned.

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Abbreviations

CCGs: Clinical Commissioning Groups. CCGs are NHS organisations comprised of all GP groups in their area and are clinically led; they replaced Primary Care Trusts in April 2013.

EPaCCS: Electronic Palliative Care Co-ordination System. Electronic patient record system for recording and sharing patient care preferences and key details. EPaCCS pilots in England began in 2009.

EPB: Executive Project Board

GP: General Practitioner

LCP: Liverpool Care Pathway

NC: Navigation Centre. Operated and funded by the hospice to navigate end of life patients and professionals to appropriate sources of information or support 24 hours a day, 7 days a week.

NHS: National Health Service

NPT: Normalisation Process Theory

PCT: Primary Care Trust

PDG: Project Delivery Group

Glossary

Blue System: the pseudonymised name of a proprietary EPaCCS tool; the first EPaCCS selected by the Project for implementation.

End of Life Care Programme: programme aimed at implementing the Department of Health's End of Life Care Strategy (2008) and NICE quality standard for end of life care for adults (2011). Came to a close on 1 April 2013.

Innovation: refers to technologies, processes, practices, and/or policies.

Partner: refers to the individual member of the Project and the organisation they represent; used interchangeably with the term 'stakeholder.'

Professional: refers to clinical and frontline positions on the ground which many stakeholders also held.

Red System: the pseudonymised name of a proprietary electronic patient data sharing tool used for a variety of patient populations, not just end of life care. The second system chosen as the EPaCCS after the Blue System.

Register: short-hand term for palliative care registers which were the precursor to EPaCCS and have been used interchangeably to refer to EPaCCS.

Stakeholder: refers to the individual member of the Project and the organisation they represent; used interchangeably with the term 'partner.'

Appendix

Appendix I: Literature search strategy

Stage 1: Explore what documents are returned in Pubmed using various terms related to the case to narrow down search terms. Search terms were selected based on preliminary exploratory reading and snowballed as search results were explored. The first page of each return was skimmed to identify relevancy of return using each term. Pubmed search strings (middle column) were reviewed to check that the term as interpreted by Pubmed accurately reflected the inputted term. MeSH hierarchy reviewed to check location of term. Terms grouped according to four areas in conceptual map (palliative care, care navigation, electronic health records, partnership) and a fifth group to limit to topic of implementation.

Search term	Pubmed search 13/03/2015	Returned
Term input to begin search. All fields included. Terms registered as Medical Subject Heading (MeSH) are indicated in brackets. Bold indicates term was included in final search strategy.	The search string created by Pubmed using the inputted search term.	Number of articles returned.
<i>'Implementation' search terms group</i>		
Implementation	implementation[All Fields]	135920
Implementation process	implementation[All Fields] AND process[All Fields]	20988
"implementation process"	"implementation process"[All Fields]	1146
Implementation research	implementation[All Fields] AND ("research"[MeSH Terms] OR "research"[All Fields])	73655
"implementation research"	"implementation research"[All Fields]	597

Process evaluation	process[All Fields] AND ("evaluation studies"[Publication Type] OR "evaluation studies as topic"[MeSH Terms] OR "evaluation"[All Fields])	98577
Health plan implementation [MeSH]	"health plan implementation"[MeSH Terms] OR ("health"[All Fields] AND "plan"[All Fields] AND "implementation"[All Fields]) OR "health plan implementation"[All Fields]	7844
Diffusion of innovation [MeSH]	"diffusion of innovation"[MeSH Terms] OR ("diffusion"[All Fields] AND "innovation"[All Fields]) OR "diffusion of innovation"[All Fields]	16469
Information Dissemination [MeSH]	"information dissemination"[MeSH Terms] OR ("information"[All Fields] AND "dissemination"[All Fields]) OR "information dissemination"[All Fields]	15710
MeSH headings returned in search for term: implementation Health Plan Implementation Regional Health Planning Annual Implementation Plans		
<i>'Palliative care' search terms group</i>		
End of life	end[All Fields] AND ("life"[MeSH Terms] OR "life"[All Fields])	50752
End of life care	"terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields]) OR "end of life care"[All Fields] OR "hospice care"[MeSH Terms] OR ("hospice"[All Fields] AND "care"[All Fields]) OR "hospice care"[All Fields] OR ("end"[All Fields] AND "life"[All Fields] AND "care"[All Fields])	61210
Palliative care	"palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields]	52822
Palliative	palliative[All Fields]	67053

Terminal care	"terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]	47146
Dying	dying[All Fields]	26639
Hospice and Palliative Care Nursing [MeSH]	"hospice and palliative care nursing"[MeSH Terms] OR ("hospice"[All Fields] AND "palliative"[All Fields] AND "care"[All Fields] AND "nursing"[All Fields]) OR "hospice and palliative care nursing"[All Fields]	1409
Palliative Medicine [MeSH]	"palliative medicine"[MeSH Terms] OR ("palliative"[All Fields] AND "medicine"[All Fields]) OR "palliative medicine"[All Fields]	16437
MeSH headings returned in search for term: end of life		
Terminal Care		
End of Life Care		
MeSH headings returned in search for term: palliative		
Hospice and Palliative Care Nursing		
Palliative Care Nursing		
Palliative Nursing		
Palliative Care		
Palliative Surgery		
Palliative Therapy		
Palliative Treatment		
Surgery, Palliative		
Therapy, Palliative		
Palliative Medicine		
Medicine, Palliative		
Palliative Care Medicine		
<i>'Care navigation' search terms group</i>		
Specialist advice	("specialization"[MeSH Terms] OR "specialization"[All Fields] OR "specialist"[All Fields]) AND advice[All Fields]	1272
Care navigation	care[All Fields] AND navigation[All Fields]	1430
Care navigator	care[All Fields] AND navigator[All Fields]	347
Navigation	navigation[All Fields]	13406

Single point of access	("single person"[MeSH Terms] OR ("single"[All Fields] AND "person"[All Fields]) OR "single person"[All Fields] OR "single"[All Fields]) AND point[All Fields] AND access[All Fields]	693
"single point of access"	("single person"[MeSH Terms] OR ("single"[All Fields] AND "person"[All Fields]) OR "single person"[All Fields] OR "single"[All Fields]) AND point[All Fields] AND access[All Fields]	Phrase not found
Patient Navigation [MeSH] – entered as patient navigators	"patient navigation"[MeSH Terms] OR ("patient"[All Fields] AND "navigation"[All Fields]) OR "patient navigation"[All Fields]	2469
Patient Navigators	"patient navigation"[MeSH Terms] OR ("patient"[All Fields] AND "navigation"[All Fields]) OR "patient navigation"[All Fields] OR ("patient"[All Fields] AND "navigators"[All Fields]) OR "patient navigators"[All Fields]	2587
<i>'EPaCCS' search terms group</i>		
Electronic palliative care co-ordination system	("electronics"[MeSH Terms] OR "electronics"[All Fields] OR "electronic"[All Fields]) AND ("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields]) AND co-ordination[All Fields] AND system[All Fields]	0
Electronic palliative care coordination system	("electronics"[MeSH Terms] OR "electronics"[All Fields] OR "electronic"[All Fields]) AND ("palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields]) AND coordination[All Fields] AND system[All Fields]	2
Electronic patient record	("electronics"[MeSH Terms] OR "electronics"[All Fields] OR "electronic"[All Fields]) AND ("medical records"[MeSH Terms] OR ("medical"[All Fields] AND "records"[All Fields]) OR "medical records"[All Fields] OR ("patient"[All Fields] AND "record"[All Fields]) OR "patient record"[All Fields])	22845

Shared electronic record	Shared[All Fields] AND ("electronics"[MeSH Terms] OR "electronics"[All Fields] OR "electronic"[All Fields]) AND ("records as topic"[MeSH Terms] OR ("records"[All Fields] AND "topic"[All Fields]) OR "records as topic"[All Fields] OR "record"[All Fields])	524
Medical Records Systems, Computerized [MeSH]	"medical records systems, computerized"[MeSH Terms] OR ("medical"[All Fields] AND "records"[All Fields] AND "systems"[All Fields] AND "computerized"[All Fields]) OR "computerized medical records systems"[All Fields] OR ("medical"[All Fields] AND "records"[All Fields] AND "systems"[All Fields] AND "computerized"[All Fields]) OR "medical records systems, computerized"[All Fields]	26798
Electronic health records [MeSH]	"electronic health records"[MeSH Terms] OR ("electronic"[All Fields] AND "health"[All Fields] AND "records"[All Fields]) OR "electronic health records"[All Fields]	16935
<i>Partnership search terms group</i>		
Partnership	partnership[All Fields]	18147
Integrated care	"Int J Integr Care"[Journal] OR ("integrated"[All Fields] AND "care"[All Fields]) OR "integrated care"[All Fields]	32904
Coordinated care	coordinated[All Fields] AND care[All Fields]	5749
Co-ordinated care	co-ordinated[All Fields] AND care[All Fields]	555
Multidisciplinary care	("interdisciplinary studies"[MeSH Terms] OR ("interdisciplinary"[All Fields] AND "studies"[All Fields]) OR "interdisciplinary studies"[All Fields] OR "multidisciplinary"[All Fields]) AND care[All Fields]	28007
Multidisciplinary approach	("interdisciplinary studies"[MeSH Terms] OR ("interdisciplinary"[All Fields] AND "studies"[All Fields]) OR "interdisciplinary studies"[All Fields] OR "multidisciplinary"[All Fields]) AND approach[All Fields]	19011

Interdisciplinary care	("interdisciplinary studies"[MeSH Terms] OR ("interdisciplinary"[All Fields] AND "studies"[All Fields]) OR "interdisciplinary studies"[All Fields] OR "interdisciplinary"[All Fields]) AND care[All Fields]	17414
Joint working	("joints"[MeSH Terms] OR "joints"[All Fields] OR "joint"[All Fields]) AND ("work"[MeSH Terms] OR "work"[All Fields] OR "working"[All Fields])	15581

Stage 2: The terms with the most relevant and comprehensive search returns were selected for final search string to retrieve papers for the five search terms groups.

Number	Search term	Returned
	Implementation	
1	"implementation process"	1146
2	"implementation research"	597
3	Health plan implementation [MeSH]	7844
	Palliative care	
4	End of life care	61210
5	Palliative care	52822
6	Hospice and Palliative Care Nursing [MeSH]	1409
	Care navigation	
7	Patient Navigators	2587
	Shared electronic records	
8	Electronic palliative care coordination system	2
9	Electronic health records [MeSH]	16935
	Partnership	
10	Partnership	18147
11	Coordinated care	5749
12	Co-ordinated care	555
13	1 [Title/abstract] OR 2 [Title/abstract] OR 3	203

Stage 3: Search builder created. Where more than 200 articles were returned (indicated in light grey text), the first string regarding implementation was restricted to just the title/abstract.

Search group:	Search Builder			Returned
Palliative care	1 OR 2 OR 3	AND	4 OR 5 OR 6	173
Care navigation	1 OR 2 OR 3	AND	7	15
Electronic health record	1 OR 2 OR 3	AND	8 OR 9	340
	13	AND	8 OR 9	15
Partnership	1 OR 2 OR 3	AND	10 OR 11 OR 12	382
	13	AND	10 OR 11 OR 12	7
Total reviewed from Pubmed search				210

Stage 4: Titles and abstracts reviewed for relevance; full text articles retrieved.

Stage 5: Additional papers identified through reference lists, suggested reading from online databases, and recommendations from colleagues.

Observations from carrying out literature search:

- Explosion of research in last 5 years in implementation. Prior to this research using above terms is sparse, mainly studies of policy implementation.
- Navigation does not have a common definition, not used consistently, e.g. describing triage nurse in A&E as navigator.
- Abstracts state that the paper describes the implementation of a service or intervention, but they describe the outcomes from implementation rather than describing the process.

Appendix 2: Observation schedules

Observation schedule for meetings

Meeting	
Location	
Date	
Start time	
End time	
People Present	
Apologies	
Documents	

Map of room

Notes

Summary of meeting for feedback, structure based on agenda/ programme components:

[Blue System] – Progress to date	
[Blue System] – Implementation plan, next phase roll outs	
[Blue System] – Linking with [ambulance] and 111	
NC – Report on calls	

WS – Progress	
WS – Plans for pathway development	
WS – Pathway from Community Nursing	
WS – Plans for Workforce Delivery	
EPB – progress to present/ future governance	
Governance & Risk Register – review of risk register	
Other	
Other	

Observation schedule for Navigation Centre site visits

Site visit to Navigation Centre

Date observed (date of additional notes added/ cleaned/ typed up)

Key

INC = incoming call, - # - = approximate number of rings before being picked up

OUT = outgoing call

M→CB = take a message to call back

Tx = call transferred

Overview of visit – summary of status of centre on arrival, who was present, arrived or left during observations.

Map of room created on first visit, noticeable changes noted on subsequent visits

Observation notes (value free):

Time Notes

Time Notes

Finished notes at [time].

Additional notes based on questions I asked during the day and overall impressions:

Appendix 3: Topic guides – interviews with project manager & stakeholders and focus group with care navigators

Included in this appendix are three topic guides: project manager interview, stakeholder interview and care navigator focus group. New topic guides were created for each project manager interview. The topic guide for each stakeholder interview was revised to include emerging themes following each interview in order to confirm or refute initial findings. Because these topic guides were unique to each of the 17 interviews, only one sample is included below for the project manager and stakeholder interviews.

Example of topic guide for one of the project manager interviews

Questions primarily used as aide memoire for discussion.

Topic guide – project manager

September 2013

1. Last met at end of July, what has happened since then?
2. EPaCCS – [Red System]
 - a. Talk through how the transition from [Blue System] to [Red System] will happen
 - b. Will anyone now be the champion of EPaCCS? Is it led by 111 now?
 - c. What parts of [Red System] are changing? Any changes to functionality, or just opening up to more users?
3. NC
 - a. Call audit results – initial reactions?
 - b. Any decision on the NC's future?
 - c. If it is to continue, will it ever take calls from non-hospice patients?
4. [X] talked about new notification system introduced in hospitals to notify hospice when patients were admitted. What can you tell me about that? How is it related to the Project, how did the sharing of information come about?
5. Follow-up service use data from [data analyst], when will that be taken from?
6. Project management
 - a. Will Executive Project Board meet again?
 - b. Is anyone leading /managing the Project?
7. What would you say have been the successes of the Project so far?
8. What have been the failures?
9. What is the future of the Project

Example of topic guide for one of stakeholder interviews

Boxes and arrows on the side are used to explain the example given.

Topic guide and questions for [stakeholder] [date and time] at [location]

- Consent form
 - Questions?
 - Turn on recorder
1. Background questions
 - a. Could you first summarise your role in the project for me.
 - b. When did you first become involved in the Project?
 2. The aim of the interview is to reflect on the Project as a whole and also what impact it has had on the work of [your organisation]. I want to cover 3 main areas:
 - a. project achievements/ successes and aims that fell short
 - b. your experience of the implementation process
 - c. lessons learned and plans for the future.

Questions	My observations/ stakeholder comments as aide memoire for confirmation/ refutation
<i>Achievements (whole project)</i>	
Reflecting back on the full two years, what do you see as the achievements of the Project (big or small achievements)? Why were they successful?	Getting [Red System] further developed, <i>EPaCCS established</i> Collecting audit data across partners <i>Navigation Centre</i> <i>Education and Medicines WS work</i> <i>Getting all the partners together</i>
What do you see as aims of the Project that were not fully achieved or were not completed?	Recruitment of ANPs (2 trainees appointed?) Piloting of register in [area] abandoned → no opportunity to trial register? Could have identified problem of competition from [Red System] Audit data not available until second year → unable to track progress in a useful time frame? <i>NC not as envisaged</i>

	<i>Register not in widespread use</i> <i>Advance care planning</i>
Why were those aims not achieved? Why do you think some elements of the Project were successful and others not? Did the Project aims match the aims of [your organisation] at the time? How well did the agenda at [your organisation] match that of the Project?	Participation by all partners? Where is social care? Buy in from GPs? Changing from PCT to CCG? <i>Different agendas/ priorities</i> <i>Changes in PCT to CCG, KCC</i> <i>Lack of strategic direction from hospice</i> <i>Communication between work streams</i> <i>Leadership from EPB</i>
Do you think the Project aims were achievable? Were they the right aims?	Too many aims?
Was there anything in place within [your organisation] for accountability or to ensure that you or others stayed engaged in the Project?	
Implementation process - the strategies that were used to achieve the Project aims (procedures, mechanisms, actions that were going to make the Project or its components like the register or NC a routine part of practice within the partner organisations)	
What did you see as the main strategies for implementation?	Partners to act as champions in their organisation Education and training, <i>raise awareness</i> Adoption of EPaCCS Coordinator role Monitoring/ audit to show improvement
How effective do you think these strategies were?	Did all partners champion the Project? GPs? Could baseline data have been used to facilitate change better?

<p>What were the barriers to implementation?</p>	<p>Some partners missing – social care? GPs? <i>Changes in staff with PCTs to CCGs, [council] and [community health trust]</i> <i>Change in management</i> <i>Funding withdrawn</i></p>
<p>How well do you think [the hospice] was placed to lead the Project? Who do you think would have been best suited to lead the project if not the hospice? How well do you think the project was managed?</p>	<p>Power of CCGs and GPs, politics <i>Commissioners</i></p>
<p>What are your views of the Navigation Centre for the provision of end of life care, generally and in relation to the work of [your organisation]? Is it filling a need? Is it well situated at the hospice?</p>	<p><i>111 as competition which was not known at the start?</i></p>
<p>What are your views on the implementation of the [Blue System]? How much do you think the issues with implementing the register had on the success of the rest of the Project?</p>	<p><i>Hospice unilateral decision on [Blue System]</i></p>
<p>Outcomes have not yet been reported, how important are they in assessing the success or failure of the implementation of the project? What do you base your assessment of success or failure of the Project's implementation on?</p>	<p>Experience of process?</p>
<p>How much was end of life care a priority for [your organisation] at the time of the Project? Where does end of life care fit in with your clinical or organisational priorities?</p>	<p>Low priority – low participation, less championing/ dissemination within their organisation</p>
<p>What impact has the project had on [your organisation], if any? Any policies in place or change in procedures?</p>	
<p>How do you feel that the model of care that was proposed in the project, i.e. the navigation centre,</p>	

end of life register and outputs from the work stream fits with the interests of the trust?	
<i>Lessons learned and Future plans</i>	
What elements of the Project will be further developed or abandoned going forward?	Navigation Centre? [Red System]
What are your views on future partnership working?	
Have there been any lessons learned, particularly about how to implement complex change programmes?	<i>Rushing in without laying groundwork</i>

Focus group topic guide with Navigation Centre care navigators

Focus group Navigation Centre [date and time]

Introductions

Background:

- Reaching the end of 2 year evaluation
- Data collection has included:
 - NC: 3 observations of the call centre including weekday morning & evening and Saturday morning, reviewed call audit data, looked through training documents from 2012.
 - Other data: observation of project and executive project board meetings, reviewed project documents, interviews with project manager.
- Still to carry out interviews with stakeholders.

Aim of the focus group:

- Find out how the NC is running, how it works now and how the way it works has changed over time, what you think it does well, what you think the gaps are in terms of what the NC does or any gaps generally that you see in how care is coordinated for patients and their families.

Rules of the group

- Everything you say is confidential, nothing will be attributed to you personally and you will not be identifiable in any reports, but if there is a possibility that the data might identify you then I will contact you to ask permission to use a quote if it might identify you.
- I might stop you if I feel something interesting has been raised that I want to know more about or if I feel that I've got enough about one topic so we can keep to time.
- You might find that some of the questions seem a bit repetitive but it's just because I have a list of topics I want to go through and I just want to make sure I cover them fully.
- Idea is for you to discuss the questions as a group, not about one person answering for all of you so if you have a different opinion then please say.
- Any questions about the focus group?

- Switch on recorder

- 11:05 (5) 1. Please say your name, how long you've been a care navigator, what type of shifts you work, and whether you have any previous call handling experience or whether you've worked in another area of the hospice.
- 11:10 (15) 2. I now just want to think about the different types of people you deal with on the phone – so that's really sort of 4 groups: health and social care professionals which would include hospice staff, patients, patient's families, and then all other callers. I just want to get a general overview of how you interact with these groups, why they call, why you call them and how you deal with the calls.
- 11:10 (5) a. The largest group from the call audit which is the professional group which represents about 50% of the calls. What are some common reasons why professionals call the NC and how do you generally deal with their phone calls? (coordination of care, advice on medicine, referral to hospice)
- i. Do they primarily call about patients who are known to the hospice?
 - ii. Are you usually able to deal with the issue? What type of issues would you deal with and what would be passed on?
 - iii. How helpful do you find professionals that you call?
 - iv. If you need to forward an issue on to a clinical member of the hospice team, do you find you're able to get through easily and do you feel that they deal with issues as quickly as patients and their families expect?
 - v. Do the professionals that call usually have access to [Red System]? Do you find that the information in [Red System] is helpful for helping professionals who call?
- 11:15 (5) b. Family of patients represent the next largest group, a quarter of the calls. What are some common reasons that family or carers call the NC and how do you deal with their phone calls?
- i. Are you usually able to deal with the issue? What type of issues would you deal with and what would be passed on?
- 11:20 (5) c. Patients are a minority of callers. What are some common reasons that patients call the NC and how do you deal with their phone calls?
- i. Algorithms and pathways were created so that you could give some advice about clinical problems at a relatively low level. Have you ever given advice to patients or carers who called using those pathways?
 - ii. Are you usually able to deal with the issue? What type of issues would you deal with and what would be passed on?
 - iii. How often would you say that you deal with issues for patients who have not been referred to the hospice?
- 11:25 (2) d. All other callers. What are other types of phone calls that you get from people who are not professionals, patients, or family?

- 11:30 (15) 3. I now want to talk about the information and tools that you use that help you to deal with calls, so this would include [hospice record system], [Red System] and before that the [Blue System], the algorithms that used to be in place but have been abandoned, and anything else you might use – how these tools support the work that you do. So what tools do you use, if any, for dealing with calls from the different groups that we’ve just talked about?
- a. How confident are you that the information held within patient records is up to date and accurate?
 - i. Are other care providers adding information in regularly?
 - b. [Red System]
 - i. Do you use [Red System]?
 - ii. Do you think that other care professionals are using [Red System]?
 - iii. Do you think that enough information is held in [Red System] for you to coordinate patient care?
 - iv. What do you think is essential information for you to have to coordinate care?
 - c. Do you think the training you’ve had was sufficient preparation for the calls you’ve had to deal with?
- 11:45 (10) 4. What do you think have been some of the key successes of the NC?
- a. Do you think that the NC is an effective way to coordinate patient care?
- 11:55 (10) 5. Do you think the NC has any weaknesses or how do you think it could improve?
- 12:05 (20) 6. How do you think that the coordination of care now compares to care coordination 18 or 24 months ago?
- a. What do you think are patients’ and their families’ expectations of what the NC can do for them?
 - b. Do you think care professionals use the NC to its full potential?
 - c. Do you think the NC is being used to its full potential?
 - d. How well do you think you are meeting the needs of people who are calling?
 - e. Do you see any gaps in how care is coordinated in general between the range of health and social care providers?

Appendix 4: Ambulatory and Home Care Record

Redacted for printing.

Appendix 5: Data analysis samples

Numbered steps below pertain to the numbered steps in analysis described in section 4.2.5.

Stage 1: Key Project events laid out in a timeline and data collected each month listed underneath.

Dec-12	Jan-13	Feb-13	Mar-13	Apr-13	May-13	Jun-13	Jul-13
<i>Blue System rolled out</i>						<i>Blue System ends</i>	
<i>PDG meets</i>	<i>PDG meets</i>	<i>PDG meets</i>	<i>PDG meets (last meeting)</i>			<i>Project manager contract ends</i>	
<i>EBP meets</i>		<i>EBP meets</i>				<i>EBP meets</i>	
<i>Planned end date of Pharmacy WS</i>							
Excluded Doc 17	Doc Meetings 13Q1-02	Doc Operational 13 Q1-03	Excluded Doc 24	Doc Operational 13Q2-01	P02 telephone interview 1,2	Doc Monitoring 13Q2-01	Doc Operational 13Q3-04
Doc Meetings 12Q4-01	Doc Output 13Q1-02	Excluded Doc 23	Doc Meetings 13Q1-01	Int Project Manager 13Q2-04	P03 telephone interview 1,2	Excluded Doc 26	Doc Operational 13Q3-01
Doc Output 12Q4-01	Excluded Doc 19	Obs PDG 13Q1-09	Doc Operational 13Q1-01	Obs NC 13Q2-03		Doc Meetings 13Q2-01	Doc Audit 13Q3-01
Obs PDG 12Q4-07	Excluded Doc 21	Doc Meetings 13Q1-03	Obs EPB 13Q1-05			Doc Audit 13Q2-01	Int Hospice Director 13Q3-05
Excluded Doc 18	Int Project Manager 13Q1-03	Obs CNC 13Q1-01	Excluded Doc 25			Obs EPB 13Q2-06	Obs NC 13Q3-04
Obs EPB 12Q4-04	Obs PDG 13Q1-08	Doc Operational 13Q1-04	Obs PDG 13Q1-10			P02 telephone interview 3	P06 telephone interview 2
P01 telephone interview 1	Excluded Doc 22					P03 telephone interview 3	P07 telephone interview 1

Doc Output 12Q4-02	Doc Operational 13Q1-02					P05 telephone interview 1	P08 telephone interview 1
Exluded Doc 20	Doc Operational 13Q1-05					P06 telephone interview 1	P09 telephone interview 1
	P01 telephone interview 2, 3					Excluded Doc 26	

Stage 2 and 3: Node hierarchy below has been exported from NVivo showing sources coded and number of references. 'X' under '*a priori*' indicates node was created for analysis prior to coding. All other nodes emerged during coding.

Node Name	Sources	References	<i>a priori</i>
Actors and Actions	23	45	X
Action points	13	36	
Decision making	25	43	
Workforce	41	69	
Acute services	16	20	
A&E	1	1	
Hospital doctor_consultant	2	2	
Hospital nursing	1	1	
Allied health professions & others	5	6	
Ambulance	13	23	
Care homes	3	3	
Commissioners	18	29	
Data analyst	4	5	
District nurse	19	32	
GP	29	47	
GP OoH	3	4	
Hospice	26	52	
Hospice consultant	2	3	
Hospice doctor	1	1	
Hospice nurse	11	13	
Trustees	2	2	
Informal carers	1	1	
Activities - informal carers	3	7	
Experience - informal carers	17	42	
Patient experience from informal carers	5	9	
Macmillan	3	4	
Marie Curie	4	5	
NC navigators	10	21	
Out -of-Hours Service	9	11	
Pharmacy	4	4	
Project manager	34	73	
Samaritans	1	1	
Social care	11	16	
Context	56	127	X
111	18	24	
Access to services	8	9	
Barriers	28	49	X
Risks	24	32	
Concurrent work	27	65	
EoL press	3	5	
Existing knowledge or experience	27	48	
NHS reform	19	37	
Organisational interest	9	14	X
Policy context - policy link	18	72	X
Resources	34	58	X
Implementation outcomes or degree	32	118	X

Implementation Process	15	41	X
Adaptation	21	25	X
Communication	49	95	X
Education and Training	39	71	X
EPaCCS and information sharing	70	181	
Governance	21	31	
Implementation strategies	35	49	
Judging success	6	8	
Leadership	15	25	
Management	30	78	
EPB	20	38	
PDG	7	8	
Stakeholder OR Professional user involvement	53	135	
Monitoring	54	136	X
Evaluation	12	20	
Planning	30	114	
Service user involvement	6	12	X
Trialability	18	24	X
Influences	0	0	
Innovation characteristics	4	4	
Clarity	12	14	
Competing innovations and existing systems	21	30	
Funding resources	12	13	
Meets users needs	30	62	
Policy link - policy context	6	7	
Partnership approach	12	18	
Individual characteristics	16	19	
Leadership	26	46	
Participation	19	30	
Priorities	17	27	
Variability in working practices	13	17	
Where to start	7	9	
Power relationships	3	8	
Other	15	28	
Perceived benefit of project	14	24	
Perceived need for change	20	34	
Recognizing EoL needs	3	5	X
Project characteristics	28	44	X
Attendance	9	18	
Navigation Centre	72	126	
Call types	17	125	
NC activities	33	103	
NC environment	5	27	
Volume of calls	10	26	
Project aims and objectives	31	49	
Workstreams	23	32	
Communication WS	22	25	
IT Audit Eval WS	16	26	
Patient pathway WS	26	38	
Pharmacy WS	31	38	
Users WS	15	17	
Workforce Education Training WS	29	40	
Project outcomes	29	62	

Coordination of care	29	56	
Learning	8	17	
Progress	11	27	

Stage 4 and 5: Coded data sorted into matrix tables. Example below shows a sample of the matrix regarding the Project Delivery Group combining data from document review and observations. Plain text summarises data; italicised texts are additional thoughts and questions as early analysis (were originally colour-coded in NVivo).

	Training/ education (a priori)	Management structure and stakeholders	Planning (a priori)	Monitoring (a priori)	Communication (a priori)
Aggregate notes from PDG 03 Docs		Project manager concerned about how EPaCCS will be implemented. Agreement that a plan should be formulated. Engagement of partners important. <i>Unclear how or who would put this plan together and how it would be agreed.</i> //EPB agreed to endorse Blue System //Not good turn out to Workforce WS meeting. Project manager to help chairs figure out how to progress the WS. <i>Already having difficulties - is this because aims are too big or not getting right people in the room or something else?</i> //Pathway WS - meeting later, members asked to bring examples of pathways	<i>Pilot register in [area]</i>	NC issues to be logged and brought to PDG for monitoring.	
Obs PDG 12Q2-03	Have bid for training money for EPaCCS pilot in Ashford, just deciding when to start training.	Project manager working with current EoL commissioner to streamline project aims and tasks - <i>work being done with those who commission services.</i> // Poor engagement by individual stakeholders - they say they are supportive but then don't show up to meetings. // PDG chair agreed that aims of Workforce WS too big. <i>People expected to lead on WS or PDG without feeling comfortable or understanding their aims, should have been involved in the planning process? Or is this a part of adaptation?</i> //PDG to keep track of risks to feed up to EPB. //FH taking a paper [about the project] to CCG federation to "sow the seeds"	PDG expect more risks to come up as WS develop their tasks.	[Stakeholder F] suggested measuring use of ACP instead of DNACPR. // Data analyst got baseline data from hospice, and detailed data from ambulance and acute (?) // Some patient issues are part of evaluation, brought up by [Stakeholder G] // Piloting the register should help identify issues in implementation.	

Aggregate notes from PDG 04 Docs		Project manager to create implementation plan for register and present to group at next meeting <i>in preparation for pilot.</i> // Workforce WS - had not had a good turnout, reviewing membership.// Small group required to oversee the implementation of the register.// Comms WS - no new chair found so LC agreed to continue. Progressing with key objectives of raising the profile of the project and communicating progress. Pharmacy asked to be included in communications.	Register pilot to begin 1 Oct 2012.	[Stakeholder H] to present baseline data report at next meeting.// Pilot of register to commence 1 Oct 2012.// [Stakeholder A] data collection of NC issues is crucial so that issues can be taken into WS for addressing.	
Obs PDG 12Q3-04		Need to engage social care commissioning. // Register needs to be approved by Ashford CCG before pilot can begin. // PDG needs to have attendance from community teams so they can be included in discussions. // Project manager trying to keep risk register up to date.		Pilot sites have been chosen to reflect different sizes and those who are good and bad at EoLC. // Have had some trouble gathering baseline data, but may be able to piece bits together - <i>how useful would piecemeal data be?</i> // [Stakeholder G] wants more reporting of issues and not less, [Stakeholder B] agreed. Project manager hopeful that Blue System will capture these issues. // [Stakeholder J] fed back on 7 cases to NC which were looked at to monitor performance - problems have been both internal hospice problems and external with out-of-hours. Issues should be fed to patient pathways.	[Stakeholder E] - communication to community trust could have been streamlined. // Good sell required to GPs to get them to add patients to Blue System as Red won't automatically do it.

	Workforce capacity	Parcelling work	User involvement	EPaCCS	NC
Aggregate notes from PDG 03 Docs	New project manager in post.	Project manager and PDG chair with actions to complete. //Workforce WS to map current workforce across all organisations that provide EoLC. Not good turn out to meeting. // Comms WS - chair hoping that someone from PCT will take over. Meeting had to be rescheduled. //IT WS - had first meeting, clear objectives and tasks. Agreed register to be implemented. Working on metrics, KPIs and unlocking data issues. Meet for first 3 months then bi-monthly.		Recommendation was made to EPB and has been confirmed that Blue System will be the system. Assurances given that Blue System can interface with Red System. // Felt that the implementation of the register will require a separate WS; agreed to formulate a plan. //Necessary to link with national local systems to push and pull information. //To be piloted in [area].	NC open to hospice patients only. Issues would be logged and brought to the group.
Obs PDG 12Q2-03	Hospice had wanted to hire 2 consultants, but only 1 being interviewed - risk of not hiring staff as planned. //Project manager unclear of her role in implementing EPaCCS.	Workforce WS feel aims are too big, want to do an audit to come up with more realistic aims. //No one present from IT WS, but much discussion about IT systems and potential problems. // WS asked to include risk assessment to the tasks of WS. //Comms WS haven't met yet. //Patient pathway WS - first meeting this afternoon. // Pharmacy WS - not enough people present for quorum for first meeting. // Users WS - hard to get people to meet	Main concern for Users group was name of NC, <i>this doesn't seem like a sufficient reason to meet, which perhaps is why it was difficult to get people to meet?</i>	Red System used by 85% of GPs and out-of-hours. // In notes: success of the project will hinge on the implementation, roll out and acceptance of the register. // [stakeholder A] suggested there be a group to manage implementation	Having trouble extricating clinical calls from non-clinical calls. Hospice patients have been given number to call and info on NC.

Aggregate notes from PDG 04 Docs		<p>Pharmacy WS - had first meeting, members tasked with identifying good practice and areas for improvement.// Workforce WS - had not had a good turnout, reviewing membership. Plan to map nursing workforce and look at upskilling.// Pathways WS had first meeting, asked to bring pathway examples to next meeting. Chair said that any pathway issues from NC should be sorted out in this WS.// Users WS have met, want to broaden membership. Discussed how to embed ACP.</p>		<p>PDG chair concerns over Blue System talking to Red System, Blue System looking into it.// Register to be piloted in 6 practices in [area] from 1 Oct 2012. EPaCCS to be standing item on agenda as register crucial to the project.// [stakeholder A] concerns over how to control the addition of patients; [stakeholder B] & [stakeholder C] reassured group that consent has to be gained.</p>	<p>Opened June 2012, some teething problems. Log of problems to be kept and sent to project manager <i>for dissemination to WSs.</i></p>
Obs PDG 12Q3-04		<p>Patient pathway WS /chair have a number of concerns about how the register will be used by partners, what will happen to NC if a lot of patients are added, and what the role of the hospice is. <i>Seems they are uncertain of how to progress until these questions are answered, but should they not be the ones to state what they think the pathway should be?</i> // Comms WS discussing how to engage staff and what literature should be produced at different staffing levels and organisations. // Pharmacy WS gathering baseline measurements. Project manager sees this WS as an opportunity to sort out long standing problems. // Workforce WS have identified wide and varied workforce, so focusing on nursing at present.</p>		<p>[Stakeholder D] asked if there is confidence that Blue System can talk to Red System. Project manager said yes, but doesn't think that Red System will automatically enter patients onto Blue System, GPs might need to do that. //[Stakeholder A] concerned about how register will be used in practice. // What to call register - EoL or PC? Preference among group is EoL. <i>Registers currently referred to as PCR so will have to overcome this.</i></p>	

Appendix 6: Research ethics approval letters

**NRES Committee South East Coast - Kent**

Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 02079722561

13 November 2012

Mrs Laura Holdsworth
Research Associate
Centre for Health Services Studies, University of Kent
George Allen Wing
Cornwallis Building
Canterbury
CT2 7NF

Dear Mrs Holdsworth

Study title: Evaluation of the Invicta Project
REC reference: 12/LO/1311

Thank you for your letter of 24 September 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites**NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		27 July 2012
Evidence of insurance or indemnity		12 July 2012
Other: AHCR Telephone Script & Data Collection Form	1	19 July 2012
Other: Interview topic guide with carer and patient	1	25 May 2012
Other: Focus Group topic guide PDG	1	25 May 2012
Other: Focus Group topic guide call handlers	1	25 May 2012
Other: CV for Laura Holdsworth		26 July 2012
Other: CV for Jenny Billings		23 July 2012
Other: CV for Michael Calnan		18 July 2012
Other: Invicta 3 UoK follow up invite letter	1	03 July 2012
Other: MCA AAHCR GP Invite letter	1	03 July 2010
Other: Invicta 2 AHCR UoK patients and carers invite letter		03 July 2012
Other: Letter to GP	1	11 September 2012
Other: Safeguarding Plan	1	11 September 2012
Participant Consent Form: Invicta 2 AHCR Telephone survey	UoK	03 July 2012
Participant Consent Form: Invicta MCA AHCR GP	1	03 July 2012
Participant Consent Form: Focus Group	1	25 May 2009
Participant Consent Form: Interview	1	25 May 2012
Participant Information Sheet: Interview bereaved carer	1	19 July 2012
Participant Information Sheet: PIS Invicta interview Carer	2	30 August 2012
Participant Information Sheet: PIS Invicta interview patient	2	30 August 2012
Participant Information Sheet: PIS Invicta Call handlers focus group	2	11 September 2012
Participant Information Sheet: PIS Invicta PDG focus group	2	11 September 2012
Protocol	3.6	11 June 2012
REC application		24 July 2012
Response to Request for Further Information		24 September 2012

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.

After ethical reviewReporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/LO/1311

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Ray Godfrey
Chair

Email: NRESCcommittee.SECOast-Kent@nhs.net

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Nicole Palmer
Dr Peter Dodds, RM&G Consortium for Kent and Medway

NRES Committee South East Coast - Kent

Ground Floor
 Skipton House
 80 London Road
 London
 SE1 6LH

Tel:
 Fax:

12 April 2013

Mrs Laura Holdsworth
 Research Associate
 Centre for Health Services Studies, University of Kent
 George Allen Wing
 Cornwallis Building
 Canterbury
 CT2 7NF

Dear Mrs Holdsworth

Study title: Evaluation of the Invicta Project
REC reference: 12/LO/1311
Amendment number: Amendment 1
Amendment date: 11 March 2013
IRAS project ID: 107932

The above amendment was by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet: Invicta patient only	1	07 March 2013
Participant Information Sheet: Invicta Interview programme manager	1	29 January 2013
Participant Information Sheet: Invicta Carer	1	07 March 2013
Participant Information Sheet: Invicta 3 UoK	2	07 March 2013
Participant Information Sheet: AHCR UoK	2	07 March 2013
Protocol	3.7	11 March 2013
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1	11 March 2013
Covering Letter	email to Ray Godfrey from Laura Holdsworth	11 March 2013
Participant Information Sheet: Invicta Patient with carer	1	07 March 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

12/LO/1311:	Please quote this number on all correspondence
-------------	--

Yours sincerely



Dr Ray Godfrey
Chair

E-mail: NRESCommittee.SECOast-Kent@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Mr Peter Dodds, RM&G Manager, RM&G Consortium for Kent and Medway
Nicole Palmer*

NRES Committee South East Coast - Kent**Attendance at Sub-Committee of the REC meeting on 27 March 2013**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Ray Godfrey	Statistician	Lay Plus
Mrs Maureen Williams	Senior Lecturer Midwifery	Expert

Appendix 7: Summary of study findings for dissemination to participants and dissemination strategy

Dissemination strategy: Two summaries have been created tailored to the interests and understanding of two groups – stakeholders and care providers who participated in the Project, and family carers who participated in the telephone interviews. The ‘Summary of findings from the evaluation of the Project’ will be disseminated to project stakeholders, commissioners, and those who participated in interviews and observations. The ‘Summary of findings from the evaluation of the Navigation Centre’ will be disseminated to carers who participated in the telephone interviews. Separate summaries have been created for the two groups because it is perceived that their informational needs and interests in the outcome of the study will be different. Carers were primarily asked about their use of services and particularly whether they used the Navigation Centre and will therefore have little or no knowledge of the other aspects of the project, particularly the workstreams and partnership and therefore it was decided that as what happened in the project with regards to implementation was quite complex, it would not be appropriate to try to summarise this for them. The summary for carers will be presented in a format following NHS ethics guidance for dissemination to service users, i.e. using a larger font.

Summary of findings from the evaluation of the Project

July 2016

Prepared by Laura Holdsworth

Background

It is perceived that patients in the last few months of life, with incurable, irreversible illness require access to a range of services which are often poorly coordinated. This results in duplication of care, repetition of information and gaps in service provision for patients and family carers, which are particularly evident out-of-hours. Health policy in England has increasingly promoted coordinated and integrated health and social care services delivered through partnerships with public, private and voluntary sector organisations. End of life care would benefit from improved coordination to enable patients to achieve their wishes.

The Project was initiated by a partnership of regional health and social care providers at the end of 2011 to address the aims of the National End of Life Care Programme. The main aims of the Project were to improve the end of life experience of patients, reduce inpatient admissions to hospital for dying patients and reduce service duplication. The Project proposed to coordinate end of life care through establishing a Navigation Centre, shared electronic palliative care patient

record (EPaCCS) and working groups to develop new patient pathways within the region. There is a gap in understanding how such complex, multi-innovative programmes are implemented by partnerships.

Aim

This study draws on implementation theory to explore the implementation process of a project delivered by a partnership, specifically the shape of the process, what influenced the shape and what implementation outcomes were achieved.

Design and Methods

The study adopted a pragmatic design using primarily qualitative methods including: a review of 112 documents, 16 observations of meetings and Navigation Centre operations, 17 interviews with stakeholders and project management, one focus group with Navigation Centre call handlers, and a total of 93 fortnightly sequential telephone interviews carried out with 23 carers. Methods were selected to collect data from both the provider and service user point of view to understand all sides of the implementation process. A thematic analysis was conducted using the Framework approach which allows for the data to be reduced and sifted to find linkages and patterns in the data by both data source and theme as part of an inductive and deductive analytical process.

Key findings

The implementation of the Project did not proceed smoothly and instead was challenged by a number of issues which meant that at the end of the two-year period, few project goals had been achieved. The project included tasks and innovations which were at various stages of development; some were fully formed and therefore just needed to be adopted and implemented, whereas others needed to be developed through partnership work during the course of the project. These development activities were particularly difficult given the sporadic engagement by a number of partners, particularly from primary and social care. There were a number of barriers to the overall implementation which included: the NHS reforms which created uncertainty in the system, lack of robust project management, interconnected project elements which meant lack of progress in one area affect progress in another, and competition from similar innovations which meant that the Project did not offer truly novel innovations. Facilitating factors within the Project included: leadership by the Hospice as experts in end of life care, innovations providing a benefit to people's work, individual motivation to improve end of life

care, and sole ownership and management over the implementation process. Each of the three aspects of the project – the Navigation Centre, EPaCCS, and partnership – will be summarised separately, followed by conclusions and recommendations for future work.

Navigation Centre

The Hospice had sole responsibility of the implementation of the Navigation Centre and by the end of the Project, it had been set up largely as envisaged though with a few changes that were determined based on a process of learning during implementation. However, the Navigation Centre was primarily used by hospice patients rather than all patients at the end of life as had been envisaged. Patients and carers called the Navigation Centre for a variety of reasons including: advice for pain or symptoms, faster access to a visit from a district nurse out-of-hours, and emotional support. The Navigation Centre was also used by professionals, particularly the ambulance service, which used it for quick access to information.

Benefits and strengths of the service:

- Bespoke service understanding of the multifaceted needs of end of life patients.
- Used as a source of information to treat patients in accordance with their wishes in a timely manner.

One night the patient had some considerable pain so the carer called the [Navigation Centre] as she didn't know what to do. The nurse called her back, then had to call the doctor for advice and then called her back again. So it was approximately 3 phone calls over a couple hours. They gave her advice which she found reassuring. It seems that if she had called the 111 then they would have sent a doctor out who wouldn't have known the patient and he would have given him an injection which she could do herself.

(Carer telephone interview P27-3)

Weaknesses of the service:

- Primarily supported hospice patients and not the whole of the end of life population, though it is unclear what unmet need exists among the wider population.
- One of a number of resources used by end of life patients and therefore had some duplication in service. Other services fulfilling similar functions as the Navigation Centre include 111 and Samaritans.
- Unable to directly send a clinician into patients' homes.

Electronic Palliative Care Coordination System (EPaCCS)

The Blue System was selected from three options at the start of the project because it best met the new criteria set out in national policy for electronic palliative care coordination systems (EPaCCS). The Blue System was first implemented in the Hospice and then rolled out to GP practices. However, uptake among GP practices was slow with only 24 of 88 practices adopting the system because of competition from the Red System which was already in use in most GP practices. Even in those practices which had adopted the system, only two patients had been added to the system by GPs during the project period. Ultimately, the decision was made towards the end of the Project to abandon the Blue System and switch to the Red System.

Benefits and strengths of the Blue System EPaCCS

- Comprehensive in meeting the criteria for an EPaCCS.
- Web-based tool for easy access by any care provider.
- Contained information and documentation necessary for caring for patients at home.

During this visit the patient showed [the paramedics] a letter which the carer says is on the [Blue System] to say that she wants to be treated at home, so they respected this and seemed to have done what was needed at home. (Carer telephone interview P07-4)

Weaknesses of the system

- An additional system which professionals had to learn how to use and maintain; it did not replace the Red System.
- Served a relatively small number of patients and therefore not used frequently.
- Alternate Red System incentivised in GP practices through Service Level Agreements thus creating competition.

Partnership approach and work groups

The Project was based on a partnership arrangement in which each partner organisation nominated representatives to participate in the various project groups and work together to solve some of the long-standing issues within the region. The inclusion of the full range of health and social care providers in the area proved to be the Project's biggest strength and weakness. Stakeholders felt that bringing everyone together for improving end of life care was a great success, yet this reliance on cooperation within the whole system proved a tremendous hurdle once the Health and Social Care Act (2012) was introduced. The Act (2012) introduced major reforms which particularly affected GPs and social care and therefore this led to a lack of engagement in the Project as they worked to adapt to the new system. The reforms played a

large part in influencing the lack of success in achieving the Project aims, yet bringing the partners together was seen as a useful learning opportunity by those who did participate.

Strengths of the partnership process

- Learning about the process and practices in other organisations.
- Agreement among partners of the importance of end of life issues.

*I think [the Project] also sort of just raised everybody's awareness of end of life issues and actually did engender some sort of joint working around end of life issues.
(Interview with Stakeholder 02)*

Weaknesses of the partnership process

- Lack of engagement by any one partner slowed the decision making process and overall project progress.
- Events external to the project easily threatened the Project which was a voluntary activity.
- Variable working practices and priorities among partner organisations were hard to align.

Conclusions and recommendation

The unfortunate timing of the NHS reforms coupled with other challenges inherent in implementing a complex change programme meant that the Project did not achieve the goals set out. However, there were a number of successes, including the establishment of the Navigation Centre and partial adoption of an EPaCCS. Other successes achieved through the partnership approach include agreement among partners of the needs of end of life patients and their families, and greater understanding of the roles that other providers play in providing end of life care and the challenges they face. The Project was seen as only the beginning of the process of working towards coordinated end of life care within the region. There are a number of recommendations and lessons learned identified for future projects such as this which were identified from this study:

- Project successes, even small ones, should be promoted within the project team to sustain engagement and encourage participation.
- More time is needed to implement such complex projects and to produce impacts on patient and family experiences.
- There are factors which seem to make projects resilient when faced with challenges, such as individual motivation and flexibility in the process, which should be identified as there are always likely to be events external to the project which threaten sustainability.

- The patient and family voice is important to listen to during the implementation process, particularly when service implementation is dependent on the back and forth interaction with service users, such as in the case of the Navigation Centre.

Summary of findings from the evaluation of the Navigation Centre

July 2016

Prepared by Laura Holdsworth

Background

It is perceived that patients in the last few months of life, with incurable, irreversible illness require access to a range of services which are often poorly coordinated. This results in duplication of care, repetition of information and gaps in service provision for patients and family carers, which are particularly evident out-of-hours. Health policy in England has increasingly promoted coordinated and integrated health and social care services delivered through partnerships with public, private and voluntary sector organisations. End of life care would benefit from improved coordination to enable patients to achieve their wishes.

A Project was initiated by a partnership of regional health and social care providers at the end of 2011 to address the aims of the National End of Life Care Programme. The main aims of the Project were to improve the end of life experience of patients, reduce inpatient admissions to hospital for dying patients and reduce service duplication. The Project proposed to coordinate end of life care through establishing a Navigation Centre which could be used by patients and their families, and care providers.

Description of the Navigation Centre

The Navigation Centre is a 24-hour, 7 days a week telephone advisory and navigating service run by the Hospice. It is staffed by trained call handlers who provide advice directly to callers where possible, or connects callers to the appropriate service to meet their needs. Most calls requiring clinical advice are forwarded to hospice clinical nurse specialists or consultants. In many cases, the care navigators take on some of the administrative tasks in phoning other services to arrange support. Users of the service include patients, family carers and health and social care. This type of service is facilitative and personal, and also comprehensive in providing support to both service users and professionals. Its dual role is uncommon among navigating services which are generally targeted at either service users or professionals, but not usually both.

Aim of the study and methods

This study aimed to understand how the Navigation Centre was implemented, how it was used by patients and their families, and what other services patients and their families used. To do this, we carried out fortnightly telephone interviews with a nominated family carer for up to six interviews. We used a structured data collection tool called the Ambulatory and Home Care Record to ask carers about what services patients had used in the last two weeks and about their experience of these services. Carers were given the opportunity to describe their experience with services in as much or as little detail as they wished. In total, 23 carers were interviewed for between 1 and 6 interviews for a total of 93 interviews. Most carers were women (16), the spouse of the patient (17) and the average age was 63. Almost all patients had cancer (20) and lived with the carer (21).

In addition to interviewing carers, we carried out a focus group with four of the Navigation Centre call handlers to understand their perspective of providing the service and carried out observations of the Navigation Centre operations at four different time points to see how it worked in practice.

Key findings

The Navigation Centre was set up within one of the Hospice sites and was opened initially to all 600 hospice patients from June 2012 with the aim of eventually being open to all life limited patients. The Navigation Centre was set up in stages, first with training call handlers and then developing the IT and call system to help manage oncoming calls. One of the major challenges that faced the Navigation Centre during the first year was the high volume of inappropriate calls, such as calls for charity shop information or Hospice staff using it in lieu of the telephone switchboard. This was a major risk to the operation of the Navigation Centre because there was concern that patients and care providers would be unable to get through for advice. It took nearly a year for the phone system to be upgraded so as to weed out inappropriate calls.

Of the 23 carers who participated in a telephone interview, eight carers had called the Navigation Centre at least once. Common reasons for calling the Navigation Centre included: advice for pain or symptoms, help with arranging access to a visit from a district nurse or doctor out of hours, to relay information to the hospice, and to have someone to talk to for emotional support.

[Carer] called the [Navigation Centre] to tell them about a nosebleed the patient had. The call handler said she would pass message onto the hospital who would then contact the carer if necessary. (Carer telephone interview P02-1)

Despite some initial trouble with getting through to the Navigation Centre because of the high

One night the patient had some considerable pain so the carer called the hospice as she didn't know what to do. The nurse called her back, then had to call the doctor for advice and then called her back again. [...]. They gave her advice which she found reassuring. It seems that if she had called the 111 then they would have sent a doctor out who wouldn't have known the patient and he would have given him an injection which she could do herself. (Carer telephone interview P27-3)

volume of calls, the experience from many carers was that the Navigation Centre was a useful and acceptable service. However, there were also a number of carers who were entirely unaware of the Navigation Centre's existence which suggests that it was not well publicized to patients and their families.

At the same time that the Navigation Centre was being established, the new NHS 111 service was being implemented nationally to deal with urgent, but not life-threatening medical help and advice. Carers used both services depending on their needs and how quickly they wanted a response. Carers seemed to use whichever service they felt would get them the fastest access to what they needed.

The Navigation Centre aimed to be a single point of access for all end of life patients, however it appears to have primarily only supported hospice patients as the call handlers reported that they rarely received a call from a non-hospice patient.

In addition to serving patients and their families, the Navigation Centre also supported care

providers and indeed over 50% of the phone calls were to or from care providers. Of the various care providers in the area, the ambulance service reported that the Navigation Centre was particularly useful because they could get information quickly about the patient's care preferences when they were called out to a patient who was on the palliative care register.

Carer had phoned the [Navigation Centre] a few times during the patient's illness. Primarily he phoned out-of-hours as a way to enable quicker access to the district nursing service. The [call handler] would phone the district nurses who would then come out [...]. He said this worked well, but only used it out-of-hours as during hours he would have called the surgery directly. (Carer telephone interview P10-3)

Conclusions

Overall, the Navigation Centre seemed to be well-received by those carers who did use it and was of particular use to the ambulance service. The service provided a number of benefits to its users, but also had a few weaknesses.

Benefits and strengths of the service:

- Bespoke, personal service understanding of the many complex needs of life limited patients.
- Used by care professionals as a source of information to treat patients in accordance with their wishes in a timely manner.

Weaknesses of the service:

- Primarily supported hospice patients and not all patients at the end of life in the area, though it is unclear what unmet need exists among the wider population.
- One of a number of resources used by end of life patients and therefore had some duplication in service. Other services fulfilling similar functions as the Navigation Centre include 111 and Samaritans.
- Unable to directly send a clinician into patients' homes, but instead had to work with other services to arrange a home visit.

Appendix 8: Participant information sheets and consent forms

Order of documents in Appendix 8:

1. Cover letter to carers for telephone interviews
2. Participant Information sheet for carer telephone interviews
3. Consent form for telephone interviews
4. Participant information sheet for stakeholder interviews
5. Participant information sheet for focus group
6. Consent form for interviews and focus group

Cover letter to carers for telephone interviews

Date

Ref: [The Project] – A study to evaluate coordinated care

Dear [CARER],

I would like to invite you to participate in a study to look at the care that people with more severe or ongoing conditions receive and the experience of their carers in supporting them. I have written to you because you have been named by [PATIENT] as his/her carer. A carer is someone who provides support to a family member or friend who may be ill, frail, or disabled. I understand that some carers may provide very minimal support, such as help with shopping or transportation, while others may be providing 24 hour care. I am interested in the full range of carer experiences, even if at this time you may be doing very little physically to support [PATIENT].

The aim of the study is to understand what services patients use and when, and the experience of their carers in supporting them. It is being carried out by researchers at the Universities of Kent and Surrey. The results will be of benefit to the NHS and other service providers in helping to understand how patients manage their conditions and the role their families and friends play in helping them. It will also help to identify any gaps in service provision so that services can be improved to better meet the needs of patients and their families.

If you are interested in participating, please read the enclosed information sheet. I will follow this letter up in about a week's time with a phone call to see that you've received the letter and answer any questions you might have.

Sincerely,

Laura Holdsworth

[THE PROJECT] – INFORMATION SHEET (07/03/2013)**Why have I been chosen?**

You have been chosen for this study because you have been identified as the main carer of a patient with an ongoing condition and we wish to know more about the support you provide. For the purpose of this evaluation, this letter refers to you as a 'carer' and [PATIENT] as 'the patient'.

We want to understand more about the services that patients and their carers need and use at this point in the patient's illness. There are a wide range of services available to patients, but they are not always organised as efficiently as they could be and sometimes carers end up doing more than they can manage because of gaps in services provided.

Do I have to take part?

It is entirely up to you whether or not to take part and your decision to participate will not affect the care the patient receives now or in the future. If you decide to take part but change your mind, you are free to do so and withdraw from the study at any time. The outcome from this study will probably not be of direct benefit to you, but will hopefully benefit patients and their families in the future.

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

If you decide to take part, please sign the consent form included and return it in the envelope provided. You will be asked to participate in a series of telephone interviews. You will be interviewed on the telephone every two weeks at a time convenient for you and each interview will last about 10-15 minutes. All telephone calls will be made by the researcher, so you should not incur any costs if you participate. With your permission, the telephone interview will be recorded for reference.

During the telephone interview you will be asked a number of questions. The first interview will include some additional background questions about yourself and the patient you care for, but each follow-up interview will likely take less time as you get used to the questions being asked.

The questions will be focused on health and social care services used by the patient in the previous two weeks, and in particular your role in helping the patient to access these services. You'll also be asked about how much time you or family and friends have spent looking after the patient, whether you've paid anything out of pocket towards their care, and a little bit about your personal experience in caring for the patient.

You will be called at most every two weeks for an interview for 3 months at which point you can decide whether you wish to continue to participate or stop. Your participation is completely voluntary and you are free to withdraw from the telephone interview at any time.

If after an interview you would like additional support you can contact [NAME] who is [ROLE] on [TELEPHONE].

Will my taking part in this study be kept confidential?

Any information collected about you and the patient you care for will be strictly confidential. Identifiable information about you will be removed from any data you give before it is analysed by other members of the research team. Once the study has finished, all personal data collected about you as well as the recorded telephone calls will be destroyed, and you will not be identifiable in any written report.

How long will the study run for?

The study will run until December 2013.

Will the findings be published?

Findings from this study will be shared with the NHS and other local health and social care services. Reports may also be published online or as journal articles in academic and practice journals.

Who do I contact for further information?

If you have any questions please contact the researcher, Laura Holdsworth at: Centre for Health Services Studies, George Allen Wing, Cornwallis Building, University of Kent, Canterbury, CT2 7NF

Tel: 01227 824928

E-mail: L.M.Holdsworth@kent.ac.uk

Consent form for telephone interviews

Consent Form – Telephone interviews

Title of Project: [The Project]

Name of Researcher: Laura Holdsworth

Please initial each box and then sign at the bottom.

Initial box

1. I confirm that I have read and understand the information sheet dated [date] for the above evaluation. 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, without my legal rights being affected.

3. I agree to have the telephone interview audio recorded for reference.

4. I understand that data collected in this study will be used in published reports.

5. I agree to take part in the above evaluation.

Name

Date

Signature

Return in the envelope provided: Laura Holdsworth, Centre for Health Services Studies,
University of Kent, Canterbury, CT2 7NF

[The Project] Evaluation

Participant information sheet for stakeholder interviews

Interview – [Executive Project Board/ Project Delivery Group Stakeholders]

As you are aware, there is an ongoing evaluation of [the Project] and the navigation centre being carried out by Laura Holdsworth, a researcher from the University of Kent. The aim of the study is to evaluate how [the Project] and the navigation centre impact on: the patient and carer experience of care at the end of life, the professional roles and organisational structures involved in its implementation, and health and social care service use costs. In order to capture the service provider perspective, the researcher observed monthly Project Delivery Group meetings and the Executive Project Board meetings to understand the processes that go into the implementation of [the Project]. Now that the 2 year project period has finished I want to find out your views on this process.

Why have I been chosen?

You have been selected to participate in the evaluation because you were a member of the [Executive Project Board/ Project Delivery Group].

Why do you want to collect information from me?

As a member of the [Executive Project Board/ Project Delivery Group], you were instrumental in determining the implementation of [the Project] and the navigation centre and so can comment on this process. Additionally, I am interested in your views as to how the service has impacted on the organisation that you represent.

Do I have to take part?

It is entirely up to you whether or not to take part and your decision to participate will not affect your employment. If you decide to take part but change your mind, you are free to do so and withdraw from the interview at any time. The outcome from this evaluation will be of benefit to [the Project] group and to those organisations involved in its implementation.

What will happen to me if I do take part?

If you decide to take part, you will be asked to participate in an interview, either face to face or on the telephone, whichever is more convenient. You will be asked to sign a consent form prior to the interview. The interview will last up to an hour and will be audio recorded with your permission. During the interview you will be asked to discuss your views on [the Project] implementation process and how it has impacted on care delivered by your organisation.

Will my taking part in this study be kept confidential?

All efforts will be made to keep information collected about you confidential and personal information about you will be removed from the transcript. However, as you represent a particular viewpoint, your comments may be identified as coming from a particular discipline of care or organisation. As it may be possible to identify you as a participant in this way, you will receive a copy of any reports in which verbatim quotes or findings may identify you as the source to approve before publication.

Will the findings be published?

Findings from this evaluation will be shared internally within [the Project] group and with local health and social care providers. Study reports may also be published online or as journal articles in academic and practice journals. Verbatim quotes may be used in written reports and publications, though your name and all personal information will be removed.

Who do I contact for further information?

If you have any questions please contact Laura Holdsworth at:

Centre for Health Services Studies, George Allen Wing, Cornwallis Building, University of Kent,
Canterbury, CT2 7NF

Tel: 01227 824928

E-mail: L.M.Holdsworth@kent.ac.uk

Participant information sheet for focus group

[The Project] Evaluation

Focus group – Navigation centre care navigators

As you may be aware, there is an ongoing evaluation of [the Project] and navigation centre being carried out by Laura Holdsworth, a researcher from the University of Kent. The aim of the study is to evaluate how [the Project] and the navigation centre impact on: the patient and carer experience of care at the end of life, the professional roles and organisational changes involved in its implementation, and health and social care service use costs. An important aspect of the evaluation is to find out who uses the navigation centre and why, and how the centre responds to patients' and carers' needs.

Why have I been chosen?

You have been selected to participate in the evaluation because you are a navigation centre care navigator.

Why do you want to collect information from me?

As a care navigator, you are the primary point of contact for patients, carers and service providers. You have knowledge about how the centre operates, why patients and carers contact the centre, what it's like to coordinate care between service providers and what challenges are faced by the navigation centre.

Do I have to take part?

It is entirely up to you whether or not to take part and your decision to participate will not affect your employment. If you decide to take part but change your mind, you are free to do so and withdraw from the focus group at any time. The outcome from this evaluation will be of benefit to [the Project] and to those organisations involved in its implementation.

What will happen to me if I do take part?

If you decide to take part, you will be asked to participate in a focus group with other care navigators. The focus group will be held within the navigation call centre on [date TBD] to allow those on duty to participate. For those who are not working during this time, you will be compensated for attending outside of normal working hours. If you are unable to attend the focus group during that time, but still wish to contribute to the study, it may be possible to arrange a one to one interview at a later date; please speak to Laura Holdsworth to arrange an

interview. At the start of the focus group session you will be asked to sign a consent form. The focus group will last approximately 90 minutes and will be audio recorded with your permission. In the focus group you will be asked about what type of calls you get, how you coordinate patient's care, and what challenges you face in your work.

Will my taking part in this study be kept confidential?

Any information collected about you will be kept confidential. Personal information will be removed from transcripts and you will not be identifiable in any written report.

Will the findings be published?

Findings from this evaluation will be shared internally within [the Project] and with local health and social care providers. Study reports may also be published online or as journal articles in academic and practice journals. Verbatim quotes may be used in written reports and publications, though your name and all personal information will be removed.

Who do I contact for further information?

If you have any questions please contact Laura Holdsworth at:

Centre for Health Services Studies, George Allen Wing, Cornwallis Building, University of Kent,
Canterbury, CT2 7NF

Tel: 01227 824928

E-mail: L.M.Holdsworth@kent.ac.uk

Consent form for interviews and focus group

Title of Project: [The Project]

Name of Researcher: Laura Holdsworth

Please initial each box and then sign at the bottom.

Initial box

1. I confirm that I have read and understand the information sheet dated [date] for the above evaluation. 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, without my legal rights being affected.

3. I agree to have the interview audio recorded.

4. I understand that anonymised verbatim quotes may be used in published reports.

5. I agree to take part in the above evaluation.

Name

Date

Signature

Appendix 9: Data list

Document review (Doc)

Documents are named using three codes following the method group code 'Doc':

1. Sorted according to type (audit, meeting, operational, output, or reference)
2. Time collected during study: prior and post indicates whether it was produced prior to the Project period or after. Documents produced during the Project period are divided into quarters whereby the first number indicates the year (e.g. 20-12, 13 or 14) and the second part indicates the quarter of that year (e.g. Q1, Q2, Q3, Q4).
3. Documents are then numbered to give a unique identifier.

Audit

Doc Audit 13Q2-01	Doc Audit post-01
Doc Audit 13Q3-01	Doc Audit post-02

Meetings

Doc Meeting prior-01	Doc Meeting 12Q2-05	Doc Meeting 12Q3-03
Doc Meeting prior-02	Doc Meeting 12Q2-06	Doc Meeting 12Q3-04
Doc Meeting prior-03	Doc Meeting 12Q2-07	Doc Meeting 12Q3-05
Doc Meeting prior-04	Doc Meeting 12Q2-08	Doc Meeting 12Q4-01
Doc Meeting prior-05	Doc Meeting 12Q2-09	Doc Meeting 12Q4-02
Doc Meeting prior-06	Doc Meeting 12Q2-10	Doc Meeting 13Q1-01
Doc Meeting prior-07	Doc Meeting 12Q2-11	Doc Meeting 13Q1-02
Doc Meeting 12Q2-01	Doc Meeting 12Q2-12	Doc Meeting 13Q1-03
Doc Meeting 12Q2-02	Doc Meeting 12Q2-13	Doc Meeting 13Q2-01
Doc Meeting 12Q2-03	Doc Meeting 12Q3-01	Doc Meeting 13Q2-02
Doc Meeting 12Q2-04	Doc Meeting 12Q3-02	

Monitoring

Doc Monitoring 12Q2-01	Doc Monitoring 12Q3-01	Doc Monitoring 12Q4-01
Doc Monitoring 12Q2-02	Doc Monitoring 12Q3-02	Doc Monitoring 13Q2-01
Doc Monitoring 12Q2-03	Doc Monitoring 12Q3-03	

Operational

Doc Operational prior-01	Doc Operational prior-19	Doc Operational 12Q3-03
Doc Operational prior-02	Doc Operational prior-20	Doc Operational 12Q3-04
Doc Operational prior-03	Doc Operational prior-21	Doc Operational 12Q3-05
Doc Operational prior-04	Doc Operational prior-22	Doc Operational 12Q3-06
Doc Operational prior-05	Doc Operational prior-23	Doc Operational 12Q3-07

Doc Operational prior-06	Doc Operational prior-24	Doc Operational 12Q3-08
Doc Operational prior-07	Doc Operational prior-25	Doc Operational 12Q4-01
Doc Operational prior-08	Doc Operational prior-26	Doc Operational 12Q4-02
Doc Operational prior-09	Doc Operational prior-27	Doc Operational 13Q1-01
Doc Operational prior-10	Doc Operational prior-28	Doc Operational 13Q1-02
Doc Operational prior-11	Doc Operational prior-29	Doc Operational 13Q1-03
Doc Operational prior-12	Doc Operational prior-30	Doc Operational 13Q1-04
Doc Operational prior-13	Doc Operational prior-31	Doc Operational 13Q1-05
Doc Operational prior-14	Doc Operational 12Q2-01	Doc Operational 13Q2-01
Doc Operational prior-15	Doc Operational 12Q2-02	Doc Operational 13Q3-01
Doc Operational prior-16	Doc Operational 12Q2-03	Doc Operational 13Q3-02
Doc Operational prior-17	Doc Operational 12Q3-01	Doc Operational 13Q3-03
Doc Operational prior-18	Doc Operational 12Q3-02	Doc Operational 13Q3-04

Outputs

Doc Output prior-01	Doc Output 12Q3-01	Doc Output 12Q4-03
Doc Output prior-02	Doc Output 12Q3-02	Doc Output 12Q4-04
Doc Output prior-03	Doc Output 12Q4-01	Doc Output 13Q1-01
Doc Output 12Q2-01	Doc Output 12Q4-02	Doc Output 13Q1-02

Reference materials

Doc Reference prior-01
Doc Reference post-01

Observations (Obs)

Observations are named using a similar structure to documents where following the method group code 'Obs', the three codes indicate the type/ place of observation, the year and quarter, and the number in the series. Numbers for the EPB and PDG meetings pertain to the chronological order of project meetings as documentation notes were available for all meetings but observations were not, i.e. observations were not conducted for the first two PDG meetings which is why the numbering system starts at 03.

EPB = Executive Project Board meeting

PDG = Project Delivery Group meeting

NC = Navigation Centre site visit

Opp = Opportunistic observation at a supplemental project meeting

In the chapters, text between <> indicates observed behaviour, such as laughing or shaking head.

Executive Project Board meetings

Obs EPB 12Q2-03 (scoping)

Obs EPB 12Q4-04

Obs EPB 13Q1-05

Obs EPB 13Q2-06

Project Delivery Group meetings

Obs PDG 12Q2-03 (scoping)

Obs PDG 12Q3-04

Obs PDG 12Q4-07

Obs PDG 13Q1-08

Obs PDG 13Q1-09

Obs PDG 13Q1-10

Navigation Centre site visits

Obs NC 12Q3-01 (scoping)

Obs NC 13Q1-02

Obs NC 13Q2-03

Obs NC 13Q3-04

Opportunistic observations

Obs Opp 13Q3-01

Obs Opp 13Q3-02

Interviews (Int)

Interviews with the project manager and hospice director are labelled using the same year/quarter format and then are numbered in chronological order.

Interviews with stakeholders were all carried out in 14Q1 and have been numbered in the order that they took place.

Interviews with project management

Int Project Manager 12Q2-01 (scoping)

Int Project Manager 12Q4-02

Int Project Manager 13Q1-03

Int Project Manager 13Q2-04

Int Hospice Director 13Q3-05

Int Hospice Director 13Q3-06

Int Hospice Director 14Q1-07

Interviews with stakeholders

Int Stakeholder 01

Int Stakeholder 02

Int Stakeholder 03

Int Stakeholder 04

Int Stakeholder 05

Int Stakeholder 06

Int Stakeholder 07

Int Stakeholder 08

Int Stakeholder 09

Int Stakeholder 10

Focus group (FG)

The focus group with Navigation Centre care navigators took place during 14Q1 and is labelled in the chapters as 'FG care navigators'.

Telephone interviews

When a reply letter was received from a carer they were allocated a participant number, e.g. P01. The table indicates how many interviews each participant completed.

	Interviews completed
P01 carer telephone interview	4
P02 carer telephone interview	3
P03 carer telephone interview	3
P05 carer telephone interview	1
P06 carer telephone interview	2
P07 carer telephone interview	4
P08 carer telephone interview	6
P09 carer telephone interview	3
P10 carer telephone interview	3
P11 carer telephone interview	6
P12 carer telephone interview	1
P14 carer telephone interview	6
P15 carer telephone interview	6
P17 carer telephone interview	6
P18 carer telephone interview	2
P19 carer telephone interview	4
P21 carer telephone interview	4
P22 carer telephone interview	2
P23 carer telephone interview	4
P24 carer telephone interview	6
P25 carer telephone interview	6
P27 carer telephone interview	6
P28 carer telephone interview	5

Appendix 10: PDG individual attendance

Attendance at Project Delivery Group meetings by individual

Organisation/ role in project	Individual code	Meeting number, month and year of meeting										Total attendance
		1 ¹ Mar 2012	2 May 2012	3 Jun 2012	4 Jul 2012	5 Aug 2012	6 ² Oct 2012	7 Dec 2012	8 Jan 2013	9 Feb 2013	10 Mar 2013	
Project manager	\$		\$	\$	\$	\$		\$	\$	\$	\$	8
Unknown	a				a							1
Voluntary 1	b		b		b			b		b		4
Hospice	c		c									1
Community care	d				d	d						2
Social care	e				e							1
Co-Chair – Workforce Edu. & Training	f		f	f		f			f			4
Data analyst	g		g									1
Voluntary 2	h		h			h				h	h	4
Community care	i					i				i	i	3
Unknown	j			j								1
Chair – Service Users	k		k	k	k			k		k	k	6
Chair – IT & Audit	m		m		m					m	m	4
Chair – Communication	N		N	N	N	N		N	N	N		7
Unknown	n				n							1
Commissioning	O		O	O	O	O		O	O	O		7
Unknown	o							o				1
Hospice	p				p					p		2
Hospital	q										q	1
Chair – Drugs & Pharmacy	r		r		r			r	r			4

Co-Chair – Workforce Edu. & Training	s	s	s					s	3	
Chair – Patient Pathway	t			t	t				2	
Hospice	W	W	W	W		W	W		W	6
Total attendance by meeting		13	7	15	8	8	6	10	7	

¹No attendance list recorded in minutes of the first meeting and no observations

²No minutes recorded for meeting and no observations

Identifiers are unique across EPB and PDG tables 5.3 and 5.4; therefore individuals who attended both meetings have one identifier in all tables.