Independent evaluation of Electronic Palliative Care Coordination Systems (EPaCCS) in England

FINAL REPORT
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This report would not have been possible without the support from a wide range of people in local sites who provided contacts, data and intelligence to inform our findings. They provided this input in amongst the many demands they face, for which we are extremely grateful.
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Executive Summary

This independent evaluation of Electronic Palliative Care Coordination Systems (EPaCCS) was commissioned by Sustainable Improvement, NHS England and has been undertaken by the Whole Systems Partnership (WSP) between November 2015 and March 2016. The project brief was to “examine both the impact of EPaCCS on the experience of care towards and at the end of life, for patients, carers and those who are important to them and staff and look at the body of evidence appropriate to the cost effectiveness of EPaCCS”.

EPaCCS, originally End of Life Care Registers when recognised as being critical to improving quality of care by the National End of Life Care Strategy (2008), are electronic systems designed to support the co-ordination of care delivery once it is recognised that someone is likely to be at or near the last year of life.

The approach to this evaluation has been to review a range of publicly available qualitative and quantitative sources as well as to undertake our own in-depth work in exploring the impact of EPaCCS on the experience of patients, carers and professionals and in seeking to understand impact using EPaCCS extracted data. Bringing these different perspectives to bear enables a rounded view of the actual and potential benefits of EPaCCS, as well as identifying the challenges being faced in its implementation and roll out.

This evaluation tells the story of EPaCCS since the launch of the National End of Life Care Strategy in 2008. It describes the early progress made and then summarises earlier evaluations undertaken by Ipsos MORI and WSP, together with a survey of EPaCCS sites undertaken in 2013 by the National End of Life Care Intelligence Network. Over these years an increasing amount of intelligence about end of life care was gathered, which is also summarised. In particular, the national survey of bereaved people (VOICES) provided a growing body of intelligence about the experience of carers in the last three months of the life of those they had cared for.

However, the commissioning context, and to some extent other organisational change within which services are now being delivered has changed significantly since 2008. Whilst the thrust of these changes is about a greater focus on achieving better outcomes for local populations it takes time to build the necessary relationships and adapt to these changes, some of which are ongoing in the context of the Five Year Forward View. Equally there is variation in the systems and applications being deployed for EPaCCS making it challenging to accurately describe national progress.

In addition, the aging population as well as the financial challenge and choices facing healthcare present their own challenges. This gives even more reason to make high quality coordinated care that provides positive patient experience, facilitated by systems such as EPaCCS, a priority. This is described briefly before setting the scene provided by the Five Year Forward View, in which the continued opportunities for improved end of life care, and the contribution that EPaCCS makes is described.

The evaluation has sought to reflect both national and local intelligence. For part of this exercise we identified five evaluation sites where EPaCCS had been in place for over 2 years, and six non-EPaCCS sites. In other parts of the evaluation we also

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1 On the 1st November NHS England Improving Quality became Sustainable Improvement, NHS England
2 End of Life Care Strategy, Department of Health (2008)
3 End of Life Locality Registers Evaluation, Ipsos MORI Social Research Institute (2011)
6 Five Year Forward View, NHS England (2014)
grouped all CCGs where there had been an EPaCCS before 2013, those with an EPaCCS in 2015, and those self reporting not to have an EPaCCS. By working with Sustainable Improvement, NHS England we were able to identify about two thirds of CCGs in this way, which fell almost equally between these three categories (an EPaCCS Data Consolidation Report based on 155 of 209 CCG’s from across NHS England who voluntarily completed a questionnaire will be finalised by the end of March 2016 and the findings shared widely).

A key part of the evaluation was twelve in-depth interviews with patients, carers and professionals from a variety of settings and agencies. We developed a framework using complementary approaches to capture experience through the stories that people told. The latter was used in two sites (one EPaCCS and one non-EPaCCS) for a wider survey in which a total of 91 people took part. In addition, we sought the insights of six local or national ‘system leaders’ who provided a strategic or leadership perspective on EPaCCS implementation and its actual or potential impact.

For the quantitative element of the evaluation we used three sources of data. First, we compared the Office for National Statistics (ONS)\textsuperscript{7} data on Death in Usual Place of Residence (DiUPR) for the three broad groups of CCGs noted above. Second, we specified a data query for Hospital Episode Statistics that was administered by i5Health, a partner in undertaking this work. This second part of the quantitative review included costs of hospital admissions during the last year of life where the person had then died in hospital. Third, we sought to extract a small number of data items from local EPaCCS, consistent with the current Information Standard (SCCI 1580).

Finally, we reviewed the case for economic benefit, reflecting findings from this evaluation and the wider published literature. When placed in the context of decisions made when someone is approaching the end of life it may be simple to suggest that it is not good for the patient, or efficient for the health care system, to take patients to hospital when they will die in two or three days’ time. However, it is possible that even where hospital admission is not in the best interests of the patient or in keeping with their wishes at the end of life that their proximity to death cannot be estimated with any great accuracy.

The findings from the in-depth interviews identified practice consistent with the purpose for which EPaCCS have been promoted, i.e. cases of early identification of need, reduced duplication, well co-ordinated services where staff feel part of the service wrapped around the patient working together across boundaries and agencies, good support to carers and people getting what they felt they needed in terms of choice. The interviews also identified situations where more work is needed, for example, to further assist in building capability amongst staff to address challenges locally in a context of competing priorities and financial constraints for the benefit of patients, carers, families, and staff using the EPaCCS system. The relational value survey also found indications of overall improved relationships, heightened system integrity and improved processes – both of the latter potentially attributable to the presence of EPaCCS.

System leaders were consistently positive about the improvements they saw as a result of EPaCCS implementation, but recognised the challenges of having better data available locally to inform the local decision making and helping build the evidence around a case for change. This was a reflection of what was found when undertaking the quantitative part of the evaluation where it was found that extracting information from EPaCCS for the purpose of monitoring, evaluation or improvement proved a challenge.

\textsuperscript{7} http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death
There were real challenges in coming to firm conclusions from the **quantitative analysis**. We believe this is due to a combination of EPaCCS specifications not including extraction of data for these purposes, and the fact that there are not as yet sufficient sites addressing the full breadth of potential end of life care needs with comprehensive access for professionals to impact in an observable way in system-wide data such as hospital costs and place of death.

Our **findings** are described at the end of the report but include:

- An indication that patients, carers and professionals in EPaCCS locations suggest that co-ordination of care is both important and increasingly being realised;
- That EPaCCS may bring an additional degree of system integrity;
- That given the evaluation design and methodology there is as yet no conclusive evidence of system-wide impacts on indicators such as deaths in hospital that can be distinguished between EPaCCS and non-EPaCCS sites;
- That there is reason to believe that overall costs associated with EPaCCS and its impact are unlikely to increase and that therefore the case for further development is good;
- That to achieve full benefit from EPaCCS a number of contextual and cultural challenges need continuing emphasis including the building of capability amongst staff, taking full advantage of technological advances and overcoming the complex nature of end of life care service delivery through building strong teams that collaborate effectively across agencies, organisations and professions.

These findings were shared at a National EPaCCS conference in mid-March 2016 and contributed to the rich learning that is emerging from the active and ongoing implementation of systems to support coordination of care at or near the end of life. Over 120 people participated in this event to share learning, which has provided a good platform on which to build.
1 Introduction

In September 2015 NHS Improving Quality (now Sustainable Improvement, NHS England) sought an independent partner to examine both the impact of EPaCCS on the experience of care towards and at the end of life, for patients, carers, those who are important to them and staff and the cost effectiveness of EPaCCS. The Whole Systems Partnership commenced work on this evaluation in November 2015.

In a complex system operating across agencies and with many identified and hidden inter-dependencies we considered it unlikely that any single measure or piece of evidence could ‘prove’ benefit beyond doubt. We also believe that the resource necessary to support ‘a good death’ wherever possible should be measured in a number of different ways, as reflected in the specification for this evaluation. The ‘Realising the Value’ report from NESTA argues that policy makers need new measures to support a wider articulation of value including wellbeing and quality of life and that such measures should capture what is most valued by people using services. This is reflected in the ‘public health approach’ to end of life care which emphasises the role and contribution of local communities at this critical time of life.

Our overall approach to undertaking this evaluation has been to identify different sources of intelligence, whether quantitative or qualitative, that have the potential to demonstrate benefits from the implementation of EPaCCS. Benefit is appropriately expressed in different ways by different stakeholders, and it is often in the balancing of these benefits that discussion will emerge. No one single measure could, or should therefore be used to evidence benefit. This evaluation therefore seeks to explore several avenues of intelligence and to triangulate these in such a way as to get a rich picture of the potential benefits of EPaCCS, even if taken individually the ‘evidence’ could be challenged. This is particularly relevant when, as has become apparent during the evaluation and despite the relatively small number of sites included, the reporting capabilities and the maturity of EPaCCS systems remains variable. This finding reflects previous reviews and is supported by the conversations we have undertaken with system leaders.

There are also few consistent and systematic sources of data that can be used to clearly demonstrate the specific contribution that EPaCCS makes. The VOICES survey is national and consistent but not granular enough to distinguish the impact of local EPaCCS. ONS data on deaths is also national and consistent, although taking into account the relatively limited number of sites that this evaluation was designed to engage with, we have not found EPaCCS to be sufficiently mature in coverage of end of life care needs, interoperability and comprehensive access to

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8 The following contributors made this evaluation possible: Peter Lacey, WSP team leader; Lucy O’Leary, Senior WSP Consultant; Dr Zoe Neill, Senior WSP Consultant; Peter West, Independent Health Economics advisor; Associate Prof Leeds University School of Healthcare Studies, Dr Elaine McNichol; Heather Wheeler, WSP Consultant. We also worked closely with i5Health (www.i5health.com) who generously contributed to the work on hospital costs data. Finally, we met regularly with the client who provided ongoing input and advice. All views expressed are those of the team based on the intelligence gathered.

9 How should we think about value in health and care? NESTA (2015)

10 Palliative care reimagined: a needed shift, Abel J & Kellehear A, BMJ Supportive and Palliative Care (2016)

11 Faith at end of life – A resource for professional, providers and commissioners working in communities, Public Health England (2016)

have sufficient impact on this measure at an aggregate level. Attempts to extract consistent reporting data from local systems has proved difficult due to the lack of reporting capability within what is primarily a tool to aid care delivery, whilst for some the challenge has been expressed in terms of Information Governance, even if some have addressed this satisfactorily.

Of particular importance in any care being provided to people with complex or multiple elements of need, is the nature and quality of the network of support that is created around them, which consists of both technical and human factors and includes carers and the local community as much as it does professionals. We have therefore sought to reflect on the experience of patients, carers and professionals using a relational perspective as a key part of the triangulation that underpins this evaluation. After telling the EPaCCS story since the launch of the National End of Life Care Strategy (2008) this evaluation therefore explores findings from a number of sources, which are then considered together as some key messages are suggested. These include:

- Undertaking in-depth interviews with patients, carers and professionals at the ‘front-line’ of care;
- Listening to a number of ‘system leaders’ about the challenges and benefits of improved co-ordination of care;
- Undertaking a survey that seeks to measure ‘relational value’ (Rv) within a system of care;
- Measuring progress in achieving outcome indicators such as Deaths in Usual Place of Residence (DiUPR);
- Comparing costs in hospital for those where this is their place of death.

In doing this we have sought to establish some degree of continuity with the previous evaluation\(^\text{13}\). Our methodology and key messages are set out clearly in the subsequent sections of this report.

## 2 Background

### 2.1 The National Strategy (2008)\(^\text{14}\)

The *National End of Life Care Strategy* (2008) was a watershed. Its publication was testament to the considerable amount of work before 2008 to raise the profile of this important area of service, but it has subsequently provided a platform to build further. Co-ordination of care was seen to be critical to improving people’s experience of care at, or approaching the end of life. The Strategy set out an expectation that care plans should be made available to all who have a legitimate reason to access them, including out of hours and emergency services. It also recommended the benefits of ‘establishing a central coordinating facility providing a single point of access through which all services can be coordinated.’

Locality-wide registers were seen as fulfilling the co-ordination function. These registers were soon re-labelled as ‘EPaCCS’ (Electronic Palliative Care Coordination Systems). However, over the past 3 years since the evaluation of the early adopter sites for EPaCCS the idea of a separate end of life care electronic co-ordination system is being challenged by opportunities for wider inter-operability and information

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\(^{13}\) Economic Evaluation of the EPaCCS Early Implementer Sites, NHS IQ (2013)

\(^{14}\) End of Life Care Strategy, Department of Health (2008)
sharing for patients with a long term condition, well before the need to recognise end of life care needs. In some instances the presence of EPaCCS has stimulated and encouraged the extension of data sharing and co-ordination systems to those with other complex needs.

2.2 Early progress in EPaCCS implementation

In June 2011 Ipsos MORI published an *Evaluation of End of Life Registers*\(^{15}\) (since re-named EPaCCS). Their evaluation focused on 8 sites, mainly Acute Trusts and PCTs, who had been supported by the Department of Health for 18 months. The evaluation focused on messages from early implementation and particularly the technical and engagement challenges. Their report identified the most likely benefits to patients as being that more would be able to die in their preferred place of choice and that their care would be ‘more seamless’. Quantifying these benefits was outside the scope of this evaluation and no economic analysis was included because of the early stage of implementation.

Since March 2012 organisations contracting for new EPaCCS were required to comply with the *National Information Standard* (SCCl 1580). This Standard has been reviewed periodically with the latest release published in September 2015\(^{16}\) (including a change of names from the ‘End of Life Care Co-ordination; Core Content’ to ‘Palliative Care Co-ordination: Core Content’). The Information Standard specifies the core content to be held in EPaCCS.

In 2012 the National End of Life Care Programme published *EPaCCS, Making the Case for Change*, and commissioned Whole Systems Partnership to undertake an *Economic Evaluation of the Early Adopter Sites*. Eight sites were included, although ‘*none of the evaluation sites had yet achieved the number of people included in EPaCCS that would reflect the 1% of people who are known to die each year.*’ The evaluation then worked with four of the early adopters in some detail, whilst gathering data on all 8 sites for comparative purposes. The aggregate findings from the evaluation did suggest emerging benefits across the evaluation domains of:

- Improved co-ordination – established through a relational audit and focus group discussions;
- Outcomes – measured in terms of death in usual place of residence;
- Economic benefits – arrived at from an analysis of hospital data with a conservative estimate of the potential savings from the implementation of EPaCCS of c."£36,000 per 200,000 population;"
- Examples of EPaCCS being extended beyond the ‘traditional’ focus on patients with cancer.

The evaluation recognised risks in generalising from a small sample but provided sufficient insights to support the case for further investment in EPaCCS at a local level. The 4 sites studied in detail did not all demonstrate these benefits, bringing a note of caution to the evaluation findings. One showed none of the benefits, although was at a very early pilot stage; one indicated that early progress was not being sustained and a third had made good progress but from a very low base. The site that had made the most progress was characterised by the following factors:

\(^{15}\) End of Life Locality Registers Evaluation, Ipsos MORI Social Research Institute (2011)

\(^{16}\) Palliative Care Co-ordination: Core Content, SCCI1580, Health and Social Care Information Centre (2015)
• Advance Care Planning had been made part of mandatory training\textsuperscript{17};
• The system had been rolled out to care homes where training had been prioritised;
• There was automatic flagging to 111, 999 and OOH for all 24/7 services;
• End of Life Care facilitator roles had been put in place in acute hospitals;
• Extensive ongoing training through a ‘train the trainer’ programme had been put in place.

2.3 One Chance to Get it Right\textsuperscript{18}

In July 2013 an independent review of the Liverpool Care Pathway (LCP)\textsuperscript{19} drew attention to instances where this protocol, originally developed in hospice care, was being applied inappropriately and in a ‘tick box’ manner. The LCP has therefore subsequently been phased out and ‘One Chance to Get it Right’ set out the priorities for care when a person is expected to die within the next few days or hours. It stresses the need for clear communication between professionals, patients and their carers, that the patient is fully involved in decisions, that the carer is also involved in decisions to the extent the patient wishes and that the needs of families and others associated with the dying person are respected and met wherever possible.

In a follow-up document\textsuperscript{20} it was recognised that progress was being made in that both the CQC\textsuperscript{21} and professional regulators were embedding the new approach in their inspection regime and other regulations. It also noted that NHS England and the NHS Improving Quality team were taking a leading role in implementation and that Palliative and End of Life Care Networks had played a central role in responding to the recommendations. Health Education England and the National Institute for Health Research had also taken action to see end of life care needs feature more highly in their programmes of work.

In addition the NICE quality standard was updated in October 2013\textsuperscript{22} following the independent review of the use of the Liverpool Care Pathway reflecting the fact that this would be phased out. The quality standard was originally published in November 2011 and covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life.

2.4 National survey of EPaCCS 2013

Building on the evaluation of the EPaCCS pilots done by WSP in 2012, in August 2013 the National End of Life Care Intelligence Network\textsuperscript{23} (NEoLCIN) conducted a...

\textsuperscript{17} Evidence of the benefits of ACP can be seen in the literature such as ‘The impact of advance care planning of place of death, a hospice retrospective cohort study’, Abel J et al. BMJ Supportive & Palliative Care (2013)

\textsuperscript{18} One Chance to Get it Right: Improving people’s experience of care in the last few days and hours of life. Leadership Alliance for the Care of Dying People (2014)

\textsuperscript{19} More Care, Less Pathway: A review of the Liverpool Care Pathway (2013)

\textsuperscript{20} One Chance to Get it Right: One Year On Report. (2015)

\textsuperscript{21} For the End of Life ‘Core Service Inspection framework for NHS acute hospitals, published in January 2016, go to:


\textsuperscript{22} https://www.nice.org.uk/guidance/QS13

\textsuperscript{23} The National End of Life Care Intelligence Network (NEoLCIN) is one of five health intelligence networks hosted by Public Health England. NEoLCIN aims to work with a wide range of partners and
survey to gather information about EPaCCS implementation and impact. A further aim of this survey was to ascertain the level of compliance with the national core Information Standard, ISB1580 (now SCCI 1580). The survey published by NEoLCIN partners on 28 April 2013\textsuperscript{24} reported usable returns representing 188 (89\%) of CCGs and identified 64 CCGs (30\%) with operational EPaCCS systems with a further 111 (53\%) that had started planning.

Of the 64 CCGs with operational systems there were varying numbers able to report on activity and outcomes. 49 CCGs could provide information on the numbers of patients registered on EPaCCS. 11 CCGs (7 systems) could provide information on deaths:

- All 7 of these systems could say how many people had their preferred place of death recorded;
- 6 of these systems could identify the numbers who had achieved their preferred place of death (although for one it was higher than the number who had their preferred place of death recorded);
- 5 of these systems could report on where people had died across the main locations.

The survey suggested that fewer people died in hospital and more at home than the national average, although the number of sites able to provide data was small. Benefits reported in the survey included improved communication, ease of information sharing between professionals and support to carers, clinicians and out of hours’ services to help make appropriate decisions about a person’s care. For those at the early stages of planning, the benefits of bringing different agencies together and highlighting needs at the end of life was seen as important.

2.5 National EPaCCS Baseline Review 2015/16

In recognition of the increasing complexity of the agenda relating to delivery of the NHS Five Year Forward View\textsuperscript{25} and its underpinning digital agenda\textsuperscript{26}, in July 2015 NHS IQ, now Sustainable Improvement, NHS England, began a major review of information relating to end of life care and EPaCCS implementation. The examination of the existing information culminated with a major data consolidation project.

Building on the data consolidation project, in September 2015 NHS IQ began a baseline review of EPaCCS systems in England with a survey developed for the purpose of gaining answers to three key questions:

- Where and what are the EPaCCS systems currently in use in England?
- Are the EPaCCS systems in England compliant with the core Information Standard SCCI 1580\textsuperscript{27}?
- Are the EPaCCS systems in England compliant with the EPaCCS recommended IT system requirements\textsuperscript{28}?
The primary objective for the baseline review is to provide a current foundation against which to monitor the development of EPaCCS nationally as it progresses towards fulfilling the national digital agenda goal of full implementation and full interoperability by 2020.

The EPaCCS Baseline Review 2015/16 is a technical review and therefore does not cover any patient experience issues or numbers of patients on the systems nor does it seek to specifically report on culture, economic, education or issues around how the system is used except as they may have been raised as specific barriers to implementation by the reporting locality. It has been conducted in parallel to this independent evaluation and will underpin it on a technical level. It is anticipated that the EPaCCS Baseline Review 2015/16 will be published by NHS England in the 2016/17 financial year.

2.6 Emerging intelligence about EoLC

The NEoLCIN published ‘What we know now 2014’ to reflect the improvement in the knowledge and understanding about the care received by people approaching the end of their lives five years on from the National Strategy. Findings of relevance to this evaluation include:

- The importance that public attitudes place on the quality of care at end of life, and that the national VOICES survey showed generally high levels of satisfaction, although these had not changed significantly between 2011 and 2013;
- That a growing proportion of people’s needs toward the end of life will reflect complex conditions and frailty – 55% of all deaths in 2014 occurred in people over the age of 85;
- That the proportion of deaths in hospital fell to below 50% in 2013 (with the latest figures indicating that 52.9% of deaths are now outside of hospital) and that reasons for this included a wide range of factors including things like marital status, medical conditions and the availability of alternatives;
- That people’s preferences for place of care and place of death is predominantly to die at home, but that there is significant variation and that people’s preferences may change over time;
- That information about costs of care at the end of life remain limited;
- That a small, but growing proportion of people with conditions other than cancer are receiving specialist palliative care services at the end of life;
- That the vital role of carers in providing support at the end of life is not always supported to the extent that is needed.

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28 EPaCCS Recommended IT System Requirements
29 What we Know Now, National End of Life Care Intelligence Network (2014)
31 The most recent data for all England on deaths by location (http://www.endolifecare-intelligence.org.uk/data_sources/place_of_death) are for the year to June 2016 (provisional) and indicate: 47.1% deaths in hospital, 22.3% at home, 23.4% in a care home, 5.7% in a hospice and 1.5% elsewhere. Deaths in usual place of residence (home, care homes and religious establishments) was 45.7%.
2.7 National Survey of Bereaved People (VOICES)

The VOICES survey was initiated by NEoLCIN to gather regular insight into the experience of the bereaved concerning the end of life care received by those they cared for. It is administered by the Office for National Statistics and is published as a statistical bulletin. The survey has been run 4 times since 2011 with the 2014 report obtaining views from 21,403 people.

The survey provides a robust statistical set of longitudinal data that can provide both a snap-shot of current views, and historic changes in the experience of bereaved people. The survey reports at all-England level and for regional geographic teams (of which there were 27 in England). 75% of people in 2014 rated the overall quality of end of life care for their relative as being outstanding, excellent or good. This was lowest when death occurred in a hospital (69%) and highest for hospices (83%). However, of particular relevance to this evaluation are two questions asked about coordination of care, where:

- One third (33%, confidence intervals of 32.3% to 34.3%) of people reported that hospital services did not work well with GPs and other services outside the hospital\(^{32}\) – in the first VOICES survey this figure was 32%\(^{33}\).
- 42% (confidence intervals of 41.2% to 43.1%) of people where the patient had spent some or all of the last 3 months of life at home said that services ‘definitely worked well together’\(^{34}\). This was different for various places of death and was answered positively for 55% of deaths at home, 40% of deaths in a hospice, 35% of deaths in hospital and 32% of deaths in a care home. This suggested, according to the survey, that co-ordinated services in the community can enable people to die at home. However, in the first VOICES survey the headline figure for this question was 45%.

2.8 The context today…

Whilst the ambition and rationale for EPaCCS plays a vital part in both NHS England’s objectives\(^{35,36}\) and in the expectations of patients, carers and professionals the immediate context for implementation also plays its part in our ability to realise the intended benefits. During this evaluation we have spoken to a wide range of people involved in both delivering the technology and those seeking to benefit from its use. There are success stories in what we have heard, as well as overwhelming support for the benefits that improved coordination, facilitated by technology, can bring.

However, we have also heard of the many challenges that people have faced. Since the evaluation of the early adopter sites the NHS has been subject to:

- Significant changes in the commissioning landscape for end of life care services and for systems support, which have in some instances delayed EPaCCS implementation or development – building new relationships and finding new ways of doing things takes time;

\(^{32}\) The wording of this question was: “Did the hospital services work well together with his/her GP and other services outside of the hospital?”
\(^{33}\) First National VOICES survey of bereaved people, DoH (2012)
\(^{34}\) The wording of this question was “when he/she was at home in the last three months of life, did the care services services work well together”
\(^{35}\) NHS England Planning Guidance 2016
\(^{36}\) NHS England Actions for End of Life Care, 2014/16
- **Financial constraints** for both services and supporting technology, which means that whilst the economic case for EPaCCS was made, it remains very sensitive to local context;

- Changes in some EPaCCS **hosting arrangements**, for example from PCT to CCG/CSU or through other contract renegotiations has led to challenges, and on occasions a backward step for progressing EPaCCS implementation and therefore potential impact;

- The welcome recognition that EPaCCS systems perform a function within the **wider inter-operability and information sharing** objectives that are being adopted for other client groups, particularly focussed on people with long term conditions.

These statements make no judgement on the merit or necessity of the changes described. However, in general they have mitigated against the type of progress that might have been expected and hoped for in respect of the scale and or timing of EPaCCS benefits being realised.

### 2.9 Looking ahead

#### 2.9.1 NHS Five Year Forward View

The **NHS Five Year Forward View** (FYFV)\(^{37,38}\) sets an ambitious vision for the future – ‘a future that empowers patients, their families and carers to take more control over their own care and treatment: a future that dissolves the artificial divide between family doctors and hospitals, between physical and mental health and between health and social care.’ It heralds the end to fragmentation through the development of new service models. Of particular relevance is the ambition to exploit the information revolution. It commits to a national focus on the key systems that provide the ‘electronic glue’ which enables different parts of the health and care services to work together, whilst leaving other systems to local organisations to decide upon and procure. Amongst the key elements being taken forward by the newly formed National Information Board (NIB) is to ensure ‘fully interoperable electronic health records’, which will be accessible to all those who need it and will support the inclusion of social care data (see 2.9.2).

The routes to securing this future are being led by 50 Vanguards. These lie at the heart of the NHS planning process as illustrated in the latest planning guidance\(^{39}\). To illustrate both the challenge and the opportunities for end of life care services, and in particular improved co-ordination across the system that the FYFV is seeking, we have summarised here the commitments made in the current NHS England Business Plan particularly pertinent to end of life care services:

- To complete information sharing across 111, 999 and hospital acute admission areas to at least a minimum of Summary Care Record, including end of life and advance care plans by March 2016;

- To make good on the NHS' longstanding commitment in the NHS Constitution to offer patients choice and control in mental health, maternity and end of life care;

\(^{37}\) Five Year Forward View, NHS England (2014)

\(^{38}\) Five Year Forward View, Time to Deliver, NHS England (2015)

\(^{39}\) Building the NHS of the Five Year Forward View. NHS England, 2015
• We will improve the information to which people have access and increase the direct control patients have over the care that is provided..... including at the end of life;

• We will improve services for people with complex needs, vulnerable groups and older people living with frailty, including at the end of life.

2.9.2 Personalised Health and Care 2020

The National Information Board has been established to spearhead the implementation of the NHS Five Year Forward View. In its 2020 vision it sets out to achieve a number of key objectives, including:

• To enable citizens to make the right health and care choices;

• To give care professionals and carers access to all the data, information and knowledge they need;

• To make the quality of care transparent;

• To build and sustain public trust.

Within these proposals end of life care is identified as the starting point to give the citizen free and accountable access to their own data, while developing seamless real-time digital data flows between professionals and carers to support individuals’ health and care. This will include the development of a national digital standard for people at the end of their life, building on the success of Coordinate My Care in London.

2.9.3 What’s important to me

This review builds on the survey of bereaved people (VOICES) and presents the case for a ‘national choice offer’ – a simple expression of what should be offered to each individual who needs end of life care. The executive summary of this report includes the following suggested commitments relevant to EPaCCS:

• EPaCCS or equivalent system coverage is increased to 100% of localities to enable the recording and sharing of people’s choices and preferences;

• EPaCCS or equivalent systems are fully accessible to view and update for all involved in the provision of end of life care services;

• That Health Education England, Local Education and Training Boards and Skills for Care should ensure appropriate training in the use of co-ordination systems such as EPaCCS (see footnote reference).

2.9.4 Ambitions for Palliative and End of Life Care

This document, expressing the ambition of a wide group of professional bodies and national charities across health and social care, statutory and voluntary sector, working in the area of palliative and end of life care, describes six ambitions:

• That each person is seen as an individual;

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41 What’s important to me: A review of choice in end of life care. The Choice in End of Life Care Programme Board (2015)
- That each gets fair access to care;
- That each is able to maximise comfort and wellbeing;
- That care is coordinated;
- That all staff are prepared to care;
- That each community is prepared to help.

Themes from this set of ambitions are reflected in this evaluation including the importance of shared records and the qualitative experience of patients and carers.

3 The evaluation landscape

3.1 Selection methodology for sites

In selecting CCGs for inclusion in the evaluation, the objective was to achieve a broadly representative mix from the four geographical NHS England areas and in terms of urban/rural, size, levels of deprivation, health status and outcomes. This was to be achieved from up to 6 sites where EPaCCS had been in place for over 2 years; up to 6 non-EPaCCS sites to act as a control group; and then other EPaCCS sites for which national data could be collected and analysed. These groupings of CCGs could also then be compared against the national backcloth of data. As the project proceeded, some of this ambition and expectation had to be moderated, as will be set out clearly in the rest of the report, which has in turn influenced our ability to reach firm conclusions in some areas.

An initial list of potential sites was developed following engagement with a range of local and regional EPaCCS leads participating in the Public Health England work on development of a national reporting standard for EPaCCS. Sites were initially contacted with an invitation to participate in November 2015, with follow up contacts to identify local leads, share briefing materials, and collect data. Despite some challenges, 11 sites have been able to contribute data and information, 5 EPaCCS and 6 control. In addition, intelligence and other feedback was gathered from other sites in the course of the evaluation and this material is indicated as appropriate in this report. A brief pen-picture of information relevant to end of life care needs is shown for all participating sites in Figure 1.
3.2 The evaluation sites

<table>
<thead>
<tr>
<th>Site</th>
<th>Region</th>
<th>Population (nearest 50,000)</th>
<th>Demographic overview</th>
<th>Cause of death intelligence</th>
<th>Description of EPaCCS</th>
</tr>
</thead>
</table>
| A    | London          | 250,000                     | - Average level of deprivation compared to England  
- Relatively ethnically diverse  
- Age structure similar to England average  
- Urban with major conurbation | Higher proportion of deaths from cancer and lower proportion of deaths from respiratory causes than England average | Co-ordinate My Care InterSystems |
| B    | South West      | 850,000                     | - Lower level of deprivation than England average  
- Relatively low ethnic diversity  
- Older than the England average, and ageing at a higher rate  
- Urban with city and towns | Proportions of deaths from main causes in line with England average | Adastra (web based) |
| C    | East of England | 350,000                     | - Average level of deprivation compared to England but with areas of very high deprivation  
- Relatively low ethnic diversity  
- Urban with significant rural areas | Lower proportion of deaths from respiratory causes than England average but not significantly so | Adastra End of Life Care record |

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**Notes:**

43 Sufficient information is provided here to indicate that the selection of sites did not introduce undue bias to the evaluation. We have committed to retain anonymity with regard to the site locations in this report but have provided Sustainable Improvement, NHS England with the ‘key’ to the sites were further analysis required.

44 2011 population (Source: PHE health profiles, relevant local authority, 2015

45 Sources: PHE Health profiles 2015, JSNA for relevant local authority, ONS urban-rural classification 2015

46 Source; PHE end of life care profiles 2015

47 Source: Sustainable Improvement, NHS England baseline survey, 2015
<table>
<thead>
<tr>
<th>Site</th>
<th>Region</th>
<th>Population (nearest 50,000)</th>
<th>Demographic overview $^{45}$</th>
<th>Cause of death intelligence $^{46}$</th>
<th>Description of EPaCCS $^{47}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>D</td>
<td>North West</td>
<td>250,000</td>
<td>• High level of deprivation compared to England</td>
<td>Higher proportion of deaths from respiratory causes than England average</td>
<td>AllScripts EPR</td>
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<td></td>
<td></td>
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<td>• Higher than average ethnic diversity but lower than London average</td>
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<td>• Younger age structure than the England average</td>
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<td></td>
<td>• Urban with major conurbation</td>
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<tr>
<td>E</td>
<td>London</td>
<td>200,000</td>
<td>• Lower level of deprivation than England</td>
<td>Higher proportion of deaths from cancer and higher proportion of deaths from respiratory causes than England average</td>
<td>Co-ordinate My Care InterSystems</td>
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<td></td>
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<td>• High ethnic diversity</td>
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<td>• Younger age structure than the England average</td>
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<td>• Urban with major conurbation</td>
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**Control sites (no EPaCCS)**

<table>
<thead>
<tr>
<th>Site</th>
<th>Region</th>
<th>Population (nearest 50,000)</th>
<th>Demographic overview</th>
<th>Cause of death intelligence</th>
<th>Description of EPaCCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>South West</td>
<td>550,000</td>
<td>• Lower level of deprivation than England</td>
<td>Significantly higher proportion of deaths from circulatory disease, and significantly lower proportion of deaths from other causes, than England average</td>
<td>N/A</td>
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<td></td>
<td></td>
<td></td>
<td>• Relatively low ethnic diversity</td>
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<td></td>
<td>• Older age structure than the England average, with high levels of inward migration</td>
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<td></td>
<td>• Mainly rural</td>
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<tr>
<td>G</td>
<td>East Midlands</td>
<td>550,000</td>
<td>• Lower level of deprivation than England</td>
<td>Proportions of deaths from main causes in line with England average</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Relatively low ethnic diversity</td>
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<td></td>
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<td></td>
<td>• Older age structure than the England average</td>
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<td></td>
<td></td>
<td></td>
<td>• Urban with significant rural areas</td>
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<tr>
<td>Site</td>
<td>Region</td>
<td>Population (nearest 50,000)</td>
<td>Demographic overview</td>
<td>Cause of death intelligence</td>
<td>Description of EPaCCS</td>
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</tbody>
</table>
| H    | North West | 200,000                     | • Higher level of deprivation than England  
• Relatively low ethnic diversity  
• Age structure similar to England average  
• Urban with major conurbation | Lower proportions of deaths from circulatory disease and cancer, and significantly higher proportion of deaths from respiratory causes than England average | N/A |
| J    | North West | 150,000                     | • Higher level of deprivation than England  
• High ethnic diversity  
• Younger age structure than the England average  
• Urban with major conurbation | Higher proportion of deaths from cancer and significantly lower proportion of deaths from circulatory causes than England average | N/A |
| K    | North West | 150,000                     | • Higher level of deprivation than England  
• High ethnic diversity  
• Younger age structure than the England average  
• Urban with major conurbation | Lower proportion of deaths from circulatory disease, and higher proportion of deaths from respiratory causes than England average | N/A |
| L    | North West | 200,000                     | • Average level of deprivation  
• Relatively low ethnic diversity  
• Age structure similar to England average  
• Urban with city and town | Proportions of deaths from main causes in line with England average | N/A |

**Figure 1:** Evaluation sites
4 Patient/Carer/Professional experience

4.1 In-depth interviews

A qualitative as well as quantitative approach has been taken in the project to triangulate the data. Nuances of participants’ experiences, particularly their feelings, thoughts and opinions about their experiences, provide a richness and depth of insight that quantified intelligence lacks. The purpose of this part of the evaluation has been to identify the benefits and any drawbacks of EPaCCS on patient/carer experience and in particular in the impact of EPaCCS on the experience of care for patients, those who are important to them, carers, staff and volunteers. It has also considered the impact on the co-ordination of care, the effectiveness of team working between agencies, organisations and professionals, and the nature of the care and support that people receive.

For this part of the evaluation we approached those primarily in EPaCCS locations, although we also interviewed two people from non-EPaCCS locations. No attempt has therefore been made to make a judgement about differences in the expression of benefits by patients, carers or professionals between EPaCCS and non-EPaCCS sites. The looked-for benefits have been derived from complementary frameworks that are described below.

4.2 In-Depth Interviews Methodology

4.2.1 Selection and pre-interview preparation

Twelve in-depth interviews were conducted. Interviewees were identified from a variety of sources. Four were suggested by Sustainable Improvement, NHS England, who were lay representatives that have been carers and a person with a life limiting condition. The remaining nine participants were identified by local clinical leads in end of life care.

Participants self-selected as being willing to participate and also being available for interview within the time frame of the project. First contact was by email or by phone if they did not have internet access. Attempts were made to have three to four participants from each of the four geographical NHS England regions, and for there to be a mix of roles (patient, carer, professional) within that number. Attempts were made to include participants where the diagnosis was not cancer. This proved difficult meaning that the sample does lack some elements of diversity, such as ethnicity, the inclusion of younger participants and that only one participant did not have a cancer diagnosis. These reflect limitations in this evaluation.

Participants were sent written information and were able to ask questions of their local lead prior to their interview and were sent a consent form, where possible prior to the interview. All participants have signed a consent form.

4.2.2 Interview Structure

A relational framework was used as a background to the semi-structured interview questions (see Appendix 2). This framework assesses relational value (Rv) and cross-checks features of organisational systems with the human dimension or values that underpin good ‘relational’ care. This approach ensures that even the concept of co-ordination is seen, understood and assessed as a means to an end and not an end in itself. The Rv framework is based on current research undertaken within WSP’s Knowledge Transfer Partnership with Leeds University School of Healthcare
Studies. It has identified an evidence-based set of statements that reflect the presence of integrity, respect, fairness, compassion and trust as attributes of relational value. It then explores these attributes across the components of a system, including technical elements such as EPaCCS.

In addition, a mind map, produced by the Sustainable Improvement, NHS England (Appendix 3) was calibrated against the Relational Framework to ensure the interview questions would be as wide-ranging as possible. Research Ethics Committee approval was not sought for this evaluation as it is an evaluation of an electronic system and therefore is not deemed to be research.

4.2.3 Interview Process

All twelve interviews were conducted by the same researcher. Two interviews were conducted face-to-face. Ten interviews were by phone. All interviews were digitally recorded. The first interview was transcribed verbatim and the remaining interviews were transcribed in note form (see supporting information). Interviews lasted between 35 minutes and 90 minutes.

4.2.4 Demographics of Participants

The demographic of the different groups of participants is shown in the table below. The professionals were two Clinical Nurse Specialists in End of Life Team for nursing homes, three GPs and one Paramedic. In addition:

- 11 participants were white British and one was British Indian;
- Five participants were from North East Essex, three from Sutton, two from London, one from Bristol and one from Sheffield;
- Ten participants were from EPaCCS areas and two from non-EPaCCS areas.

<table>
<thead>
<tr>
<th>Participant:</th>
<th>Group:</th>
<th>Gender:</th>
<th>Age band:</th>
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<tbody>
<tr>
<td></td>
<td>Patient</td>
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<td>Prof.</td>
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Table 1 Demographic for in-depth interview participants
4.2.5 Method of analysis
Interview notes were read and coded using the relational framework and the mind map as a guide. The emergent codes used for the final analysis are based upon what was found in the interview data in addition to the themes already identified prior to the interviews.

Only one of the interviews was transcribed verbatim, so no qualitative analysis software was used. Statistical analysis and interrater reliability has not been included in the qualitative analysis. However, since the interviews and coding were all done by the same researcher, a high level of consistency has been achieved and the recordings have been made available where this seen to be helpful at a future point. The interview recordings, transcripts and interview notes were shared with two other researchers who have challenged and corroborated the analysis findings. This review by two other researchers was intended to mitigate the potential for subjective bias when using only one interviewer.

4.3 Pen-pictures for interviewees

Female carer, 47 (non-EPaCCS): [Name A] has a background in non-clinical NHS work. [Name A] was a carer for her elderly friend, who was diagnosed with heart failure and then with ovarian cancer. [Name A] had previously also cared for her late parents who both died from cancer. Her friend had no other family, so [Name A] was her only carer and she became the main co-ordinator of her care. [Name A] felt that her friend achieved a ‘good death’ in her preferred place of care, her nursing home.

Female carer, 63 (non-EPaCCS): [Name B] was a carer for her daughter who died from breast cancer. “Everything that could go wrong, did go wrong.” She was mis-diagnosed initially. Difficult conversations were avoided by [Name B], family and clinical staff. [Name B] managed the whole of her daughter’s end of life care at her daughter’s home, supported only by [Name B]’s mother. At the end of her tether, [Name B] phoned 999 on a Friday evening, waited 4 hours for an ambulance, and her daughter died in A&E on a busy Friday evening. [Name B] has set up a supportive and palliative care centre, providing services for people with cancer and other life limiting and progressive illness, and their family and or carers.

Recently [Name B]’s mother-in-law died and her death ‘was as beautiful as a death can be. Everything that could be done, was done.’

Female carer, 75 (EPaCCS): [Name C] is the main carer for her husband [Name D] who has multiple myeloma. They were told about the diagnosis on an open hospital ward, with no warning. The ward sister was there for her, even taking her home that evening. A referral to palliative care specialist services was done by the hospital and as a result, hospice respite care has been arranged on a number of occasions. The community palliative care nurses have been very supportive, even helping them get a house cat and this made a significant difference to her [Name D]’s mood. [Name C] has “no complaints at all with the system” and feels they have both been treated very well. The Hospice Phone Service in [County] has responded effectively to their urgent calls on a number of occasions. [Name D] has been reluctant to talk about his preferred place of death but [Name C] has had lots of emotional support surrounding end of life conversations from the community palliative care team.

Male carer 67, (EPaCCS): [Name E] cared for his wife [Name F] who had T-cell Non-Hodgkin’s Lymphoma. It took 6 months to get a diagnosis as she had many negative investigations. They had a “huge network of support”. The hospital, hospice and general practice support they had was great. “The whole system worked well.” [Name F] had one hospital admission where the patient in the next bed had a violent
psychotic episode but otherwise her care was very good. The response of the system to [Name E’s] changing needs was swift. Communication between different staff teams was good. The Hospice Phone Service in [County] responded very promptly on a number of occasions. [Name F] “died where and how she wanted, like a Hollywood death”. [Name E] now works as an ambassador for their local hospice.

Male patient 69, (EPaCCS): [Name H] was found to have stage 4 metastic prostate cancer when he was diagnosed in 2010. He was expecting a diagnosis of emphysema but instead he and his wife were told it was cancer. They were ‘traumatised’ for three days after this conversation. He was treated privately by a urologist and then an oncologist, then transferred to the NHS. He says his initial treatment was ‘second to none.’ His wife, [Name S], his main carer, looked up Macmillan on the ipad in 2012. Until then, “we were on our own with things”. The hospital and their GP never mentioned any other support. Since then, they have had “crucial emotional support” from Macmillan. [Name H]’s experience of hospital care was that he was “handled badly” because “the hospital is under stress.” The hospice care, was by contrast “fantastic”. The hospice arranged his home care who visit three times daily. The Hospice Phone service has responded very quickly to their needs, day or night. [Name H] feels strongly that people should be put onto the EPaCCS register at the time of their cancer diagnosis because he “missed two to three years of support.”

Male patient 49, (EPaCCS): [Name T] had confirmation that he had multiple sclerosis (MS) after many years of being under consultant care for suspected MS. As a result of his voluntary work, he became involved with palliative and End of Life Care. Despite on a number of occasions ‘trying to provoke the conversation with my GP’ he has had the response that he isn’t considered to be in the last year of life. He would like access to the services but ‘it’s closed off’. He has taken it on himself to plan his own funeral and found it ‘empowering’. He has been ‘frustrated with…putting palliative care in the corner.’ He finds it ‘morally wrong’ that not everyone is able to make the plans he has been able to make. One particular nurse assessor ‘understood the whole of me’ and made a real difference to his quality of life. He has been heartened by funeral planning advertisements in the national press. ‘Look guys, take control of your life, you have the last say.’

Clinical Nurse Specialist in End of Life Team for Nursing Homes, 37, (EPaCCS): [Name J] has been a clinical nurse specialist in a pilot project in [City] with 5 residential care homes for a few months. Her role is to provide teaching sessions and peer support to empower nursing home staff to provide end of life care. She helps with recognising dying, symptom management, bereavement and advance care planning. She supports nursing home teams to develop independence in provision of EoLC. She uses the Co-ordinate My Care (CMC) computer system, and because the residential homes do not have an N3 connection, she enters the data for care plans, whilst the residential homes keep a paper copy. She is aware that “EPaCCS is only as good as the information on it and that it has to be updated and reviewed. That takes time that is unavailable for many staff.” She recognises that “identifying people in the last year of life is difficult and that those conversations are taboo. We need instead to think ahead and plan ahead.” [Name J] has found that “EPaCCS gives people confidence in decision-making when the information is shared across services.”

Clinical Nurse Specialist in End of Life Team for Nursing Homes, 46, (EPaCCS): [Name K] has been a clinical nurse specialist who supports nursing homes in [City] for two years. She provides teaching and education for nursing home staff so that they can become independent in their provision of EoLC. Her experience of EPaCCS in a
nursing home situation is that it is “one-dimensional, not live.” It is limited by IT challenges and lack of an N3 connection. Nursing home staff complete a paper proforma, then [Name K] inputs this into the Co-ordinate My Care (CMC) computer system. She has seen how CMC is part of the communication with [City] Ambulance Service and how that has prevented residents being taken to hospital and instead keeping them comfortable, allowing them to die in their preferred place of death. CMC also has a feedback mechanism where care has been inappropriate. Sometimes ambulance crews are so quick to arrive that they haven’t had time to contact their clinical hub. Nursing home staff keep a paper copy for this eventuality. She sees the leadership and culture in a nursing home as being “key to good end of life care.”

Male paramedic, 57, (EPaCCS): [Name L] has been a paramedic for 37 years and is a clinical advisor to the [City] Ambulance Service. A palliative care consultant contacted him in 2006 to ask why, when one of her hospice patients had a clear end of life care plan, did they end up dying on a trolley in a hospital corridor. From this conversation, they worked together to set up a system where details of hospice patients were faxed to the ambulance service and ‘flagged’ on their system as being end of life. Over the years, this developed into Co-ordinate My Care, a shared care record available for everyone to see. He feels that “all of us must have access to EPaCCS.” He sees EPaCCS as supporting patient choice, “although this doesn’t mean absolute choice. Sometimes beds are full; there are no staff, and that’s due to lack of funding and resources.” He is aware of inequity in provision of specialist palliative care services across [City] and the UK. [Name L] feels the care plans on EPaCCS must be up-to-date, reviewed regularly, and accurate.

Female Hospice Clinical Director, 44, (EPaCCS): [Name M] is a GP by background and is now clinical director at a hospice, having been in post for 3 months. She is using an EPaCCS template on the Adastra computer system. EPaCCS can be a good system “but only works if you start with what’s happening in primary care.” It is a “postcode lottery among the practices. Most are functioning but some are not. They don’t have a palliative care register; they can’t recruit GPs.” [Name M] believes the [......] register is fundamental to quality end of life care. She believes in promoting early conversations with patients so that they are known earlier to the hospice. “It is because of the stigma associated with the word hospice. We need to free up GP time for palliative care. More planning means fewer admissions.”

Female General Practitioner, 49, (EPaCCS): [Name Q] is the End of Life Care Lead for her practice. She is the only permanent doctor for 3,000 patients. She keeps track of all the new diagnoses of cancer and chronic disease. The Hospice Phone system provided by the hospice “can be a bit of a battle as they don’t understand GP workload.” Macmillan nurses are ‘hard to get’ and [Name Q] is sometimes “inundated with requests to discuss and review Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) status. With Hospice at Home, it’s now like GPs are the hospice doctors.” [Name Q] considers it a significant event, and is upset if her patients don’t die at home. She feels that the Macmillan nurses are either not reading or do not have access to what she has written on EPaCCS. She feels end of life care is “challenging because of the time needed to do it properly.” Care is good “once the ball gets rolling as all professionals go the extra mile”. [Name Q] feels there is lack of support for GPs and “huge educational need.”

Female General Practitioner, 52, [City] (EPaCCS): [Name R] is the End of Life Care Lead in her practice and the Clinical Commissioning Group EoLC Lead. She promotes the use of EPaCCS and has experience of seeing how when a Co-ordinate My Care record is used, it’s much more likely that someone will achieve their preferred place of care and death. [Name R] sees how EPaCCS encourages the
correct conversations and aids communication between healthcare professionals out of hours, giving authority to staff to get their voice heard. “The lack of time as a GP, and the lack of GPs is a problem. It’s not the time it takes to do the data entry, it’s the correct conversation with the patients, carers and families that take time.” She highlights the recruitment crisis in General Practice: “No-one realises what a critical point general practice is at. This type of work cannot be done by locum GPs who deal with the immediate problem. District nurses are so busy that they cannot find time to discuss patients with us.” [Name R] feels that identification of people at the end of life is the biggest issue. “EPaCCS may struggle because society’s approach is not wanting to talk about it. My aim is instead for the best death possible.” She feels that reviewing and updating the EPaCCS care plan is essential.

4.4 Themes emerging from the interviews

Using the framework outlined in section 2.2 we have organised this material by themes and distinguished between the views of patients and carers on the one hand, and professionals on the other.

4.4.1 Understanding and identification of needs – early entry onto EPaCCS

The patient and carer participants from EPaCCS sites had different experiences of being identified for palliative care, some identified at diagnosis, others after considerable delay. Some professionals are aware that identifying patients to go on EPaCCS is challenging because of the conversations that may be involved. Some professionals feel that EPaCCS can be used for other long term conditions, not just palliative care. Professionals feel that it can be difficult to recognise when someone is dying but that all teams should have palliative care skills.

**Patients and carers commented:**

"After her diagnosis, our GP made a note of [Name F]’s wish to die at home… She was willing to talk about anything and everything…we both knew things were not good.” Male carer, 67, EPaCCS site

“My husband was told after his diagnosis he needed palliative care. The hospice nurse came to see us every 3 or 4 weeks after that and really helped.” Female carer, 75, EPaCCS site

“It was 2 years before we got into the system. My wife looked up Macmillan on her ipad and then we asked our GP to refer us. The hospital and GP never mentioned it. They [Macmillan] opened up doors we didn’t know existed. There should be an automatic referral…at diagnosis…we didn’t think we were entitled to that sort of thing. Once people are in the know, it’s okay. People think the hospice is where you go to die. Crucial help was missed despite us being intelligent people. Our GP should’ve picked this up.” Male patient, 67, EPaCCS site

“I tried to provoke the conversation with my GP, I asked for it. They’re a very good practice but for the last 2-3 years when I’ve tried to raise it, I’ve been told, ‘Well we don’t consider you as being in the last year of life, so we won’t put you on the register.’ I had a UTI and was hospitalised. It was pretty scary and shocking because I was just there for a UTI, then I was being told I needed a nephrostomy to save my life. How can they say I’m not in the last year of life when I could’ve been in the last days? I can’t play the game. It’s as if they’re saying, ‘It’s our football and you’re not playing.’” Male patient, 49, EPaCCS site

**Professionals commented:**

“Identification is the biggest issue. There’s a huge missed population. It’s not seen as a
priority in all quarters...only 50% of practices are engaging with this contract in [City]. We’re hoping that EPaCCS entry will become part of the admissions procedure. We’re more likely to see preferred place of death happening because the right conversations happen at the right time. Our EPaCCS system is about 50% cancer versus non-cancer but that’s not shifting.” Female GP, 52, EPaCCS site

“When people hear palliative care, they think that someone’s dying and that the hospice is involved. Sometimes it’s looking at their understanding of it. People have difficulty recognising dying in the elderly: it’s hard to recognise that earlier. It’s thinking ahead and offering opportunities earlier. Palliative care can be done in all teams and that isn’t recognised...It’s about asking, ‘Is this becoming palliative?’.” Female Clinical Nurse Specialist, 44, EPaCCS site

“We’ve got 26,000 patients on EPaCCS. It goes very well. It’s not just for palliative care, it’s all long-term conditions, for example neuromuscular disorders. These patients call us infrequently as they’re well managed. It can be used for anyone and everyone, for rare conditions like Addisonian crisis, for example. It’s useful to have that information. The correct thing to do may be different from what the paramedics usually do.” Paramedic, 57, EPaCCS site

4.4.2 Information sharing/record keeping

Having a shared record speeds up care (e.g. by highlighting co-morbidities, pain relief medication etc.), prevents re-telling of a complex story, and enables patient choice to influence decision-making.

**Patients and carers commented:**

“With [Name], information, seemed to be in the right place at the right time, so I’m a firm believer in what EPaCCS can achieve. Why can’t there be a set of records so that the notes follow the patient, like maternity notes.” Female carer, 47, non-EPaCCS site

“There’s no generic system for sharing ideas. If there was one really robust system, we could use it across the country. We need more information sharing.” Female carer, 67, non-EPaCCS site

“You haven’t got to go through the whole story because they’ve got your computer record. Just one phone call explains the problem and they get on with it.” Male carer, 67, EPaCCS site

“For me as long as the technology should be an enabler that lets the clinicians do their job effectively, and efficiently communicate information at the time it’s needed most. Patients’ needs should be at the centre.” Male patient, 49, EPaCCS site

**Professionals commented:**

“[City] Ambulance Service know the plan and status of a patient and that has stopped them going to hospital. Or a 111 GP has been called out of hours and rather than the patient going to hospital, the GP makes them comfortable. [EPaCCS] can help by giving people confidence in decision-making, like with the ambulance service. It’s good because it’s shared between GPs, the ambulance service, hospices and community nurses.” Female Clinical Nurse Specialist, 44, EPaCCS site

“Care plans are formulated and then available to everyone. If we’re called, we can access the records and care plan. It gives information about local contacts so you can ask the hospice registrar, ‘What do you want us to do? Things have changed from the plan and the family aren’t coping, now what?’ All of us must have access to EPaCCS. It’s useful to be able to go to the latest care plan. I don’t know the patients or their family dynamics. I need to find this stuff out very quickly. EPaCCS slices through a lot of these difficulties. The care
plans need to be up to date and accurate otherwise it’s useless.” Male paramedic, 57, EPaCCS site

4.4.3 Integrity of system – system co-ordination and response

The patient and carer participants found that the system worked well the majority of the time. It was responsive to their needs in a timely way. With the help of an electronic record, ambulance crews can arrange appropriate admission.

Patients and carers commented:

“[Name] went through multiple assessments for carers, funding, social care and it was very time-consuming for everyone. You’d have thought they might have streamlined it so she didn’t have to do it again and again.” Female carer, 47, non-EPaCCS site

“We called an ambulance and waited 4 hours, even asking the police for help. She went to A&E and died on a busy Friday evening. As a carer I was screaming on the inside. How can they leave people with us as carers? We didn’t know what was available. How do you pull these ideas out of thin air?” Female carer, 67, non-EPaCCS site

“He goes to see Dr [Name] the oncologist every 2 months and we get a letter back every time. The hospice oversees B’s care. We have open access to the specialist nurses. They come out quicker if it’s palliative care. I’ve no complaints at all with the system…I phoned the hospice phone service and she came round later that day to see us.” Female carer, 75, EPaCCS site

“I phoned in the middle of the night and within 10 minutes there was a 999 ambulance arriving…Similarly I phoned at 2am because her mattress blew and she was in considerable pain. Within 20 minutes the district nurse had arrived and upped her pain control. Within 2 hours an engineer had arrived and fixed the mattress…All of the work went on in the background behind me, it all just happened. One day I phoned the GP at 9am and 45 minutes later I was at the pharmacy collecting some new medication. Once [Name F]’s infusion pump went wrong, it was a foggy night and the nurse took 2 hours to get to us. It was just sod’s law.” Male carer, 67, EPaCCS site

“The hospice phone service responds very quickly, even at night. They follow up the next day too. Our GP had very little to do with us. The hospice has rung the GP but we see the GP rarely.” Male patient, 67, EPaCCS site

Professionals commented:

“Admission can be arranged appropriately, not just via ED. Referrals can be made from an informed base. We’re called when there’s carer fatigue, when they’re at the end of their tether, or the patient unexpectedly declines and their family is unable to cope. They know an ambulance will turn up to help them. We didn’t use to know the plan but now I do. Electronic records are invaluable.” Male paramedic, 57, EPaCCS site

4.4.4 The need for education

Patients and carers want to know more about their disease and how to manage it, about what services are available, and about what financial and practical support is available. Healthcare professionals and care home staff have great educational needs surrounding end of life care. All need education around what choices are realistic in a given situation.
Patients and carers commented:
“I would’ve like to have known more about myeloma. I’ve got a booklet that tells you a bit.” Female carer, 75, EPaCCS site
“Twice now, I’ve told people waiting in the urology outpatients about Macmillan and the Care Allowance. It’s a shame there isn’t enough education out there.” Male patient, 67, EPaCCS site

Professionals commented:
“There is a lack of support for GPs and great educational need.” Female GP, 49, EPaCCS site
“We need a big education programme about end of life care for our staff. It’s counter to the usual paramedics way of thinking. For example, one call I might be dealing with a cord prolapse, trying to save a baby and a mother. The next call is end of life care. It’s a total paradigm shift. To not intervene whilst someone is dying is very difficult. We’re getting more confident in using just-in-time medication. Crews don’t carry midazolam or haloperidol but they can use it if it’s in someone’s house.” Male paramedic, 57, EPaCCS site

4.4.5 Advance care planning
Patients and carers vary in how much they talk about advance care planning. Healthcare professionals are not resourced to do advance care planning, even where EPaCCS supports those conversations. These conversations take a considerable time if they are to be done well and then will support pro-active rather than reactive care.

Patients and carers commented:
“They’d already noticed it [in the nursing home] and talked to the GP about it. So she never reached that crisis. In the nursing home her care was far more planned.” Female carer, 47, non-EPaCCS site
“He can’t grasp the fact it’s terminal. He doesn’t like knowing how long he’s got. It’s nice for me having someone to talk to. We’ve got our funeral plans in place. [Name D] doesn’t want to know. He says it brings it closer to home and he’d rather not know. I’m living each day as it comes. I don’t like to think about it anymore.” Female carer, 75, EPaCCS site
“She wanted to die at home because it has been such a happy place. Our GP made a note of her wishes. I mentioned to one of the district nurses that we were having problems getting upstairs. Two hours later a bed arrived and everyone swung into action. The funeral was all planned...ages in advance. We weren’t embarrassed about talking about it.” Male carer, 67, EPaCCS site
“I’m waking up to the reality of it all. [Name] (community palliative care nurse) helped us talk through things. [Name] the Reverend helped us organise my funeral. I need to know what, where and when. I like to be in control. I knew from day 1 when we met [Name] (community palliative care nurse) that we were talking about end of life care.” Male patient, 67, EPaCCS site
“It was empowering to take it on myself to sort out my funeral plan. It was personal, I wanted to take control back. I’ve discussed resuscitation with my MS nurse; I’ve explored these issues. It would’ve been nice to have someone put their arm around my shoulder and say, ‘This is what we need to look at’. I feel it’s been a lonely place. It would be nice to have
10 minutes dedicated to those kinds of issues with my GP. I’ve tried to write a document expressing some of my wishes. I’m saying like I know all the options – that’s what I need to explore.” Male patient, 49, EPaCCS site

**Professionals commented:**

“Advance care planning is not resourced, although it can be a standardised discussion. You’d need an hour to do a decent care plan. There isn’t a GP in the land who has that hour.” Female GP, 52, EPaCCS site

“GPs do weekly ward rounds in our care homes. The care is pro-active rather than reactive. It’s all about relationship, planning and preparation; making sure the patients’ wishes are known. It’s thinking ahead, recognising, and offering opportunities earlier.” Female Clinical Nurse Specialist, 44, EPaCCS site

### 4.4.6 Carer and family support

Carer support was usually more than adequate but one carer felt carers should be reviewed routinely by their GP and a patient felt that Macmillan referral should be done much earlier. Community Specialist Palliative care nurses and Macmillan nurses were praised for their support for patients and carers but with some exceptions.

**Patients and carers commented:**

“Even though I’d never been there before, I’d already been identified as the person who needs to know things. When you’re a carer, it’s the ‘are there enough nighties?’ mind-set that everyone else has to support. And it’s that thinking, the carer’s always thinking slightly ahead. They thought to ring me when she was dying.” Female carer, 47, non-EPaCCS site

“The Macmillan nurse visited and told us that we were doing so well that she left immediately. We didn’t ask for help. I was ignorant of so many things and struggled on. I should’ve spoken out to that Macmillan nurse. If you speak to a carer, ask twice, ‘How are you really?’ If things are there, just knowing there’s a safety net is enough. You need to understand carers needs, how well can they cope, what if they have health issues? Carers are brave, then when it comes to it, if there’s an emergency, things change.” Female carer, 67, non-EPaCCS site

“[Name] (Community palliative care nurse) was brilliant. She supported [Name D] to get a cat and had a word with the housing officer. It’s made such a difference. They made you feel [in hospital] as though you mattered, not as if you were just a number. The hospice offered me massages and things like that.” Female carer, 75, EPaCCS site

“At every stage support was there. No-one let me down. There’s always people I can phone and open doors all over the place. GPs should be making more regular appointments to see carers. I was worrying more about [Name F] than me. I’d been feeling unwell but ignored it until I woke up in hospital with a strangulated hernia and a bowel re-section. [On another occasion] I began to get delirious after 3 nights without sleep, then I got a phone call from Marie Curie to say, ‘I understand you need a nurse. There will be someone with you tonight.’” Male carer, 67, EPaCCS site “Who’s responsible for sitting down to talk to people? Whose function is that?” Male patient, 67, EPaCCS site

**Professionals commented:**

“I have great rapport with relatives and they can access me directly. I request opinions from relatives.” Female GP, 49, EPaCCS site
4.4.7 Taboo/difficult conversations

Breaking bad news conversations and difficult conversations are proving a challenge and as a society we need to do more to facilitate these conversations. These conversations can dramatically influence subsequent care and decision-making.

Patients and carers commented:

“When she was given the initial diagnosis, the consultant told her on the ward with no personal support. She said, ‘I just sat in my bed and cried’. So when she got the news about ovarian cancer, I’d asked one of the nurses to make sure I was there to support her. And that nurse made that happen and it was a whole lot better. J wouldn’t talk to anyone about dying really. I was able to express my concerns about her having a good death. She wouldn’t talk about where she wanted to die. She just wouldn’t talk about it. And that wasn’t through effort of people trying.” Female carer, 47, non-EPaCCS site

“We chose not to talk about it and that was the wrong decision. One day the oncologist said, ‘This is the end of the road.’ I was embarrassed that I hadn’t contemplated it till then. We never talked about death, funerals and even then, slightly in denial, we plodded on from day-to-day. It’s important to instigate difficult conversations.” Female carer, 67, non-EPaCCS site

“They gave me a cup of tea but they told me on an open ward, with the curtain round, with no warning. I went to pieces in the Sister’s room. No-one else was there for me.” Female carer, 75, EPaCCS site

“People said we were the most open they’d spoken to.” Male carer, 67, EPaCCS site

“It was the chest specialist who broke the bad news. After he said the word ‘cancer’ we couldn’t listen any more. We were traumatised. The urologist just kept us with him all the way through. Then when it went to my bones, we went to the oncologist. No-one ever talked to us about it.” Male patient, 67, EPaCCS site

“I’ve been fortunate with my MS nurse to talk about the possibilities of DNR and other such... The nurse assessor understood all of me – not just a checklist. In some ways it gave me a lot of dignity back because there was finally someone who looked at all of me. It’s made a big difference to me in terms of living with my illness.” Male patient, 49, EPaCCS site

Professionals commented:

“One young woman died of breast cancer aged 29 and hadn’t had any contact with the hospice until the day before she died. She had no family grief work done, no support for her children, no memory work done. It was because of the stigma associated with the word hospice. We did an audit of oncology deaths. Of 17 deaths in one month, only 4 were known to the hospice. None were on the [...] register. They were waiting for the oncologist to say ‘enough’ but they never did. One oncologist locally can’t bear discussing end of life care.” Female Hospice Clinical Director, 44, EPaCCS site

“There’s a changing emphasis in facilitating a good death, rather than being scared of death. We see the younger doctors coming through, with fear of litigation and doing something wrong. They fear that letting someone die is doing something wrong or letting someone down. We’re not getting conversations in early enough. COPD/asthma are a difficult group to target. Most of the time they go into hospital to get better. The conversations are harder. Patients under social care with complex packages who are well cared for are seen only with acute problems, but the gradual deterioration towards end of life care is not being picked up. The Ambitions document says it’s everyone’s responsibility, not just health.” Female GP, 52, EPaCCS site

“There’s fear, people aren’t raising the conversations. Avoiding them doesn’t make it better. It can cause real bereavement issues or people don’t end up dying where they want to. It’s giving people the confidence to introduce it. It’s planting the seed so they can have an
opportunity to think. It stayed with me for years, an oncologist telling a lady who was clearly
dying, ‘Go home and we’ll see you when you’re better.’ Nobody had that conversation with
her. She came into palliative care and died. The mother of that young patient said to me
that if she’d known she was dying, she’d have spent every day with her daughter. It stayed
with me, it was so sad.” Female Clinical Nurse Specialist, 44, EPaCCS site

4.4.8 Review and updating of care plans

Professionals commented:

“Once care homes can access EPaCCS, communication will improve and they can record
real-time changes in care that are sometimes missed. With it being live, they will be able to
read what other people have written.” Clinical Nurse Specialist, 46, EPaCCS site

“EPaCCS is only as good as the record that’s put on. It needs to be reviewed and updated.
I’m interested in adding where the patient dies, but once they’ve died, that patient is not
going to be a priority for busy GPs.” Female GP, 52, EPaCCS site

“Historically, even though it’s on 111 and the ambulance systems, [the EPaCCS
information] wasn’t filtering down to the staff on the ground. It was only available at high
level access. Someone quite junior attending wouldn’t know about it. It needs be to
accessed by the relevant people.” Female GP, 52, EPaCCS site

“EPaCCS is a massive governance issue for care homes. It’s an IT challenge – there are
lots of access issues.” Female Clinical Nurse Specialist, 46, EPaCCS site

“The system has changed and is more intuitive, streamlined and easier to add people.
Some people have had problems logging on, or they can’t print out stuff for meetings.
Getting a new login is a frustrating procedure. One of the issues with EPaCCS is how often
are people reviewed and their care plans updated. It’s only as good as the information on it.
Care homes without an N3 connection can’t put the information on. The information isn’t
always that relevant to them.” Female Clinical Nurse Specialist, 44, EPaCCS site

4.4.9 Individual preferences

Details really matter in end of life care and personalisation of care is important in how
the quality of care is perceived overall.

Patients and carers commented:

“Just small decisions like keeping her light on so she wasn’t on her own in the dark at night,
and they opened her curtains during the day. Just little, small things. From my
understanding of how hospice care operates, they just go that little extra bit, it’s the detail.”
Female carer, 47, non-EPaCCS site

“It’s not the big things. It’s the smaller things. I want people to remember end of life care for
all the right reasons. My GP was wonderful, came to see me at our house, asked if I
needed any help. The oncologist and various hospital people just left us to our own devices.
We would ring up the hospital and ask to go there. There were no home visits and no
anticipatory drugs.” Female carer, 67, non-EPaCCS site

“I asked for a room on his own because I could see he was going downhill. The people
around him were upsetting him. And the nurse arranged that. He picked up from that day.”
Female carer, 67, EPaCCS site
“The hospice is a jolly place, full of laughter. I realised once that someone asked to have tea and cakes in the garden, so they wheeled them out in their bed into the garden. One of the Marie Curie night sitter nurses woke up me and said, ‘Whatever you do, don’t go out today.’ [Name F] got washed and dressed, even put a bit of lipstick on. I held her in my arms and kissed her one last time, then she gave a sigh and died.” Male carer, 67, EPaCCS site

“The hospice went out of their way to secure local home care. They go the extra mile and always follow through.” Male patient, 67, EPaCCS site

“I’m clear about where I want to spend my last few days. Taking a step back, I’ve got that ability. It’s all been me pushing. What if I wasn’t able to? To me, that’s morally wrong. There are people out there who can’t do that.” Male patient, 49, EPaCCS site

**Professionals commented:**

“Individual needs are catered for with individual care planning. The system allows for that.” Female Clinical Nurse Specialist, 44, EPaCCS site

“Care plans are drawn up between clinician and patient. The plan is only as good as the person writing them.” Male paramedic, 57, EPaCCS site

**4.4.10 Culture, leadership and personalities**

Personalities and the culture of an organisation are key to providing quality end of life care.

**Patients and carers commented:**

“You walk into a place and people are warm. And people know who you are and say hello and smile. Even the tiny little things make so much difference. As soon as I walked into [the nursing home] I thought, ‘Actually, this is a really special place.’” Female carer, 47, non-EPaCCS site

“There are some really good people but there’s a lot more to do.” Female carer, 67, non-EPaCCS site

“The girls [at the hospital] are wonderful. It’s like walking into a family house. They make a joke of things. We’ve been treated wonderfully and they all gave him a hug when he left.” Female carer, 75, EPaCCS site

“[County] carers were friendly, helpful and co-operative.” Male patient, 67, EPaCCS site

“It’s criteria based. We don’t consider you as being in the last year of life, so we won’t put you on the register. I’m wanting to talk about it, but it’s closed off. It’s been disappointing that I’ve had to drive that. There needs to be recognition that this is the most important part of people’s lives…we need to get this right…we do need to cut to the chase because at the end of the day it will affect us all.” Male patient, 49, EPaCCS site

**Professionals commented:**

“The personalities we’ve got doing the Clinical Nurse Specialist jobs are amazing. It’s been so successful. It’s all about the people and the communication that happens. The care home manager in the care home I look after is amazing. She has changed the system. She is key to it. It creates the ethos for the whole place. The leadership of the organisation, if it’s their priority…you reap the benefit.” Female GP, 52, EPaCCS site
“Care home managers are key. If they're a strong, committed manager, that helps. It's down to leadership. They're a huge influence. If they're not on board, things break down. Their relationships are key. The care home manager is the continuity person who knows all about their patients. We show them that they can do End of Life Care so staff feel supported. They get a good service because key partners are committed. Younger nurses see value in their roles, in engaging with staff, residents and in education.” Female Clinical Nurse Specialist, 44, EPaCCS site

“Letting someone die isn’t doing nothing”. Female GP, 52, EPaCCS site

4.4.11 Equality/variation in care

Care provision is variable and depends upon personalities, resource availability and therefore geography/postcode.

Patients and carers commented:

“[Name] refused to see the Macmillan nurse when she came to see her without making an appointment, so the Macmillan nurse discharged her, and wrote her off the books.” Female carer, 47, non-EPaCCS site

“They don’t get treated fairly always. Depends on how empowered the family is. If you’ve got a gentle, timid family, they often don’t fare as well as those brave enough to ask questions. If you’re able to ask a question, that goes a long way. You need to be able to ‘speak healthcare’. We need a different attitude.” Female carer, 67, non-EPaCCS site

“People are not treated fairly. It’s a bit of a postcode lottery. It’s all a bit of chance. There are definitely people who get a lot better services than other people.” Male patient, 49, EPaCCS.

Professionals commented:

“There’s discrepancy in ethnic minorities accessing EPaCCS and specialist palliative care locally. Historically that’s due to family structures. That model of care isn’t apparent now but we’re still not seeing access. There is erratic service provision, even in one GP practice. There are different personalities and priorities in a service. So is end of life care fair? Probably not.” Female GP, 52, EPaCCS site

“People are treated fairly within a particular [nursing] home but from home to home, care is very different, due to staffing levels and commitment to individuality. There is no nursing home standard of care, as long as they can justify it’s safe. Resources aren’t always available for them to die in their care home. In this area they are but not in all areas.” Female Clinical Nurse Specialist, EPaCCS site

“In some parts, services aren’t available. There are demographic boundaries. For one patient in one area, I can make calls to nine different services, taking nearly 3 hours. For another patient, it’s a call to one service, which takes 15 minutes to get to the same endpoint. Inequality is getting better compared to a few years ago.” Male paramedic, 57, EPaCCS site
4.4.12 Time as a resource

All the professionals interviewed were concerned about the lack of time clinicians have for quality palliative and end of life care, including the supervision and support needed by staff.

Professionals commented:

“It’s not the time it takes to do the data entry, it’s the correct conversations with patients, carers and families that take time.” Female GP, 52, EPaCCS site

“End of life care is a complex area. It takes up a lot of time and it’s emotional work. It’s stressful but rewarding. It’s challenging because of the time needed to do it properly.” Female GP, 49, EPaCCS site

4.4.13 Lack of resources

All participants mentioned the impact on end of life care when resources were not immediately available, such as response delays or there being no spare capacity or staff available to meet someone’s needs.

Patients and carers commented:

“End of life care is two things: communication and resources. Even with the best will in the world to get the communication right, if the resources aren’t there, there’s a failure.” Female carer, 47, non-EPaCCS site

“When he was first diagnosed, he fell in the bathroom and couldn’t get up. He’d fractured 5 ribs. It took two and a half hours for the ambulance to get to him. He fell another time in the front room and I waited two hours before calling the ambulance back. One and a half hours after that, [Name D] crawled across the floor and got up onto a chair. He spent such a long time on the floor in agony. I wrote a letter of complaint – the ambulance got called to two other emergencies.” Female carer, 75, EPaCCS site

“There was no bed at the hospice so she was taken to a ward in [City] General. The patient next to her had a violent psychotic episode during the night, smashing up the ward. [Name F] was terrified and just wanted to get home.” Male carer, 67, EPaCCS site

“I was handled badly as an outlier in [City] General after getting pneumonia. I had a driver on, but no-one took any notice of the alarm going off. It took 90 minutes on the ward to get some pain relief and it was only by [Name C] [my wife] asking that I got anything. It was only by [Name C] bumping into the Prof in the canteen that I was moved into a side room. The hospital is very stretched. I rate them very highly – we had mostly good experiences at the hospital.” Male patient, 67, EPaCCS site

“I don’t think the system is set up for the scale of people. If done properly, you’d save money: if it’s done efficiently and it’s what people want. If there’s a crisis and everyone’s flapping you end up costing more money.” Male patient, 49, EPaCCS site

Professionals commented:

“Currently, the stretching of resources, like district nurses, cannot be proactive about using EPaCCS because they’re stretched too thinly. There may be fewer hospital admissions but because GPs are paid per patient, there is an uncosted impact. There are sometimes delays in anticipatory prescribing…it’s not a perfect system.” Female GP, 52, EPaCCS site
“Macmillan nurses are sketchy and we can’t access them directly. There are some nurse specialists but not enough of them. Most queries could be dealt with by a nurse specialist with GP advice.” Female GP, 49, EPaCCS site

“EPaCCS is good but only works when you start with what’s happening in Primary Care. There’s value in knowing which GPs are and aren’t coping out there. Some practices aren’t functioning. They can’t recruit [GPs]. We need to free up GP time for palliative care. More planning means fewer admissions.” Female Hospice Clinical Director, 44, EPaCCS site

“Emergencies cause problems. It can put your case load behind because it takes time. Resources are limited. If there are no hospice beds then you have to have Plan B. We try to meet all their needs. I can’t say hand on heart this is what happens. The community nurses are understaffed and really busy. It’s much harder, there’s not enough time and resources. Who will put that information on EPaCCS? It might save time but it’s added pressure for everyone. If you haven’t seen that in action, you don’t always understand it.” Female Clinical Nurse Specialist, EPaCCS site

“In the end, it’s where do you spend your health pounds? We need a lot more action to ensure 24/7 specialised palliative care services. Where is the funding for the right type of service to do it properly and well? There are some real champions funded in some areas. Everyone does want to help but there’s so much fatigue, day in and day out. There’s no point trying to refer as you just get stonewalled, so people end up in ED.” Male paramedic, 57, EPaCCS site

4.4.14 Compassion

Most participants felt that people were treated with compassion some of the time, with some notable exceptions.

**Patients and carers commented:**

“It’s great to feel supported but I hated seeing [Name] so frustrated by the fact she felt pestered. So many people wanted to see her. I used to be like a PA answering the phone. It would be social services, or a GP, or the cardiac nurse or a Macmillan nurse. There has to be some acknowledgement that sometimes people want to be left alone.” Female carer, 47, non-EPaCCS site

“For all healthcare professionals, this is an everyday experience. This is a one-off for families and patients. In a few weeks’ time, this person will be just a statistic but for the family, it will remain with them forever. For me, the local undertaker was the only one to show compassion and care.” Female carer, 67, non-EPaCCS site

“We were more supported than others who had more difficult home lives. I can’t think of any examples where we weren’t treated with compassion.” Male carer, 67, EPaCCS site

“We were begging for hospice transfer. The care there [hospital] was horrendous. I was treated as if I was a waste of time and no compassion was shown. I said I never wanted to go back. They were careless and too busy. The hospital is in special measures. The family were upset but no sympathy was shown. It’s just another day at the office for them. The hospice was so different and the nurses were fabulous... It was like a hotel on our holidays.” Male patient, 67, EPaCCS site

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“When it’s a care agency the level of service is so variable that it’s just a functional job. But it can go the other end where it’s an incredible level of care. So it goes back to this variability and fortune thing...The emotion, the hysteria, the damage it can do to the bereaved people left behind. We need to get this right.” Male patient, 49, EPaCCS site
Professionals commented:

“[Compassion] is a priority. But if you look at the evidence of what patients feel like, it’s not what they feel they’re getting.” Female GP, 52, EPaCCS site

“I have a skewed view but people are treated with compassion and empathy. There are moments when the doctor talks about DNACPR before the patient is ready.” Female Hospice Clinical Director, 44, EPaCCS site

“There is compassion with advance wishes, and with quality of life before they die. Care homes go all out to make wishes happen, above what they need to. District nurses are understaffed and really busy. They sometimes become ‘task orientated’: ‘doing to’ instead of ‘being with’. People may not come across as compassionate but they’d be horrified they were being like that. It’s understanding the bigger picture and the pressures everyone’s under. It’s not always black and white.” Female Clinical Nurse Specialist, 44, EPaCCS site

“People say they would like to help but then also say, ‘It’s not my problem’. They’re sympathetic but there’s no bleeding action though! There’s a huge amount of compassion, sympathy and empathy and people doing the right thing.” Male paramedic, 57, EPaCCS site

4.4.15 Preferred place of care/death

Patients and carers see this as a priority and professionals strive to achieve it.

Patients and carers commented:

“She wasn’t in her own home but she was actually really looked after. She died peacefully and wasn’t in pain, and that’s all we could ask for really.” Female carer, 47, non-EPaCCS site

“To make Preferred Place of Death happen, we need a team approach. If everyone dies at home, it’s a lot cheaper. There’s an incentive because we do need to save money. A lot of people are frightened of dying in hospital. There is often no side room, so no space around the bed, no privacy.” Female carer, 67, non-EPaCCS site

“She died where and how she wanted, like a Hollywood death.” Male carer, 67, EPaCCS site

Professionals commented:

“I promote the use of EPaCCS. I definitely see that when someone has an EPaCCS record, then it’s more likely that the preferred place of death is achieved.” Female GP, 52, EPaCCS site

“Preferred place of death is a pseudo quality marker. It does increase quality.” Female Hospice Clinical Director, 44, EPaCCS site

“People can die where they want, at home. We get real results.” Female Clinical Nurse Specialist, 44, EPaCCS site

“People talk about being cared for at home but they may change their minds as their illness progresses. It’s important to record those changes and to talk about them.” Male paramedic, 57, EPaCCS site
4.4.16 Trust/team working

Generally, patients and carers showed high levels of trust in the system to do what was right for them. The healthcare professionals were less certain, particularly across care transitions e.g. admission into hospital.

Patients and carers commented:

“She trusted the oncologist. He was friendly and approachable but I think she did generally trust doctors. She had a lot of experiences of cancer care and all of her experiences were good. She valued her GPs, they never forgot her and they were always aware of circumstances.” Female carer, 47, non-EPaCCS site

“Some mistakes were made because of communication and there was a delay in treatment. This was a problem with the liaison between the pharmacy and the GP.” Male carer, 67, EPaCCS site

“I feel it’s better to make sure this is in writing. You can call that an insurance-type policy. I think the system will try to do its best but I do feel it’s my duty to minimise the room for misunderstanding. There has to be a strong value-based system that drives people morally.” Male patient, 49, EPaCCS site

Professionals commented:

“In liaising with the hospitals, people are often quick to point fingers. They make assumptions about the care that’s been happening in the care home. The Vanguard is trying for people to work as a team across all the different areas.” Female Clinical nurse specialist, 44, EPaCCS site

“EPaCCS is only a platform. I can only trust what I deliver. Whilst I have great colleagues, I can’t say what will happen. I can only say what I will do. The system is so stretched, that even with the best will in the world, I can’t trust the system to do what’s right. I would never criticise them individually but I can’t trust the system.” Female GP, 52, EPaCCS site

“I’ve got a helpful, hardworking team who all muck in. Everyone goes the extra mile. There’s a lot of respect, lots of understanding, it’s a high-trust system.” Female GP, 49, EPaCCS site

“In the hands of a good functioning GP, I trust the system 70-80%. People trust one another. People trust the hospice. They don’t trust the oncologists to see them in three months’ time.” Female Hospice Clinical Director, 44, EPaCCS site

“We are lucky with the Vanguard and our key partners. We have good relationships with [City] Ambulance service, with geriatricians. There’s lots of support, it’s exceptional. There is a no blame culture.” Female Clinical Nurse Specialist, 44, EPaCCS site

“We do trust each other but (lack of) resources gets in the way”. Male paramedic, 57, EPaCCS site.

4.4.17 Expectations, demands and choice

Professionals were clear that whilst they strive to achieve patients and carers wishes, it isn’t always possible within a finite system.

Professionals commented:

“I know my patients inside out. It can be a bit of a battle as the single point service doesn’t
understand GP workload. GPs aren’t like a hospice, they can’t just drop everything and go out on a home visit. Carers can express their wishes and they’re wishes are recorded and respected. Everyone goes out of their way to provide for those wishes.” Female GP, 49, EPaCCS site

“There is space for choice and discussion about it. It can be clunky. Choice is allowed for in a slightly broken system.” Female Hospice Clinical Director, 44, EPaCCS site

“There needs to be lots of education around the patients’ wishes. Can they realistically be carried out? That’s a conversation with the patient and their family and it’s an extremely difficult one; the public perception of what’s on offer versus what’s actually available.” Male paramedic, 57, EPaCCS site

“We all want to cure and help. With really young people we say, ‘this is what we can do’ or ‘this is what we can’t do.’ That way people can plan.” Female Clinical Nurse Specialist, 44, EPaCCS site

“[EPaCCS] is key to patient choice and patient care. Some relatives, however, think this means absolute choice. They might say, ‘I demand to go to the hospice’ and I’ll say, ‘But there are no beds.’” Male paramedic, 57, EPaCCS site

4.5 Survey of relational value (R^v)

4.5.1 Objectives

Establishing and maintaining the relationships necessary to underpin high quality service delivery relies on a number of things. These include continuity and reliability in relationships together with the means by which to develop a dialogue to enable shared vision and common purpose to be built. Effective co-ordination between professionals and agencies delivering end of life care is one way to recognise the presence of good relationships, and is consistently highlighted in reports and evaluations as a key factor in improving the experience of patients and carers (for example in the output from the VOICES surveys).

EPaCCS is designed to support this coordination. However, improved co-ordination is a function of both technical and human factors and the objective of this strand of evaluation was to test the contribution of EPaCCS both directly through co-ordination of information, and indirectly through supporting clinicians to work better together. The 2013 evaluation of the contribution of EPaCCS to the co-ordination of care was generally positive. It included a small study, using a different tool, to assess relationships between professionals only. However, it did also highlight the risk that its presence could lead to the unintended consequence of an over-reliance on technical systems and thus to reduced opportunities for professionals to gather contextual and non-verbal clues about aspects of the care from individual interactions.

The objective for this evaluation was to investigate system relationships from the perspective of patients, carers and professionals working in end of life care. We have used a framework for assessing relational value (R^v) that cross-checks features of organisational systems with the human dimension or values that underpin good ‘relational’ care. This approach ensures that even the concept of co-ordination is

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49 The framework is based on current research undertaken within Whole Systems Partnership’s Knowledge Transfer Partnership with Leeds University School of Healthcare Studies. It has identified an evidence-based set of statements that reflect the presence of integrity, respect, fairness,
seen, understood and assessed as a means to end and not an end in itself. The evaluation has compared the extent to which these relational ‘human factors’ could be evidenced against the presence of EPaCCS in the experience of patients, carers and professional staff. The framework allows for a distinction to be made between that part of the end of life care system that relies on the technical or process dimensions of care, i.e. EPaCCS, and the cultural or people part of the system.

4.5.2 Methodology

Relational value statements: A short survey containing 20 statements, plus some demographic information, was developed with three versions, one each for patients, carers and professionals (see Appendix 4). An original set of statements was developed in a way that was consistent with the research being undertaken by WSP with the University of Leeds. These were then tested and revised with a group of carers and a service user at a National End of Life Care Conference in November 2015 to ensure appropriate syntax and language, whilst retaining the original intent of the statements.

The testing of the survey statements ensured that we used language that was simple and unambiguous, and enabled them to be specifically tailored to the three groups of survey participants, i.e. patients, carers and professionals. This was evident, for example, in removing any ambiguity between the potentially different experiences of the patient and the carer and making some of the language more accessible such as substituting ‘interconnect’ with ‘working together’.

The statements reflect five dimensions of R, namely integrity, respect, fairness, compassion and trust. They also relate to four components of a socio-technical system, namely vision, people, process and infrastructure (see Appendix 4). Respondents were asked to respond to each statement and to indicate where, in their experience of the end of life care system, the statement fell between being ‘not at all true’ (scoring 0) and being ‘completely true’ (scoring 5).

Testing and ethics: The statements were reviewed against the mind map developed by Sustainable Improvement, NHS England to ensure that the issues of interest to them were addressed (see Appendix 3). Dr Elaine McNichol, academic lead for patient and public involvement in the School of Healthcare at Leeds University, provided advice on the need for ethics approval. It was agreed that approval would not be required as standard because this was a survey about experience of the system and not related to the quality/ nature of clinical care. Evaluation sites were, however, encouraged to discuss this locally and obtain any approvals required to secure their participation.

Administration and recording: Participating sites were asked to develop distribution lists of patients, carers and professionals and the survey was sent to them via email and, where this was more appropriate for carers and patients, by post. All completed survey returns were recorded and average scores for each dimension and system component calculated for each respondent cohort.

4.5.3 Participating sites

All EPaCCS evaluation sites were asked and positively encouraged to participate in the survey, but only two, Site C and Site G, did so. This section therefore provides a side-by-side comparison of two sites, one (Site C) with an EPaCCS and one (Site G)
without. The results in this section of the report can therefore not be viewed as conclusive evidence of differences in the wider cohort of EPaCCS and non-EPaCCS locations. They do, however, provide some pointers to potential areas of interest which could be explored in further work on relational value within end of life care systems with and without EPaCCS in the future. The number of completed responses for each site is shown in Figure 2 below:

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Site C (Mature EPaCCS)</th>
<th>Site G (no EPaCCS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>Carers</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Professionals</td>
<td>53</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total for site</strong></td>
<td><strong>70</strong></td>
<td><strong>21</strong></td>
</tr>
</tbody>
</table>

**Figure 2:** Completed responses to relational value survey by cohort and site

### 4.5.4 Analysis of survey responses

Outputs in this section include a number of ‘spider charts’. In these, the higher the score the closer to the outside of the ‘web’ it appears. When scores for the set of 5 dimensions are shown, therefore, a larger pentagon represents a higher overall Rv score than a smaller one. Figure 3 shows the overall comparison between the two sites. Site C (with EPaCCS) rated Rv consistently higher than Site G (without EPaCCS), although the difference was not statistically significant.

![Spider chart](image)

**Figure 3:** Relational value by dimension, all respondents by site
Figure 4 shows the same information in bar form, to enable the difference between sites for each dimension to be compared more easily. It can be seen that the largest gap is for integrity – i.e. the consistency of interactions between parties, leading to a sense of unity and ‘pulling together’. This is perhaps what might be expected if EPaCCS is having an impact on the consistency of approach used across organisations and professionals sharing information.

Figure 5 and Figure 6 show the same responses analysed by the system component to which they relate. Site C (with EPaCCS) again rated all four elements more highly than Site G (without EPaCCS). Here the difference was greatest for process and smallest for vision. If the presence of EPaCCS has an impact on system R', we would expect this to be seen in the ‘process’ area since its aim is to facilitate better communication and sharing of information.

Figure 7 and Figure 8 show the responses for patients, carers and professionals in Sites C and G respectively. In both cases, patients and carers rated relational value in the system more highly for most dimensions than professionals, with the difference more marked in site C (with EPaCCS). This may reflect the fact that professionals have experience of the system over a longer period of time (and for many different patients, which is obviously not the case for most patients and carers).

![Figure 4: Relational value by dimension, all respondents by site](image-url)
Figure 5: Relational value by system component, all respondents by site

Figure 6: Relational value by system component, all respondents by site
Figure 7: Relational value by dimension and respondent type, Site C

Figure 8: Relational value by dimension and respondent type, Site G
4.5.5 Comments from respondents

The survey provided the opportunity for respondents to comment on any aspect of the system as they experience it. Some chose to comment on their/their relative’s clinical care and these comments were not retained to comply with the agreed ethical basis of the survey. A selection of other comments that focused on the overall experience of the system are provided below:

<table>
<thead>
<tr>
<th>Patients</th>
<th>Carers</th>
<th>Professionals</th>
</tr>
</thead>
</table>
| **Site C:**<br>The help etc. that I get has been very good and helpful, helping me to cope on bad days.<br>End of life care is crucial in providing not just the physical support but more importantly the emotional support for my wife as well as myself.<br>I have no doubts that my preferences would be taken into consideration and value the support of [information service]<br>To clarify, the systems involved in my end of life care involve:<br>a) The hospital … Good communication with me … good follow-up from clinical nurse specialists.<br>b) My GP practice… the system works adequately.<br>c) My local hospice …Superb. Lots of staff and volunteers, all very holistic.<br>Volunteers assist with transport to and from hospice appointments - my regular volunteer is helpful and reliable.<br>**Site G:**<br>It all worked all right for me, I could not wish for a better team<br>Feels very well supported Palliative nurse is excellent. [service] day care, staff and volunteers good, feel supported | **Site C:**<br>The support which we received … was exemplary in all areas. Everyone that we came into contact with … were at all times, helpful, understanding and went out of their way to support us, way beyond what we could have reasonably expected.<br>We were lucky enough to have the most fantastic hospice nurse. If [name] was unable to resolve our problem she was able to take on the responsibility of contacting the relevant people to sort it for us. I assume this was possible because the information was available through the different facilities.<br>There is not any end of life care. I lost my husband in 2011. For 2 years he was neglected, very little care or compassion was given to him. He was moved from hospital to hospital constantly. He was dehydrated and in the end at [location] starved to death.<br>In this home end of life = dying alone Being told different information by different staff… Tell management and staff to not just listen to relatives but HEAR us.<br>**Site G:**<br>My father now cared for very well. I'm relieved and heartened by how much support is available | **Site C:**<br>Locally I have a great End of Life care team. the practice has been very well supported by a very experienced MacMillan nurse for many years. He has recently been promoted and we worry we will not get the same quality of care from the less experienced nurses who will replace him. All clinicians feel strongly that this is a very important aspect of our work and are fully committed to providing an excellent service. This is at the cost of significant administration time.<br>**Site G:**<br>District nursing need to input more information into GP systems to ensure consistent care & enable better sharing of information<br>Some GP's need to listen to staff more when being asked for anticipatory drugs for patients and all follow the same course of action when dealing with this issue and not act as individuals<br>Communication between health professionals in the community is poor… staff in the community all seem be at odds with each other<br>Non-specialist palliative care doctors are still finding it hard to have difficult conversations (discussing poor prognosis, asking about PPC & PPD) so patients do not have options open to them. Time is a factor but lack of confidence in their own communication skills is probably the real block
4.5.6 Points for further discussion

This strand of the evaluation was only able to capture information from two sites. It should, however, be noted that the non-EPaCCS site nevertheless has a good reputation for effective and close working across agencies in end of life care – which sets the bar high with regard to identifying added-impact from EPaCCS. Given the limited data, no inference can be made concerning comparisons from specific survey outputs. However, two anticipated impacts from EPaCCS, that they would improve process and that system integrity would also be greater, have both come out marginally better in the EPaCCS site. This suggests that it would be useful to gather more data to see what insights this uncovers.

5 System leaders

During the evaluation we undertook a small number of interviews with system leaders who have extensive experience in End of Life Care service delivery or research. The conversations focussed on implementation challenges and the emerging benefits that they could point to, either from local studies or the stories and experience of a range of staff as they have engaged with EPaCCS. The emerging themes are outlined below.

For patients and carers:

- That the goals of EPaCCS are equally relevant for people with complex needs and that therefore potential applications and benefits are transferrable;
- It is most likely that benefit is being realised out of hours when the technical systems can support collaboration in the absence of key players.

For professionals:

- There were several examples of significant improvements in how professionals were now engaged in end of life care services with significantly improved staff satisfaction in the work they were doing where patients have end of life care needs;
- However, there remain challenges in securing clinical engagement with systems that do not meet with expectations of functionality in some parts of the system, particularly for GPs. This is despite significant efforts at making EPaCCS systems quick and easy to use;
- The importance of developing capability amongst the wider workforce in a range of care settings through training and awareness of end of life care needs was also mentioned;
- EPaCCS or equivalent systems still face the challenge of addressing what for some is a sensitive issue that some will steer away from.

Organisational insights:

- The difference in make-up of large organisations covering wide geographical areas, such as Acute Trusts or Ambulance services, compared with small and often local services where good practice can thrive, such as a care home, GP practice or locality team, means that for many there remains the sense of a patchy or fragmented picture for the use of EPaCCS;
- The number of providers commissioned to deliver or contribute to end of life care services also leads to increased complexity;
There was a consistent message about building capability in the use of EPaCCS or equivalent systems across a wide range of agencies and teams and that this needed to be sustained over the long term to ensure continuing benefits are realised;

A mix of technical progress and building capability means that there are examples where some parts of the system are increasingly engaging well in end of life care, for example care homes where benefits are seen in reducing hospital admissions and improved levels of training for staff in order to deliver better care, whilst others face particular challenges, for example ambulance services where there are issues associated with variation in the local services they need to engage with – however, neither of these comments are universally true.

The technical challenge:

In some locations EPaCCS is leading the way in inter-operability and data sharing and is therefore at the forefront of achieving greater integration across a wider range of services. EPaCCS therefore can and does on occasion provide an important learning space for wider technology and integration projects;

A consistent view has been expressed that the longer term benefits of inter-operability with integrated care records is worth short term delays in achieving full implementation of EPaCCS functionality – however, this may mean that end of life care is not necessarily given priority in the overall technology pathway locally;

Whilst there is generally good compliance with the EPaCCS information standard SCCI 1580 inadequate attention has been paid to generating monitoring and reporting intelligence despite this being recommended in earlier evaluations and evident in the 2013 EPaCCS baseline review. Whilst EPaCCS provide operational benefits this deficit has hampered opportunities for improvement as well as limiting what can be claimed across the system in terms of benefits;

There is a view that in the light of the wider inter-operability agenda the requirements for EPaCCS, or equivalent systems, should be expressed in terms of functionality as well as content;

Data sharing rather than the creation of a register is the core technical challenge, which means that information governance remains a key challenge in achieving wider inter-operability and data sharing;

Further benefits from inter-operability and data sharing agreements should be pursued, particularly where data-linking approaches can be used to inform local improvement projects.

Evidence of benefits or impact:

System leaders consistently found it difficult to point to ‘hard evidence’ of impact, although they often reported anecdotal evidence of positive impact, particularly for staff, but with a strong implication that this also meant improvement in patient and carer experience;

There is an emerging consensus, which we believe is broadly backed up by the intelligence gathered in this evaluation, that improved co-ordination adds value to patient, carer and professional experience of services and that
EPaCCS can play a part in opening up the conversation about choice of care and preferred place of death;

- With respect to reductions in the number of deaths in hospital at a population level we have not found that EPaCCS sites have, as yet, lead to marked differences. We therefore suggest that EPaCCS or equivalent is a necessary but not sufficient condition to achieve reductions in the number of deaths in hospital;

The care systems within which EPaCCS are being implemented are incredibly varied and invariably complex given the type of patient needs that EPaCCS is seeking to address. Whilst the above feedback from system leaders reflects the ‘polka-dot’ experience of implementation, with each location having its own mix of benefits and challenges, it is clear that achieving comprehensive co-ordinated care at or approaching the end of life is neither ‘just a technical challenge’ nor a simple challenge in the current context and climate of health and social care service delivery.

More fundamental changes, such as those envisioned in the Five Year Forward View, may well be needed if EPaCCS or equivalent systems are to have their full effect. There was virtually universal agreement that achieving EPaCCS functionality within local technical solutions was the right way to go, although there was equally universal recognition that the challenges were perhaps greater than originally envisaged.

To conclude this section one quote stood out:

“It's all about relationships and collaboration at the end of the day. We need things to facilitate this, not as a substitute.”

This is a reflection of the ‘mood’ surrounding efforts to address a complex but ultimately very rewarding objective to improve the coordination of care for those at or approaching the end of life. In the view of system leaders EPaCCS is, and should continue to play its part in realising this goal.

6 Analysis of place of death using national data

6.1 Objectives

The NHS Improving Quality website sets out clearly the expected benefits of EPaCCS on place of death:

National surveys have shown that most people would prefer to die at home, so the proportion of deaths in the usual place of residence (DiUPR) is a key performance indicator. Nationally, this figure has increased steadily from 38% in 2009 to 43% by the start of 2013 and it is likely that the rollout of EPaCCS has contributed to this success51.

The proportion of deaths in the usual place of residence (defined as deaths at home or in a care home) is also a key performance indicator for CCGs in relation to end of life care. This strand of the evaluation therefore seeks to measure and analyse differences in the distribution of actual place of death between CCGs with an EPaCCS and CCGs without, to test the validity of this statement (which was based on the 2013 evaluation report) in an environment where EPaCCS has been adopted more widely throughout England. The earlier evaluation of early adopted sites (2013) did find a difference in the progress made on improving DiUPR, albeit with a small

sample. This evaluation therefore provides an opportunity to further test this in the context of our wider findings.

6.2 Methodology

Data on place of death: As with the earlier study, this analysis used ONS data on place of death. This is released quarterly and is publicly available\(^\text{52}\). The analysis compares the percentages of deaths in each location in the four full years 2011/12 to 2015/16, providing overlap with the earlier evaluation.

Data on presence of EPaCCS by CCG: From the 2013 evaluation of EPaCCS, the list of areas (then consisting of PCTs) which had an EPaCCS in summer 2012 was used as a basis for identifying the cohort of CCGs with an EPaCCS in 2012. Only those CCGs covering an area wholly enclosed by a former PCT on the list were included, any CCGs whose boundary extended outside the relevant predecessor PCT were excluded from the group.

Responses from Sustainable Improvement, NHS England’s 2015 baseline data consolidation of CCGs in England was used to identify CCGs self reporting to have an EPaCCS in late 2015, and those that reported not having one. At the time of the evaluation this had achieved a 66% response rate, although this has subsequently risen to 73% (there is therefore potential to update the analysis reflected in this evaluation. It is recognised that ‘not having an EPaCCS’ does not necessary imply that there is no electronic system for co-ordinating care or sharing information, or that localities are not working well together to effect good coordinated care in other ways. Any unclear or missing responses were excluded.

It is also clear from our review of EPaCCS implementation, and our discussions with system leaders, that EPaCCS itself has evolved over time, and that individual locations may be developing how EPaCCS works locally. However, as a proxy for the roll-out of EPaCCS, and to enable us to explore potential impact, we considered this to be a reasonable line of enquiry given these caveats. What is evident is that there is a growing ‘critical mass’ of locations where EPaCCS is now in place where, in the majority of places we must assume that EPaCCS will either be new or will enhance previous methods or systems for coordinating care.

Cohorts for comparison: Based on the information outlined above, three cohorts of CCGs were identified:

- CCGs with an EPaCCS in 2012 = 43
- CCGs with EPaCCS established after 2012 = 43
- CCGs with no EPaCCS in the 2015 survey = 53

6.3 Place of death

Figure 9 shows the average percentage of deaths occurring in the usual place of residence for each of the cohorts, and for England as a whole. It is notable that the overall percentage of deaths in the CCGs with EPaCCS in place in 2012 is significantly lower than that in England as a whole\(^\text{53}\). The difference in actual performance was not assessed in the 2013 evaluation, which focused on the rate of

\(^{52}\) The ONS release used in this analysis is available via the National End of Life Care Intelligence Network at [http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death](http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death)

\(^{53}\) Significant at 5% using a T-test on annual differences between cohort values and England values (p<0.0001)
improvement for these areas compared to the England average over the initial implementation period.

Figure 9: deaths in usual place of residence as % of all deaths, CCGs by EPaCCS cohort, 2011-2015 (sources: ONS, Sustainable Improvement, NHS England baseline survey)

Figure 10 shows the rate of change of the DiUPR percentage in each cohort over the period, indexed to the 2011/12 rate. While the DiUPR percentage has increased for all cohorts (and England as a whole) there are no significant differences between the cohorts in either the level or pace of change achieved.

The 2013 evaluation concluded that sites with EPaCCS had achieved a faster rate of improvement than England as a whole in the period between 2009 and 2012. Whilst this was clearly the case for the small number of early adopters in that study it does not seem to hold for the next wave of uptake. As the proportions of deaths in the usual place of residence have increased for all cohorts, the proportions of deaths in hospital have (as would be expected) decreased. Figure 11 and Figure 12 show the corresponding results for each cohort.
Figure 10: Deaths in usual place of residence - % change on 2011/12, CCGs by EPaCCS cohort, 2011-2015 (sources: ONS, Sustainable Improvement, NHS England baseline survey)

Figure 11: Deaths in hospital as % of all deaths, CCGs by type of EPaCCS, 2011-2015 (sources: ONS, Sustainable Improvement, NHS England baseline survey)
6.4 Discussion

This analysis sought to identify differences between locations with EPaCCS (both those in place by 2012, and those established more recently) on performance against the key metric of deaths in the usual place of residence (DiUPR).

EPaCCS does not cover all deaths in those locations where it has been established and therefore only has the potential to make a partial contribution to the overall pattern of place of death for sites with EPaCCS. One also needs to take into account the type of sites and general ‘history’ of EPaCCS when interpreting this data. The pre-2012 systems were predominantly, though not exclusively, Acute hospital systems. They were also predominantly, though not exclusively, stand-alone systems with minimal inter-operability with other systems.

The potential for growth in DiUPR for EPaCCS locations cannot therefore be assumed apart from the natural growth within the initial scope and coverage, i.e. growth that reflects the fact that identifying and adding people to an EPaCCS system up to a year, or sometimes earlier, before actual death means that the numbers on the system, and therefore with the potential to benefit, will grow over such an initial period – certainly for a full year and potentially for longer. However, it would be unusual, and not consistent with what has been described in our discussions with system leaders, not to expect local plans to be seeking, and achieving wider coverage at early EPaCCS sites.

The data, however, suggests that there is no discernable ‘added advantage’ in terms of making progress to increase DiUPR where EPaCCS has been implemented for longer, or the reverse where there is no reported EPaCCS system in place. This could reflect the fact that EPaCCS is an enabler rather than the whole solution. It may also point to significant unrealised potential, as described in the limited but consistent intelligence from other parts of our evaluation, which suggests that whilst some progress beyond support to people with Cancer is being made there is still a long way to go in terms of patient coverage and organisational/professional access.
The data currently presents a counter-intuitive set of findings, even when caveats are taken into account. There is therefore the need to undertake a closer analysis, whilst not losing the expectation that system-wide improvements in DiUPR, or other high-level indicators, should be observable wherever the expectations of what EPaCCS can help to achieve are fully realised. It is likely that the ‘answer’ will lie in factors over and above the technical EPaCCS solutions, given that these remain important.

7 Hospital admissions and costs for those who die in hospital

7.1 Objectives

In evaluating the benefits of EPaCCS to the whole system of health, the potential for it to result in changes to the pattern of hospital use for people at the end of life was identified as a key line of enquiry. The 2013 evaluation included a small study in one early adopter site which suggested that patients on EPaCCS who went on to die in hospital might be referred to hospital less frequently, and at lower cost, in the last 6 months of life than the wider population.

This strand of the evaluation seeks to investigate the potential economic benefit of EPaCCS on hospital use, and to identify whether EPaCCS has an impact on the frequency and cost of hospital admissions in the last year of life for those people who subsequently died in hospital. This represents 40-60% of all deaths for most CCGs (as shown in the analysis of location of death in section 6).

This is inevitably an incomplete picture as equivalent data for those who do not die in hospital is not available in a consistent and comprehensive way when compared to Hospital Episode Statistics, on which this analysis has been based. We have considered complementing this analysis for the CCGs identified with an assessment of the percentage of deaths that occurred in hospital, as it could be argued that there were actually fewer in the EPaCCS sites. Our earlier analysis, however, suggests that this is unlikely.

If EPaCCS has an impact on clinical decision-making and referral behaviour then we would expect to see a difference in hospital activity and costs. This may not be reflected in a reduction in absolute numbers due to underlying demographic change, but should be evidenced in either a reduction in the proportion of deaths in hospital over and above changes in non-EPaCCS sites, and/or a reduced rate of increase in absolute numbers. The premise on which much economic evaluation of end of life care is based (see later section) is that improved early recognition through better coordination of end of life care will result in less admissions and an ability to discharge sooner through the provision of improved joined up care, thus releasing potential costs for investment in the community.

However, a decision not to admit may lead to unacceptable escalation of need, particularly if there is no support in place, and a subsequent hospital admission that then costs more; or earlier and quicker recognition of needs that results in more admissions and possibly longer stays in hospital due to the need to arrange better support in the community, although these scenarios could be countered by improvements in community based care. Finally there is the need to understand and account for the tariff system which particularly in the case of earlier discharge may only reflect a small effect on cost through excess bed days and ‘trim-point’ calculations based on marginal costs.

The findings from the review of literature on economic benefit described elsewhere in this report, suggests that there is at least no contrary evidence to us expecting reduced costs in hospital, even when taking into account the variations and individual
scenarios possible on a case by case basis. We might therefore expect to see a
difference between locations with an established EPaCCS and those without in the
number and/or cost of hospital admissions, especially for those groups of patients
where EPaCCS coverage is highest, albeit taking into account caveats made in
discussing comparisons of DiUPR data in the previous section.

7.2 Methodology

Data analysis for this strand of evaluation was developed by i5 Health
(www.i5health.com) at the request of the relevant CCGs. The evaluation team thank
i5 for their contribution to the work. To undertake this analysis HES data for 2012/13,
2013/14, and 2014/15 was extracted as follows:

- The number of deaths in hospital in the age bands 1-17, 18-64, 65-74, 75–84
  and 85+ years excluding babies;
- The cause of death in line with the ICD10 coding convention allocating each
deadth to one of five age bands;
- The average count of hospital admissions in the year prior to death (last year
  of life) for patients in each age band;
- The average cost of hospital admissions in the year prior to death (last year
  of life) for patients in each age band.

Costs were adjusted for CCG local market forces factors, to enable like-for-like
comparison of costs between sites. All cost data in this section of the report refers to
these adjusted costs. The count and cost of hospital admissions for each site, and
the average for sites with EPaCCS and sites without EPaCCS, were compared.

An additional check to ensure the validity of the comparison was made by comparing
data on the proportions of deaths occurring in hospital by cause of death\[^{54}\]. This data
covers 2011-13 and (in light of the similarities in the rate of change of proportions
of all deaths by location discussed in section 6) forms a reasonable estimate for the data
collection period in this section. The results are shown in Figure 13 and suggest that
the underlying proportion of deaths in hospital are comparable between evaluation
sites and control sites suggesting that the subsequent comparison of costs will be
broadly valid.

<table>
<thead>
<tr>
<th>Cohort</th>
<th>All deaths</th>
<th>Deaths from cancer</th>
<th>Circulatory disease</th>
<th>Respiratory disease</th>
<th>Other causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPaCCS</td>
<td>50.5</td>
<td>37.9</td>
<td>57.3</td>
<td>65.9</td>
<td>49.2</td>
</tr>
<tr>
<td>No EPaCCS</td>
<td>50.5</td>
<td>35.5</td>
<td>58.8</td>
<td>64.7</td>
<td>50.0</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>50.5</strong></td>
<td><strong>36.6</strong></td>
<td><strong>58.1</strong></td>
<td><strong>65.2</strong></td>
<td><strong>49.7</strong></td>
</tr>
</tbody>
</table>

Figure 13: percentage of deaths in hospital for all causes and selected causes,
evaluation sites by cohort, 2011-13 (Source EOLC Intelligence Network)

\[^{54}\] Source: www.endoflifecare-intelligence.org.uk/profiles/CCGs/Place_and_Cause_of_Death/atlas.html - full data extracted for
evaluation sites
The sites which provided data for this strand of the evaluation were B, C, D, E (EPaCCS) and F, G, H, J, K, L (non-EPaCCS). Cost data for site G was subject to a data error relating to coding by the local acute provider in parts of 2013/14 and 2014/15. This had a significant impact on the calculated average cost of admission. Site G’s data has therefore been excluded from the analysis that follows.

7.3 Comparing hospital resource use

Figure 14 shows the average tariff cost (i.e. excluding all interventions outside hospital) for all hospital admissions in the last year of life for people who died in hospital with cancer, and Figure 15 the average number of admissions in the last year of life, per patient for people dying in hospital in the three-year period with cancer as the cause of death. There are no significant differences in costs between the EPaCCS and non-EPaCCS sites. While the average number of admissions in EPaCCS sites as a whole is greater than the non-EPaCCS sites, this is skewed by the high number recorded in Site E.

Both cohorts had similar proportions of deaths from cancer occurring in hospital in 2011-13 (37.9% for the EPaCCS evaluation sites, compared to 35.5% for the non-EPaCCS evaluation sites, as shown in Figure 13). Appendix 5 shows the equivalent information for deaths from circulatory and respiratory disease which, together with cancer, represent the most common causes of death across the evaluation sites as a whole (and in the majority of the sites taken individually). As with cancer, there are no significant differences between the evaluation sites with EPaCCS and without EPaCCS in either average costs or average numbers of admissions per patient.

![Figure 14: Cancer – average cost of hospital admissions in last year of life of those dying in hospital, 2012-2015 (source: I5 Health from HES data, all providers for each CCG)](image-url)
Fig. 15: Cancer – average hospital admissions in last year of life for those dying in hospital, 2012-2015 (source: I5 Health from HES data, all providers for each CCG)

7.4 Points for further discussion

This analysis sought to identify differences between locations with EPaCCS and those without in the level and cost of hospital admissions in the last year of life, for people dying in hospital. No assumptions have been made in this section about the impact of EPaCCS on the costs of care outside hospital (which would include primary care, community care and social care costs).

If EPaCCS has an impact in reducing the likelihood of admission for patients in the last year of life this should be reflected in a lower average number of admissions, and lower total admission costs, in EPaCCS sites compared to non-EPaCCS sites. The impact would be expected to be greatest for groups where the proportion on EPaCCS is highest, notably for patients with cancer. Neither of these effects is evident from the data analysed above. Further analysis to test this would require data matching between EPaCCS and hospital data (which would not currently be feasible given the issues with EPaCCS data quality and access). On the basis of this analysis, there is no evidence that the presence of EPaCCS has an impact on hospital resource use for the groups of people for which data was analysed, although further work based on more focussed cohort studies, possibly using linked data sets, could be undertaken to explore this further.

8 Analysis of EPaCCS data

8.1 Objective

The evaluation sought to analyse the progress over time in the use of EPaCCS in each locality in order to understand the proportion of end of life care patients whose care was managed within EPaCCS, and therefore the scale of current and potential future impact, including the economic benefit within the local system.
8.2 Methodology

Based on our experience from the 2013 evaluation, and following discussion with local leads at a national event hosted by Public Health England as part of their work to develop reporting from EPaCCS, an assumption was made that a basic data set would be available from local sites. A small set of key EPaCCS data items was identified at the above event to provide the basis for our analysis. These were, for all records created since 1 April 2013: record creation date; person date of birth; person gender; primary diagnosis; first choice preferred place of death; date of death (if relevant); actual place of death (if relevant).

Whilst it was recognised that local EPaCCS were variable in terms of reporting capability it was assumed that this basic data set would be available. All evaluation sites with EPaCCS were asked to supply the data, checking first that all potentially patient-identifiable material was removed. Data was received from four of the five evaluation sites with EPaCCS in place (A, B, C and E).

However after significant efforts locally the non-London sites (see section 8.4 below) experienced difficulty in extracting one or more of the data items. Our original assumption was therefore, in hindsight, incorrect and has meant that what can be concluded from this part of the analysis has been affected.

8.3 London sites

These sites were both covered by the London-wide Co-ordinate My Care system and data was provided for both sites by the central CMC information team. It should be acknowledged that CMC effectively acts as a 'call centre' as well as providing the functionality of an EPaCCS, but it was able to provide some useful and data in the context of this evaluation.

Scope of EPaCCS:

The number of EPaCCS records created by year of death is shown in Figure 16 and Figure 17 below, for all diagnoses and for cancer diagnoses only. Note here that 'not recorded' will include people who have not yet died.

<table>
<thead>
<tr>
<th>All diagnoses</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>Not recorded</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site A</td>
<td>23</td>
<td>90</td>
<td>415</td>
<td>6</td>
<td>756</td>
<td>1290</td>
</tr>
<tr>
<td>Site E</td>
<td>149</td>
<td>289</td>
<td>286</td>
<td>6</td>
<td>509</td>
<td>1239</td>
</tr>
</tbody>
</table>

Figure 16: EPaCCS records created by year of death, all diagnoses (source: Co-Ordinate My Care information for sites A and E)

<table>
<thead>
<tr>
<th>Cancer diagnoses only</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>Not recorded</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site A</td>
<td>16</td>
<td>54</td>
<td>251</td>
<td>1</td>
<td>264</td>
<td>586</td>
</tr>
<tr>
<td>Site E</td>
<td>101</td>
<td>146</td>
<td>131</td>
<td>1</td>
<td>106</td>
<td>485</td>
</tr>
</tbody>
</table>

Figure 17: EPaCCS records created by year of death, cancer diagnoses only (source: Co-Ordinate My Care information for sites A and E)

Error! Reference source not found. shows the percentage of records created in each year which relate to a cancer diagnosis.
Table: Percentage of records with cancer diagnosis

<table>
<thead>
<tr>
<th>Site</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>Not recorded</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site A</td>
<td>69.6%</td>
<td>60.0%</td>
<td>60.5%</td>
<td>16.7%</td>
<td>34.9%</td>
<td>45.4%</td>
</tr>
<tr>
<td>Site E</td>
<td>67.8%</td>
<td>50.5%</td>
<td>45.8%</td>
<td>16.7%</td>
<td>20.8%</td>
<td>39.1%</td>
</tr>
</tbody>
</table>

Figure 18: Percentage of EPaCCS records relating to patients with a cancer diagnosis by year of death (source: Co-Ordinate My Care information for sites A and E)

This indicates that EPaCCS is increasingly being used in both sites for patients with diagnoses other than cancer. For 2013 and 2014, the number of deaths recorded on EPaCCS can be compared with ONS data on the total number of deaths for each site\(^{55}\) and this is shown in Figure 19.

<table>
<thead>
<tr>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths, all causes, cases on EPaCCS</td>
<td>Deaths, all causes</td>
</tr>
<tr>
<td>Site A</td>
<td>23</td>
</tr>
<tr>
<td>Site E</td>
<td>147</td>
</tr>
</tbody>
</table>

Figure 19: EPaCCS records as a percentage of all deaths, by year of death (source: Co-Ordinate My Care information for sites A and E)

Although this percentage is likely to have increased for both sites since 2014 (given the rise in the number of cases recorded for deaths in 2015 seen in Figure 16, the percentage of deaths which were included in EPaCCS is still relatively small. This limits the impact which EPaCCS can be expected to have on the performance of the system of end of life care as a whole, and on the key indicators such as DiUPR discussed elsewhere in this report.

Preferred and actual place of death:

Figure 20 shows the extent of recording of preferred place of death, for patients whose death was recorded in each year 2013-2015.

<table>
<thead>
<tr>
<th>2013</th>
<th>2014</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>PPD recorded</td>
<td>PPD not stated or not specified</td>
<td>% of cases where PPD recorded</td>
</tr>
<tr>
<td>Site A</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Site E</td>
<td>106</td>
<td>43</td>
</tr>
</tbody>
</table>

Figure 20: Percentage of EPaCCS records with recorded preferred place of death, by year of death (source: Co-Ordinate My Care information for sites A and E)

Figure 21 shows the extent of recording of actual place of death, for patients whose death was recorded in each year 2013-2015.

\(^{55}\) Source: ONS, Rolling_Annual_Q4_2010_11_to_Q1_2015_16.xlsx, 2015
<table>
<thead>
<tr>
<th>Place of death recorded</th>
<th>Place of death not recorded</th>
<th>% of deaths with a recorded place of death</th>
<th>Place of death recorded</th>
<th>Place of death not recorded</th>
<th>% of deaths with a recorded place of death</th>
<th>Place of death recorded</th>
<th>Place of death not recorded</th>
<th>% of deaths with a recorded place of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site A</td>
<td>8</td>
<td>15</td>
<td>34.8%</td>
<td>27</td>
<td>58</td>
<td>31.8%</td>
<td>138</td>
<td>270</td>
</tr>
<tr>
<td>Site E</td>
<td>100</td>
<td>47</td>
<td>68.0%</td>
<td>194</td>
<td>91</td>
<td>68.1%</td>
<td>147</td>
<td>136</td>
</tr>
</tbody>
</table>

Figure 21: Percentage of EPaCCS records with recorded actual place of death, by year of death (source: Co-Ordinate My Care information for sites A and E)

There is a clear difference between the sites, with only a minority of cases in Site A having a recorded place of death as opposed to a majority in Site E. The falling percentage in Site E may be linked to the increase of non-cancer cases recorded in 2015/16 and may indicate that staff using the system from specialities other than cancer care may be less likely to enter this data into the system.

8.4 Other sites

There were significant data quality issues with the information that the other sites were able to access and share. The potential for analysis of this data was therefore extremely limited.

8.4.1 Site B

Site B’s data did not include preferred place of death for any records, and actual place of death for only a small minority. A diagnosis was not recorded in 6% of records. A small number of records were identified as duplicates by NHS number of other records by the local site. The other data fields (date of record creation, date of death, date of birth, age and gender) were not available.

8.4.2 Site C

It was identified by site C that the data able to be extracted from the system (a total of 2,780 records) did not cover the total number of people known to have been supported by EPaCCS, although it was not clear why this was the case.

653 records were identified as having a date of death in 2014 (212 with a cancer diagnosis, 436 with a non-cancer diagnosis, and 5 for which a diagnosis was not recorded). This represented 19.5% of the total deaths in 2014. However, it is not known how many records were omitted, and therefore the true level of coverage of EPaCCS in the area. A preferred place of death was recorded for 2,223 records (80% of the total), but an actual place of death for only 707 (25% of the total).

In the majority of records for this site, the date of record creation was the same as the recorded date of death. The exact cause of this duplication is still being explored, although the most likely explanation is the nature of the reporting functionality in the existing EPaCCS system.

8.5 Observations and points for further discussion

It has become clear in undertaking this evaluation that our expectations of EPaCCS providing consistent and comparable outputs from a number of sites for purposes of monitoring and evaluation were not able to be realised. This does not necessarily
reflect varying levels of implementation, nor that EPaCCS sites that were unable to provide outputs for these purposes were not otherwise functioning effectively. There are, however, benefits at a local level in receiving and reflecting on such monitoring information, as attested by more than one of the system leaders we spoke to. This may, therefore, be a factor that inhibits the pace at which benefits can be realised for individuals and the wider system.

The development of a national reporting system may help those finding it difficult to extract data for these purposes, but implementing it is still likely to be challenging. The difficulties experienced by all sites in extracting meaningful data on activity and outcomes from EPaCCS should not be underestimated. The challenges in accessing and using data from EPaCCS, as identified by the evaluation sites and by others who provided intelligence, included:

**Technical issues:**

- EPaCCS had been developed as an add-on to the existing primary care information system, with limited functionality beyond simple identification of cases (i.e. as a simple register);
- EPaCCS had not been designed to deliver reporting at a system level.

**Data input issues:**

- Recording of information on EPaCCS was not a regular part of staff training (except for some staff working with cancer patients);
- Preferred place of death may change over time, but may only be recorded once (at the time of initial record creation) and therefore may not represent an accurate picture of the preferred place of death at the time of death. Comparisons between recorded preferred place of death and actual place of death may therefore be unreliable as evidence of the extent to which the system is meeting individual patient needs and preferences.

**Changes in contracting or data management arrangements:**

- Where EPaCCS is now managed by a CSU, any reporting not covered by the service level agreement will only be undertaken on an ad hoc basis and will incur costs to the CCG;
- Other changes in who manages EPaCCS locally have also been shown to cause a temporary, though significant, loss of confidence and therefore momentum in realising benefits from the system, as described by one of our interviewees.

Although it was not possible to analyse data from the evaluation sites as planned, there is a key message evident from those sites (A, C and E) that could provide some data by date of death, namely that EPaCCS is, as yet, covering only a small proportion of people who could be identified as having an end of life care need even in locations where EPaCCS has been in place for some time. Any economic and quality impacts of EPaCCS are therefore currently subsumed within the behaviour of the larger overall system of care making it difficult to evaluate, though not necessarily reflecting an undesirable position with regard to the systems themselves and the drive to greater interoperability.
9 Financial and economic evaluation

9.1 Background

The 2013 evaluation of four early adopter sites suggested that there was an economic return on investment from the implementation of EPaCCS (see section 2 of this report). Some other published work, such as an evaluation of advance care planning (ACP) provide evidence of improved realisation of preferred place of death, and of financial savings accruing from reduced hospital costs in the last year of life. However, this report was focussed on people receiving care from a hospice and was primarily for people with cancer. It is therefore unclear as to how this, and other similar focussed pieces of cost-benefit analysis might be transferrable to the wider population.

There had been other earlier attempts, such a workshop convened by the National End of Life Care Programme in November 2010, to combine knowledge about costing methodologies and provide, for example indicative community costs as alternatives to hospital, or the costs of specialist palliative care services. Given the wide range of parties in the delivery of this range of services, including Hospices with the particular funding model, means that such exercises face significant challenges.

Other work since 2013 is referenced in later parts of this report section. However, this report has identified increasing difficulty in isolating both the cost and benefits of EPaCCS from other systems or other outcomes because of the increasing focus on wider inter-operability and integration of service responses, for example with those for people with long term conditions. It has therefore not been possible to identify a clear link to economic return on investment or financial savings at this stage, although this does not discount the potential benefit of further work in this area.

9.2 The Economics of EPaCCS

EPaCCS is a system which is intended to broaden the sharing of information among health professionals. The information includes the characteristics, recent treatment and wishes of patients for particular types of care (or avoidance of types of intervention) at the end of their lives. In particular, it is expected that by giving all clinical and related staff access to information on patients and their wishes at the end of life, more appropriate decisions will be taken about patients’ care. An economic assessment of EPaCCS could take several forms:

- Cost Minimisation study;
- Cost Effectiveness study;
- Cost Utility study.

A Cost Minimisation study would begin from the standpoint that outcomes are not included (though they may be thought to be approximately equivalent, with and without EPaCCS) and that only the costs of services, with and without EPaCCS, are considered. Although cost minimisation studies can include costs to all the relevant stakeholders, they typically focus on the costs to formal care providers, such as the NHS and social services.

A Cost Effectiveness study would begin with the assumption that outcomes can be measured in standard units (a case diagnosed, a case treated, a patient death), with and without EPaCCS, and would focus on the cost per unit of standard outcome. (In

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56 The Impact of advance care planning on place of death, a hospice retrospective cohort study. Abel et al. BMJ Supportive & Palliative Care, (2013).
practice there is wide variation in the use of the term “Cost Effectiveness” in the literature. This definition will be used here.) Outcomes are typically outcomes for patients while costs are typically costs for formal care providers and also all other stakeholders, depending on the study perspective.

A Cost Utility study would assume that outcomes are potentially different, with and without EPaCCS, and so would have the objective of measuring the outcomes for patients, families and other stakeholders and valuing these outcomes using the utility or value to the individual of each outcome. Outcomes could include not only changes in health but changes in wellbeing brought about by changes in the level of patient or family anxiety about a patient, for example. Utility studies typically use measures of health gain such as the Quality Adjusted Life Year (QALY) where one QALY is the equivalent of one year lived in perfect health. These studies have the advantage (subject to the quality of measurement) of bringing all health and related outcomes onto a common scale. Costs in this kind of study can again be limited to the costs for formal providers or for all stakeholders.

Economists take the view that, at least in principle, all relevant costs and outcomes should be included. If, for example, a family member gives up many hours of time to look after a relative at home, this has a cost in the lost use of their time for their own preferred activities. The time involved could be valued at the wage at which they sell it but even where a carer is not in employment, economists assume their time is of value to them and should be counted. Saving the NHS money by shifting care from hospital to home may appear attractive but the cost to families and carers should be included if society as a whole is to make more efficient decisions.

9.3 What do we know about the Economics of Care at the End of Life?

In general, there is little argument that a large amount of healthcare resources in the UK are used for the treatment of patients who, in hindsight, were in the last year of life. Combined with moves to allow patients more autonomy around the end of their lives and how and where their life ends, this has led to a view of end of life care that highlights savings from reduced interventions on those close to death. If we could prevent treatments that are of little longer term benefit to patients (because they could not enjoy any such benefits for more than a year) then we might increase the efficiency of the NHS.

It should be noted that NICE, the National Institute for Health and Care Excellence, uses a threshold of around £30,000 as the value of one Quality Adjusted Life Year (QALY) in its assessments. A treatment that costs £30,000 would be justified if it added one year of life in full health (or ten years of life with a health gain of one tenth of a QALY) to the average patient’s health and longevity. Clearly, for any significant episodes of hospital care to be justified using this threshold, the patient needs to live for some time after the intervention as well as enjoying some health improvement. For a patient in poor health, whose life may be extended without an increase in their health status, the level of expenditure justified by this threshold may be very low. (In practice, NICE has also used the concept of Best Supportive Care as a baseline for alternatives to treatment that does not need to be justified. It is, essentially, the least society can do for those with chronic health problems.) Viewed from this perspective, extensive hospitalisation for those with poor health and a poor prognosis, in their last year of life, may not be justified in many cases by the value of health outcomes achieved.

The expectation that follows from these perspectives is that extensive hospitalisation in the last year of life is not, generally, efficient and therefore that reducing it is likely to be cost-effective as well as cost-minimising. For example, a study by the National
Audit Office (NAO), one of the most comprehensive studies of costs of end of life care, includes models showing the savings from reducing hospital admissions in the last year of life for a range of different disorders.\

As noted earlier in this report, there is also an increased concern in the NHS to respect patients' wishes at the end of life and ensure that, as far as possible, their preferences for interventions (or not) and place of death are respected. EPaCCS represents one of several interventions which, by both increasing the knowledge of, and in turn response to, what patients want and, in consequence, potentially reducing "unnecessary" or "unwanted" hospital admissions close to death, will achieve better outcomes while also reducing the cost in NHS resources.

There is, however, one serious limitation in much of the literature on this topic. It tends to assess costs and outcomes after the event, patient death, when there is no uncertainty about the outcome whereas the key decisions to commit resources are taken before death. A simple hypothetical case study to highlight this is set out below.

- A patient with advanced, inoperable lung cancer on a palliative care programme has expressed a wish not to be resuscitated (DNACPR) if their heart stops beating;
- The patient knows and understands that they are close to death;
- The patient is fully conscious, sometimes in pain, and fully able to take decisions about their health;
- The patient has a devoted partner/carer who spends a large amount of time providing care;
- This patient lives at home with a care package in place and with a high level of informal care from their partner;
- The patient suffers from periodic problems with pain and with breathing that can be improved, to some extent, by more intensive treatment that can only be provided in a hospice or hospital;
- The patient’s main carer becomes very distressed during episodes of uncontrolled pain and breathing difficulties.

This patient might be seen as the type of patient whose regular admission to hospital is not particularly effective or cost-effective. Yet this patient may wish to be admitted to hospital from time to time, to reduce their pain and discomfort or to reduce the burden on their informal carer, even though they wish to die at home. Unless they can be certain that they have a few days to live, and should stay at home to die, they may wish to be taken to hospital when they or their carer has problems. That is, while it is simple to suggest that it is not good for the patient or efficient for the health care system to take patients to hospital when they will die in two or three days’ time, it is possible that for some, possibly many, patients in this and similar situations, their proximity to death cannot be estimated with any great accuracy, or indeed that they may wish to die in hospital. Therefore, the decision whether to transfer the patient to hospital is much less clear cut than the patient’s condition and DNAR might suggest. Looking at the problem after the event gives a false perspective of certainty – that patient should not have been admitted but allowed to die at home – when there was no certainty when the decision to admit was being taken.

57 End of Life Care, National Audit Office (2008)
Put more simply, rational use of resources in the last year of life might mean fewer admissions and fewer treatments for patients in their last year of life. However, unless the date of death and circumstances leading up to the death are known in advance, there is the potential for improvements in outcomes that are associated with more, rather than less admissions to hospital, right up to the actual time of death. These gains in outcomes could, for example, include gains in reduced anxiety and lower costs for family members. Without certainty over the date of death, which determines the time for which a patient may enjoy some improvement (or slower deterioration) in their health, it is not clear that wholly rational decisions on admission can be taken.

If, as suggested here, it is difficult to identify which patients receiving or suitable for a palliative care regime do not need to be admitted to hospital, it follows that all deaths in hospital among patients receiving palliative care may not be avoidable. If many of such patients would prefer to die at home, given their prognosis and palliative care regime, a proportion may nonetheless die in hospital because, at the time the decision to admit them was made, there were perceived benefits from their admission. This is a consequence of the uncertainty of the time of death, which much of the research on end of life care seems to ignore. In the time available, relatively little research has been identified on this issue. Gott et al.\textsuperscript{58} have however examined this issue and found that only 6.7 per cent of admissions for patients suitable for palliative care regimes were potentially avoidable. It should be noted that these findings relate to patients who were suitable for palliative care regimes, though they may not actually be receiving palliative care. The findings are described by the authors as challenging the assumptions that many admissions for patients receiving palliative care are avoidable.

A key factor in the process of admission to hospital (or not) for patients close to the end of their lives, and who wish to die at home, is the timing of their expected death. Predicting death is not simple and not 100 per cent accurate. In a recent review, as part of their development of a predictive tool, Cardona-Morrell and Hillman\textsuperscript{59} note 9 definitions of end of life and 14 prediction tools. It should be noted that their tool is designed to predict death in a period of 3 months ahead. (A validation of CRISTAL is understood to be in progress but as yet not reported.)

This is not to suggest that shared knowledge of an advance care plan (ACP) and a choice of place of death cannot reduce hospital use. As noted earlier, Abel et al., (2013) where (hospice) patients have an ACP and a wish to die at home, this can reduce their use of hospitals in the last year of life, by over £3,500 per patient. There was also a reported impact on emergency admissions, with patients dying outside hospital having 1.7 emergency admissions in the last year of life and those dying in hospital having 2.2 admissions in the last year of life, suggesting a potential saving.

However, this could be misleading as patients who died in hospital must clearly have at least one admission in the last year of life whereas patients who die outside hospital could have zero admissions in some cases. (The research literature does not make clear if the final admission for patients who die in hospital is counted as an admission in the last year of life but it seems reasonable to assume that this admission is indeed counted.) Putting aside other issues about the generalisability of the results here (hospice patients with cancer may experience distinctly different care pathways) a further issue concerns the impact of EPaCCS in widening the sharing of

\textsuperscript{59} Cardona-Morrell and Hillman, BMJ Support Palliat Care doi:10.1136/bmjspcare-2014-000770
information that may already be shared in other ways, e.g. home records of ACP and DNAR. Where effective systems are already in place, EPaCCS may make less of a difference, making the impact of EPaCCS less discernable in any evaluation. This does not, however, mean that there is no additional benefit, for example in access to information out of hours.

In summary, there is a risk that, as in other studies "health economists take a difficult problem, turn it into a simple problem, solve the simple problem and give themselves a round of applause" (Gorden Best, former director, King’s Fund College). The difficult problem is understanding the anticipated costs and outcomes at every point where a decision is made about patient care, as well as the actual outcomes. If the focus is on the simple problem, can the NHS save resources by not admitting people close to the end of life to die in hospital when they wished to die at home, then we may be able to find some solutions. For example, the NAO report noted earlier contains estimates of savings from reduced admissions and shorter stays for patients close to the end of life. Clearly, the simple question, will reduced admissions save money, is easy to answer. The harder questions are:

- How is this to be achieved?
- At what cost?
- With what consequences in costs and outcomes for the person, their carers and other stakeholders?

The focus of an assessment should really be on understanding anticipated costs and outcomes at every stage, when the date of death is not known and may be relatively uncertain for at least a proportion of patients.

### 9.4 The Literature on Costs of End of Life Care

In the time available for the economic component of this study, it was not possible to undertake a systematic review of the literature on end of life care. Key papers are noted here, in particular systematic reviews.

There is a very large literature in health economics on the costs of care at the end of life (e.g. PubMed has 5,066 citations and 436 UK citations). This has focused typically on showing how large a share of health care resources are used in the last year of life, with the implication that this use of resources may be inefficient, given the lack sufficient time after treatment for health gains to be enjoyed. This is based, as noted above, on potential simplifications of the resource decisions actually faced by health care professionals at the time of admission. There is a smaller literature on the costs of palliative care compared to other types of care. A recent review by Optimy Inc has concentrated on identifying evidence of cost effectiveness and proposed approaches to cash-releasing savings and the incentives to introduce different models of care. This work is yet to be fully published.

The Nuffield Trust examined the costs of hospital and out of hospital care for patients in the last 90 days of life. This showed costs of hospital care in the last 90 days of life averaging £4,580 (£5,890 for those suffering from cancer). The report concludes that reduced hospital activity at the end of life would be likely to be cost-saving as the potential costs of community care or other care for patients no longer admitted to hospital would be relatively small. This finding is clearly consistent with

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60 Understanding the Health Economics of Palliative and End of Life Care, Optimit (2016) – not yet fully published

the broader knowledge of the relative intensity and staffing inputs of inpatient settings compared to community settings. This study is relatively unusual in that it focuses on the introduction of specific care models, Marie Curie nursing, at a relatively late stage, 8-14 days before death. The study used matched controls to estimate the potential impact of the Marie Curie service on admissions.

Unsurprisingly, in the period up to this time, over the last year of life, patients with and without end of life care from Marie Curie nursing had similar levels of hospital admissions. Over the whole cohort of patients, the Marie Curie patients had 2.5 fewer days in hospital than the controls. However, this result also illustrates the relatively low rates of admission for patients at the end of life, at least in this study. Admission rates reported per 1,000 patients were found to be around 10 per 1,000 for the Marie Curie group and up to almost 70 per 1,000 patients in the control group. That is, even for those not receiving Marie Curie care in the community, admissions were below 10 per cent of all cases on any single day. However, a crude estimate of all admissions in the last two weeks of life suggests that around 500 admissions took place per 1,000 patients at the end of life. That is, around half of the control group died in hospital or had an admission very close to death, a figure that appears consistent with other data on place of death.

Overall, the finding that shifting care at the end of life out of hospital would be cost-saving is consistent with expectations and other research. However, in common with other research examined, this study does not address the issues of the predictability of death or the reasons for admission. While it might be possible to reduce the number of patients admitted to hospital at the end of life, it is plausible that many admissions reflect decisions where the exact end of life was unknown and where they may have been a range of benefits anticipated from a hospital admission. These aspects of admissions will have big implications for the success or otherwise of attempts to reduce hospital admissions at the end of life.

To provide a narrower focus for this brief review, Advance Care Planning (ACP) and its impact on costs were used to identify systematic reviews. ACP is a key element in the potential impact of EPaCCS. If a patient has a plan for the end of their life and if this plan influences their subsequent care then sharing information on that plan and its existence may help achieve the potential impact of ACP. Clearly, for patients receiving palliative care but without an ACP, there may be differences but at the same time a decision by a patient to enter a palliative care regime can be seen itself as a form of planning for less interventional future care. Two systematic reviews were identified. These provide a convenient but not necessarily comprehensive assessment of the current state of research on the cost impacts of ACPs.

In a recent systematic review of the effects of ACP on costs near the end of life, using predominantly US sources, Klinger et al.\(^{62}\) conclude that costs are reduced by an ACP. While this study may be influenced by the use of US data, where there may be a tendency to intervene more extensively in the last year of life, it demonstrates some impact. The authors also propose that more research is needed, particularly controlled trials to determine which elements of ACP are most cost-effective.

A systematic review of the economic evidence for advance care planning, carried out in the UK\(^{63}\), concluded that there are no published cost effectiveness studies of ACP. Available studies tend to concentrate on “healthcare savings, usually associated with reduced demand for hospital care”. The authors conclude that savings can be

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\(^{62}\) Klinger et al. DOI: 10.1177/0269216315601346 pmj.sagepub.com

identified for some patients in some circumstances and also that there is no evidence that ACP increases costs (though this may depend on the extent of measurement of community and social costs).

Based on this limited literature, it appears that ACP is unlikely to increase costs for health care, which is consistent with the potential impact of reduced interventions at the end of life. If ACPs can generate some savings for the health care system, then it seems plausible that sharing information on ACPs through EPaCCS in the UK may generate savings for the NHS. However, the extent of these savings and the impact of ACPs and changes in hospitalisation on other agencies and carers is not known.

Public Health England has recently commissioned a report on the costs and outcomes of palliative care. This report concludes:

“Even though none of the studies performed a robust cost effectiveness analysis of palliative care, few studies argue that palliative care services and models are not cost saving or cost effective.”

This conclusion is entirely plausible, assuming care at home has a lower cost than care in other settings. However, it does not directly address the effectiveness of EPaCCS in achieving a preferred place of care, which is of course consistent with its focus on palliative care. The studies reviewed are not comprehensive and so do not address issues such as the perceived benefits to patients and families of hospital admission even when a patient is in a palliative care regime.

On balance, while it seems likely that reducing hospital admissions at the end of life would be cost-saving, it is less clear whether some health-related outcomes (pain, symptoms, anxiety for patients and carers, carer burden) would always be lower or higher as a result of reduced admissions and more deaths in the preferred place of death.

9.5 An Economic Assessment of EPaCCS

Based on the discussion above, a comprehensive study of both costs and outcomes, a Cost Utility study in the terms used here, would require:

- Data on each decision to change a patient’s place or type of care;
- Data on the anticipated outcomes from this change, for all the relevant stakeholders (patient, carers, family…);
- Data on the anticipated costs from this change in treatment, to NHS hospitals, NHS community services, hospice inpatient and community services, patients themselves, carers and families;
- Data on actual outcomes and costs, including costs to families;
- Valuation of anticipated and actual outcomes, using appropriate instruments for assessing the wellbeing or utility associated with each change in care;
- Data on actual costs of systems implemented in order to change patient care (e.g. EPaCCS).

For the present study, almost none of this data exists and so a comprehensive study is not possible. For a detailed cost minimisation study, based on the assumption that admissions close to actual death were of no or negligible value, the data required comprise:

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• Costs of hospital admissions for patients with ACPs, receiving palliative care or with other known reasons for reduced hospital interventions, with and without EPaCCS, ideally drawn from a controlled study in which EPaCCS shared data on only some patients in an area;

• Analysis of the costs of care for similar patients, from the time of designation as an ACP or palliative care patient to the end of life, (even if this is longer than one year) in areas with and without EPaCCS. Since the date of death is arbitrary, and since time from designation may affect hospitalisation, it would be particularly helpful to understand patient hospitalisations from the date of designation. For example, three patients with an ACP set up at the same date may receive different care in the last year of life if one dies relatively soon after the ACP, (when pre-ACP hospitalisations would be included in the last year of life), a second dies after about a year (during which some elements of intervention may have continued even with an ACP) and a third dies several years’ later (when increased frailty may be a factor in reducing hospitalisation);

• Costs of care in the community (care home, patient’s home, hospice care) with and without EPaCCS;

• Costs of EPaCCS introduction.

Only a limited use of a control group has been possible in this evaluation and so any data is most likely to come from before and after studies of hospital admission close to time of death and preferences for place of death. A substantial rise in the proportion of patients dying in their preferred place of death would provide evidence of an impact from EPaCCS through other factors, e.g. general resource constraints, higher background levels of hospital bed occupancy, could lead to fewer admissions of elderly and frail patients not directly attributable to EPaCCS. That is, reduced admissions and more patients dying in their preferred place of death would potentially provide an over-estimate of the impact of EPaCCS if resource constraints were likely to have changed at the same time. A trial of similar patients in an area, known and not known to an EPaCCS system, would avoid this and other potential biases.

It is notoriously difficult to obtain comprehensive, accurate costs of community health and social care because of the lack of systems monitoring resource use in the community. Care home costs are more directly measurable but care at home less so. In principle, costs to family and carers can be obtained from direct data collection but data collection close to the time of death could well be seen as intrusive. No significant data has been generated in the present evaluation on the costs to community and informal care as a result of decisions on hospital admissions.

The cost of EPaCCS implementation should be relatively easy to identify where it is implemented as a single system, although we have seen that this is increasingly not the case. There are therefore an increasing number of circumstances where the cost of EPaCCS cannot be estimated:

• EPaCCS could be developed within the NHS by organisations that do not recharge directly for the cost of their services;

• More commonly, if EPaCCS is not implemented as a single system but as part of wider changes in systems for data sharing across a health economy, there is no easy way of identifying what part of the overall total cost was attributable to the elements that share information on the patients’ end of life health state and preferences for care.
A further difficulty common to evaluations of changes in records and information technology is that different areas may already have different systems in place to share information. For example, a clear summary of a patient’s wishes, set up to be clearly visible to ambulance and other health care personnel, could achieve the same effects as EPaCCS. It would be important to have a clear baseline in each area of the extent of information sharing on ACPs and the extent to which this information is actually shared. The current position is that EPaCCS is increasingly not been implemented as a single stand-alone system, which might imply that some savings from a stand alone approach are envisaged.

In general, arising from the earlier work in this area and the findings from elsewhere summarise here such as the ACP analysis, if it can be shown that EPaCCS has a relatively low cost, relative to the cost of care in the last year of life, then it would be plausible to argue that EPaCCS has the potential to reduce costs for hospitals. However, this would still leave open questions about the cost to other agencies and to families.

10 Evaluation findings

This evaluation has taken a broad qualitative and quantitative sweep of the EPaCCS landscape to explore the extent to which EPaCCS is making a positive contribution to improved experiences for people at or approaching the end of life as well as being cost-effective.

In undertaking this evaluation we have faced challenges in identifying quantitative evidence of impact from EPaCCS over and above that experienced in non-EpaCCS sites. We have pursued three avenues of investigation to identify system-wide benefits in sites where EPaCCS has been implemented, i.e. local EPaCCS, nationally available data or Hospital Episode Statistics. There are some possible areas where impact can be discerned but generally the evidence is lacking.

This may be because of a relatively small sample of evaluation sites where we were reliant on either EPaCCS data or Hospital Episode Statistics. In the case of nationally available data there are uncertainties in what the self-reporting from CCGs fully represents in terms of the extent of EPaCCS implementation. However there has been a consistent message from this part of the evaluation, in part confirmed in our discussion with system leaders, that quantitiive evidence of impact from EPaCCS is not currently available on a consistent, system wide basis. The current survey of EPaCCS sites to be published later this year is expected to suggest a similar picture, i.e. that whilst increasing numbers of locations have EPaCCS in place their potential for system-wide impact remains in its early stages.

We have also identified examples of other challenges in realising wider interoperability of systems to support health and care. This includes the impact of organisational change, technical issues and information governance requirements, all of which have impacted on EPaCCS implementation in one or more locations. We are also concerned that despite the National End of Life Care Strategy and subsequent reviews emphasising the importance of good information about end of life care services for monitoring and improvement, this is currently sorely lacking. These limitations are hampering the benefits that EPaCCS has the potential to bring.

We have also found that on occasion there is an over reliance on technical solutions to secure improved co-ordination, which carries risk if people lose confidence in these systems due, for example, to factors such as poor handling of changes in who manages them. This has been illustrated in one location where a new provider was commissioned for a service that also hosted the EPaCCS system – despite pressing
for reports the CCG failed to secure reporting for over 6 months, which led to a loss in clinical engagement and therefore reduced the use of the system. In another location significant barriers to implementation arose due to the use of ‘IT language’ that was inaccessible to professional and project managers.

However, we have identified a consistent message when exploring the experience of patients, carers and professionals – that they want and expect services to work closely together to support ‘a good death’, where choices are respected and staff are able to provide good quality, compassionate care and support to both the patient and their carer. In our in-depth interviews with people whose care has been provided in the context of a local EPaCCS system services broadly met expectations, for example:

- There were cases of good, early identification of end of life care needs;
- The presence of a shared record does speed up care and avoid duplication;
- ‘System integrity’ was generally reported as being good – i.e. things seemed to work together well;
- Support for carers and families has been reported as being good;
- Individual preferences are broadly being met, with some examples of ‘going the extra mile’ and of showing real compassion in care;
- Realising someone’s preferred place of death does feature highly for patients, carers and professionals;
- There is a high level of trust between patients/carers and the professionals in making difficult decisions, such as admission to hospital.

Some learning from these interviews suggests that:

- Confidence, and associated training to build capability in being able to raise the subject of end of life for some staff is still not universal and may therefore be hampering progress;
- Time and resource can both sometimes militate against good practice, such as undertaking advance care planning, so the benefits that EPaCCS can bring is again not fully realised;
- Emphasis on ensuring the review and updating of care plans needs to be increased;
- There is still variation, if not fragmentation, in some areas of end of life care.

When we undertook the relational value (R’) survey we also found indications that the findings from the in-depth interviews could be corroborated. In particular, when comparing an EPaCCS site with a non-EPaCCS site we found that there was a consistent, though not statistically significant, alignment of differences to what would be expected from the introduction of EPaCCS – and this difference was present despite the non-EPaCCS site being known for its effective collaboration and integrated working. These findings suggested:

- That the overall quality of relationships were higher in the EPaCCS site;
- That the biggest difference in survey outputs was for system integrity, i.e. that things ‘work together well’, something that you would expect from the introduction of EPaCCS;
Similarly, there was a difference when the survey considered the contribution that good ‘process’ made to improved relationships.

Our conversations with system leaders provided a consistent and positive message about the impact of EPaCCS, although for some this was still aspirational and for most there was a heavy reliance on anecdotal evidence. Defending this to some extent one person commented to the effect that “if there were anecdotes of poor care and negative impacts from EPaCCS I would not be experiencing an almost universally positive reception from my staff”.

Despite some of the challenges faced in identifying quantified evidence this evaluation has found that EPaCCS can make a significant and positive contribution to an improved experience for patients, carers and professionals. We have also concluded, along with similar recent work, that cost-effectiveness is at least not reduced through an emphasis on early recognition, improved co-ordination of care and choices being realised about place of death.

Our findings can therefore be summarised as follows:

1. That generally it is not possible to demonstrate that EPaCCS is making the difference in system level outcomes compared to non-EPaCCS sites because:
   a. The range of clients for whom EPaCCS is being used remains focused on cancer, with some evidence of more general progress in areas such as dementia.
   b. That the ability of EPaCCS systems to report on progress and outcomes remains generally very poor.

2. There is a view that whilst deaths in hospital, DiUPR and realising preferred place of death have provided the basis on which outcomes have been measured to date, that they should not be the sole determinants of measuring impact from EPaCCS. Patients, carers, professionals and system leaders have all been as concerned about ‘achieving a good death’ i.e. about maintaining control, being treated well and respectfully, and being with the ones they love. EPaCCS is just as essential to supporting these outcomes but they are not what we are systematically measuring at a local level.

3. It remains difficult to determine a true economic benefit arising from EPaCCS due to a number of factors, including: generally poor reporting functionality in EPaCCS (i.e. for evaluation, monitoring and improvement purposes); the move to seeing EPaCCS as part of a wider system (thus not making it possible to separate out costs); a continuing lack of information at a system level for the cost of alternatives to hospital care; and gaps in our knowledge of the wider costs such as those taken on by carers and relatives. However, the fact that investment continues is as much a reflection of the general imperative to enhance technology support within the NHS and the drive to greater integration, inter-operability and sharing of information across the health and social care systems, as it is to a strict economic evaluation of one part of that system.

4. That the experience of end of life care can be positive where EPaCCS is present, but that this is not guaranteed – technology in isolation is not guaranteed to bring benefits, which means that it’s very important that healthcare teams work together and provide services that are in the best interests of the patient and family.
5. Service users and carers continue to express how important coordination of care at the end of life is, and we have an indication that where EPaCCS is in place that the integrity of the system that supports compassionate care is enhanced.

6. That those involved as 'system leaders' say that they, and the professionals they work with, continue to see EPaCCS as an important tool to improve coordination of care and outcomes at the end of life and that anecdotal evidence of benefit is plentiful if not always systematically captured.

In isolation individual findings are either tentative or highlight areas where additional work could be undertaken. However, taken together as a range of different perspectives on a complex and challenging area of service, we conclude that EPaCCS has a vital role to play where embedded in effective service offerings and in a positive relational context and makes a contribution that is valued by patients, carers and professionals.
Appendix 1: Semi-structured interview questions

1 Professionals

Introductions – purpose of the interview, who we are, interview recording, expectations of time for the interview etc. (10 mins)

I’m interested in your experience of the system of end of life care in [locality]. (20 mins)

- what’s your role?
- What kind of relationship do you have with patients/carers/other team members?
- Do you have an EPaCCS system in your area [prompt: an electronic system for co-ordinating information about palliative or end of life care]. If YES: what’s your experience of working with it? If NO: how does the team share information and co-ordinate care?

I’d like to talk about how you see the system of care working here (30 mins – approx. 6 mins per domain)

- How is the system co-ordinated? Have you experienced any delays or inconsistencies in the way care for end of life is provided?
- How does the system allow for the fact that everyone’s different, and has different needs and preferences?
- How fair do you feel the system is? [prompt: are people treated fairly, regardless of their needs, given the demands on the system as a whole?]
- Are people treated with compassion and empathy? [prompt: Can you give examples of where this has/ hasn’t happened?]
- How much trust do you have that the system will do what’s right for patients? Do you think people in the system trust one another? [prompt: Can you give examples of where this has/ hasn’t happened?]

Is there anything else that you’d like to say about your experience of end of life care here that we haven’t already talked about?

Conclusions – thanks, what we will do with the information, offer to share report.
2 Patients and carers

Introductions – purpose of the interview, who we are, interview recording, expectations of time for the interview etc. (10 mins)

I’m interested in your experience of the system of end of life care in [locality]. Could you tell me your story? (20 mins)

- how was your condition diagnosed?
- when did you first have a conversation with someone about end of life care?
- what has happened since then?

I’d like to talk about how you see the system of care working here (30 mins – approx. 6 mins per domain)

- How is the system co-ordinated? Have you experienced any delays or inconsistencies in the way care for end of life is provided?
- How does the system allow for the fact that everyone’s different, and has different needs and preferences?
- How fair do you feel the system is? [prompt: are people treated fairly, regardless of their needs, given the demands on the system as a whole?]
- Have you yourself been treated with compassion and empathy? [prompt: Can you give examples of where this has/ hasn’t happened?]
- How much trust do you have that the system will do what’s right for you? Do you think people in the system trust one another? [prompt: Can you give examples of where this has/ hasn’t happened?]

Is there anything else that you’d like to say about your experience of end of life care here that we haven’t already talked about?

Conclusions – thanks, what we will do with the information, offer to share report
3 Consent form

Participant Identification Number: _________________

EPaCCS study: in depth interviews
Researchers: Dr Zoe Neill

Consent Form

I have read and understand the information sheet for the above study.  

I have had the opportunity to consider the information and to ask questions about the above study.

I understand that my participation is voluntary and that I am free to withdraw from the study up to the data synthesis stage.

I agree to take part in the above study.
I agree to the interview being audio recorded.

I agree to being interviewed by the researcher in my workplace or other suitable venue that is mutually agreed to.

I agree to anonymised direct quotations being used in the report and possible publications or presentations.

Participant’s name: ___________________ Signature: _________________ Date: ____________

Researcher’s name: ___________________ Signature: _________________ Date: ____________

Please return to Dr Zoe Neill, 2 Leadhall Road, Harrogate, HG2 9PE
## Appendix 2: The relational value (R') framework

<table>
<thead>
<tr>
<th></th>
<th>Definition</th>
<th>For example…..</th>
<th>What it would look like…....</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Integrity</strong></td>
<td><em>How things interconnect and function</em>: Reflects the consistency with which interactions between parties to a relationship can be relied upon and leads to the development of a sense of unity, wholeness, coherence, cohesion, undividedness, togetherness, solidarity or coalition.</td>
<td>When decisions or actions about the care of an individual are carried out as agreed, with no single party pursuing alternative routes through lack of timely information.</td>
<td>The purpose or function of the system is understood and owned by all with clear boundaries, within which everybody pulls together – genuine common purpose.</td>
</tr>
<tr>
<td><strong>Respect</strong></td>
<td><em>How we treat others</em>: Ensures due regard for the feelings, wishes, or rights of others. Comprises: consideration, thoughtfulness, attentiveness, politeness, courtesy, civility, taking into account, making allowances for, taking cognisance of, observing, paying heed/attention to, bearing in mind, being mindful of.</td>
<td>When there is mutual understanding and appreciation of the needs of each party to a relationship such that our actions do not undermine each other.</td>
<td>That each party, individual, group or organisation, has a recognised contribution to make, without which the purpose or function of that system cannot be achieved to its full potential.</td>
</tr>
<tr>
<td><strong>Fairness</strong></td>
<td><em>How equity is achieved</em>: Occurs where parties to a relationship are treated equally, for example with respect to executing procedures, and where the explanations provided to people are open and accessible to all, having the effect that any prior disadvantage is removed to the greatest extent possible.</td>
<td>Where there is openness about the implications of choices being made in the context of wider resource issues and where decisions are made jointly in the context of intended outcomes.</td>
<td>That no one individual, group or organisation is seen to take advantage of a weakness in another; which may arise through privileged information or other influences.</td>
</tr>
<tr>
<td><strong>Compassion</strong></td>
<td><em>How much we understand each other</em>: Is expressed through relationships based on compassion. In an organisational context this means that we make efforts to understand the pressures experienced by other parties and work together to address these over time and across settings.</td>
<td>That we act in ways that enable the full breadth of the others situation to be taken into account and are willing to ‘go the extra mile’.</td>
<td>That each individual, group or organisation is able to ‘live in someone else’s shoes’ and by doing so be sensitised to the risks arising from a lack of integrity, respect or fairness.</td>
</tr>
<tr>
<td><strong>Trust</strong></td>
<td><em>How much we put ourselves in other people’s hands</em>: Is the optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for their interest. This leads to the emergence of reciprocity, obligations and common identity and the emergence of a range of behaviours such as: cooperation, risk taking, obligations arising and being adhered to, belief in the future value of cooperating and the ability of systems to deal with complexity.</td>
<td>That we are confident that others will always act in our own interest even when it’s difficult for us to take action ourselves.</td>
<td>That others will act in your interests, and visa versa, as a means to achieve the overall purpose and function of the relationship within which you are operating and are committed to.</td>
</tr>
</tbody>
</table>
Appendix 3: Mind map for EPaCCS benefits

Expected benefits from EPaCCS described and mapped by Sustainable Improvement, NHS England, used to inform the initial structuring of the in-depth interview and relational value survey tool.
## Appendix 4: Statements of relational value ©

<table>
<thead>
<tr>
<th>Patient version</th>
<th>Carer version</th>
<th>Professional version</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. All the services I have contact with have the same ideas about what good care should look like.</td>
<td>1. All the services I have contact with have the same ideas about what good care should look like.</td>
<td>1. All the services involved have the same ideas about what good care should look like.</td>
</tr>
<tr>
<td>2. All my physical and emotional needs are met by appropriately skilled staff.</td>
<td>2. All the patient's physical and emotional needs are met by appropriately skilled staff.</td>
<td>2. All the patient's physical and emotional needs are met by appropriately skilled staff.</td>
</tr>
<tr>
<td>3. Important information is shared in a reliable and consistent way</td>
<td>3. Important information is shared in a reliable and consistent way</td>
<td>3. Important information is shared in a reliable and consistent way</td>
</tr>
<tr>
<td>4. I know who to speak to about what, and how to get in touch with</td>
<td>4. I know who to speak to about what, and how to get in touch with</td>
<td>4. I know who to speak to about what, and how to get in touch with</td>
</tr>
<tr>
<td>5. My own views about the best possible care for me are respected and included in how staff work.</td>
<td>5. My own views about the best possible care for the patient are respected and included in how staff work.</td>
<td>5. My own views about the best possible care for the patient are respected and included in how staff work.</td>
</tr>
<tr>
<td>6. Staff listen to, and acknowledge, what it is that matters to me.</td>
<td>6. Staff listen to, and acknowledge, what it is that matters to me.</td>
<td>6. Staff listen to, and acknowledge, what it is that matters to me.</td>
</tr>
<tr>
<td>7. I never have to repeat myself</td>
<td>7. I never have to repeat myself</td>
<td>7. The patient never has to repeat themselves when talking to different members of the team</td>
</tr>
<tr>
<td>8. My quality of life is improved by the use of aids and adaptations where necessary.</td>
<td>8. The patient's quality of life is improved by the use of aids and adaptations where necessary.</td>
<td>8. The patient's quality of life is improved by the use of aids and adaptations where necessary.</td>
</tr>
<tr>
<td>9. My ideas about the best possible care I would like are treated fairly considering all the demands there are on services.</td>
<td>9. My ideas about the best possible care I would like for the patient are treated fairly considering all the demands there are on services.</td>
<td>9. My ideas about the best possible care I would like for the patient are treated fairly considering all the demands there are on services.</td>
</tr>
<tr>
<td>10. Everyone in the team of people whose care and support I receive is equally available to me.</td>
<td>10. Everyone in the team of people whose care and support I receive is equally available to me.</td>
<td>10. Everyone in the team is equally available to the patient</td>
</tr>
<tr>
<td>11. When things go wrong I am always given a reasonable</td>
<td>11. When things go wrong I am always given a reasonable</td>
<td>11. When things go wrong I am always given a reasonable</td>
</tr>
<tr>
<td>12. I am able to access all the care and support I need.</td>
<td>12. I am able to access all the care and support I need.</td>
<td>12. I am able to access all the care and support the patient needs.</td>
</tr>
<tr>
<td>13. My views about what I think really good care for me would look like always seem to be considered</td>
<td>13. My views about what I think really good care for the patient would look like always seem to be considered</td>
<td>13. My views about what I think really good care for the patient would look like always seem to be considered</td>
</tr>
<tr>
<td>14. I feel like I am treated like a whole person and that people really understand 'all of me'</td>
<td>14. I feel like the patient is treated like a whole person and that people really understand 'all of'</td>
<td>14. I feel like the patient is treated like a whole person and that people really understand 'all of'</td>
</tr>
<tr>
<td>15. Families, friends or carers are able to contribute to decisions made about my care.</td>
<td>15. Families, friends or carers are able to contribute to decisions made about patient care.</td>
<td>15. Families, friends or carers are able to contribute to decisions made about patient care.</td>
</tr>
<tr>
<td>16. The environment in which care is provided is fully suited to my needs.</td>
<td>16. The environment in which care is provided is fully suited to the patient's needs.</td>
<td>16. The environment in which care is provided is fully suited to the patient's needs.</td>
</tr>
<tr>
<td>17. I believe that everyone is working together in the same direction to give me the best care.</td>
<td>17. I believe that everyone is working together in the same direction to give the patient the best care.</td>
<td>17. I believe that everyone is working together in the same direction to give the patient the best care.</td>
</tr>
<tr>
<td>18. I trust people to have my best interests at the heart of what they do.</td>
<td>18. I trust people to have the patient's best interests at the heart of what they do.</td>
<td>18. I trust people to have the patient's best interests at the heart of what they do.</td>
</tr>
<tr>
<td>19. People are open and honest when things go wrong and work hard to make sure it doesn't.</td>
<td>19. People are open and honest when things go wrong and work hard to make sure it doesn't.</td>
<td>19. People are open and honest when things go wrong and work hard to make sure it doesn't.</td>
</tr>
<tr>
<td>20. I am supported to access all the places that are important to me.</td>
<td>20. The patient is supported to access all the places that are important to the patient.</td>
<td>20. The patient is supported to access all the places that are important to the patient.</td>
</tr>
</tbody>
</table>
Appendix 5: Analysis of deaths in hospital

1) Causes of death
   a) Circulatory disease

   Figure 22: Circulatory disease – average cost of hospital admissions in last year of life of those dying in hospital, 2012-2015 (source: I5 Health from HES data, all providers for each CCG)

   Figure 23: Circulatory disease – average number of hospital admissions in last year of life of those dying in hospital, 2012-2015 (source: I5 Health from HES data, all providers for each CCG)
b) **Respiratory disease**

Figure 24: Respiratory disease – average cost of hospital admissions in last year of life of those dying in hospital, 2012-2015 (source: I5 Health from HES data, all providers for each CCG)

Figure 25: Respiratory disease – average number of hospital admissions in last year of life of those dying in hospital, 2012-2015 (source: I5 Health from HES data, all providers for each CCG)
2) Age groups
   a) 18-64 year olds

Figure 26: 18-64 year olds – average cost of hospital admissions in last year of life of those dying in hospital, 2012-2015, all causes (source: I5 Health from HES data, all providers for each CCG)

Figure 27: 18-64 year olds – average number of hospital admissions in last year of life of those dying in hospital, 2012-2015, all causes (source: I5 Health from HES data, all providers for each CCG)
b) 65-74 year olds

Figure 28: 65-74 year olds – average cost of hospital admissions in last year of life of those dying in hospital, 2012-2015, all causes (source: I5 Health from HES data, all providers for each CCG)

Figure 29: 65-74 year olds – average number of hospital admissions in last year of life of those dying in hospital, 2012-2015, all causes (source: I5 Health from HES data, all providers for each CCG)
c) *75-84 year olds*

Figure 30: 75-84 year olds – average cost of hospital admissions in last year of life of those dying in hospital, 2012-2015, all causes (source: I5 Health from HES data, all providers for each CCG)

Figure 31: 75-84 year olds – average number of hospital admissions in last year of life of those dying in hospital, 2012-2015, all causes (source: I5 Health from HES data, all providers for each CCG)
d) 85+ year olds

**Figure 32:** 85+ year olds – average cost of hospital admissions in last year of life of those dying in hospital, 2012-2015, all causes (source: I5 Health from HES data, all providers for each CCG)

**Figure 33:** 85+ year olds – average number of hospital admissions in last year of life of those dying in hospital, 2012-2015, all causes (source: I5 Health from HES data, all providers for each CCG)