

Project title: Electronic Palliative Care Co-ordination Systems (EPaCCS) in end of life care: evaluating their implementation and optimising future service provision

Project reference: NIHR129171

Version: 0.1

Date: 29th June 2020

Chief Investigator: Dr Matthew Allsop

Research Team: Professor Michael Bennett, Professor Suzanne Richards, Professor Robbie Foy, Dr Samuel Relton, Dr Maureen Twiddy, Dr Katherine Sleeman, Dr Catherine Evans, Mr Paul Carder, Dr Pablo Millares Martin, Ms Barbara Hibbert, Mr Nicholas Plant, Research Fellow Leeds (TBA), Research Fellow London (TBA)

Sponsor: Mrs Clare Skinner, Head of Research Integrity & Governance, Faculty of Medicine and Health, University of Leeds

Funder: National Institute for Health Research, Health Services & Delivery (HS&DR) programme

NIHR CRN portfolio number: TBA

Research ethics approval: TBA

Start date: 1st September 2020

End date: 28th February 2023

Protocol version control

Version	Date	Author(s)	Details
0.1	29-06-2020	Applicant team	Original detailed project description (DPD) submitted as part of the stage 2 (full) application, unchanged following panel feedback

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1. Summary of research

Background: Electronic Palliative Care Co-ordination Systems (EPaCCS) are central to end of life care policy despite critical gaps in the evidence base underpinning their use. It is not clear how EPaCCS are being implemented across England and there has been a distinct lack of research to understand their use in routine care.

Aim: To understand how EPaCCS are currently being used in routine care and guide the development of interventions to support their optimal implementation and maximise patient benefit.

Research objectives:

1. To examine how EPaCCS are being implemented nationally, their intended impact, cost, and existing processes for monitoring uptake and use.
2. To examine community and hospital-based healthcare professional perceptions of the value and impact of EPaCCS on advance care planning (ACP) in the management of patients with progressive chronic illnesses.
3. To explore factors influencing uptake and use of EPaCCS to support ACP in routine clinical practice.
4. To explore the perspectives of patients with progressive illness and their caregivers on EPaCCS, the anticipated impact from their use, and expectations for their future development.
5. To synthesise findings to form a conceptual map underpinning EPaCCS, detailing optimal implementation, linkages with the intended outcomes, monitoring, methods of evaluation and identification of future intervention development to support user engagement.

Methods: We combine international expertise in palliative care research and intervention development to support improvements in palliative and end of life care. In partnership with NHS England and Public Health England, using a mixed method approach, our study will involve five related work packages:

WP1: Online questionnaire survey of end of life care leads at clinical commissioning groups in England. Building on a previous survey by the team and working jointly with Public Health England, we will identify models of EPaCCS implementation, barriers and facilitators experienced, and the extent of information sharing via EPaCCS.

WP2: Online survey of community and hospital-based healthcare professionals in West Yorkshire and London to identify the perceived value and impact of EPaCCS on ACP and the management of patients with progressive chronic illnesses, identifying how EPaCCS are used in routine care delivery and how intended outcomes from EPaCCS use are understood.

WP3: Qualitative interviews with a sample of survey respondents (WP2) to understand use of EPaCCS in routine care, determinants of when and how they are used, and barriers and facilitators to uptake.

WP4: Workshops with patients with progressive chronic illnesses and caregivers to explore perspectives on EPaCCS and anticipated positive and negative impact from their use, alongside identifying expectations around access to their own EPaCCS record.

WP5: Regional and national Theory of Change workshops, presenting and validating a synthesis of findings from WP1 – 4 in a conceptual map. We will agree the ultimate intended impact from EPaCCS, determine preconditions, and identify ways of enhancing or developing new interventions to optimise their implementation.

Anticipated impact and dissemination: Provision of evidence needed to inform planned national rollout of EPaCCS as part of routine NHS service delivery. Supported by NHS England and Public Health England, we will ensure our findings can directly inform future development of EPaCCS.

2. Background and Rationale

Electronic Palliative Care Coordination Systems (EPaCCS) were proposed and initially developed by the Department of Health in 2009 to facilitate the documentation and coordination of advance care plans (ACPs) for patients with progressive chronic illnesses. EPaCCS form part of an electronic clinical record system where information relevant to the delivery of a patient's care can be easily recorded and accessed. This electronic record is typically initiated by healthcare professionals in the community and is designed to be shared across healthcare providers to improve coordination of care for patients with progressive chronic illnesses, and in particular for those nearing the end of life. This type of data sharing can be referred to as Health Information Exchange, and is integral to visions to transform and modernise healthcare, yielding a more effective, efficient and personalised service[1]. The UK Government has called for national roll-out of EPaCCS by 2020 to all areas in line with existing policy and commitments on end of life care[2-5]. However, NHS England have opted to review this expectation and are keen to collaborate with our team to generate the evidence required to inform future implementation.

The problem is that there has been a distinct lack of research to (a) understand the use of EPaCCS in routine care, (b) guide future implementation, and (c) optimise the impact of this important aspect of NHS service delivery. Despite a policy-level drive for EPaCCS, a 2013 survey by Public Health England showed wide variation in the uptake and use by healthcare professionals, and little reach into social care, notably care homes[6-8]. More recently, we showed 16% and 56% of clinical commissioning groups (CCGs) within the four English health authority sectors did not have an electronic palliative care system in place by 2017[9]. In those CCGs that did, reported challenges included the engagement of GPs, clinicians and nurses. This suggests that underutilisation could be a major barrier to EPaCCS supporting improvements in care for people living and dying with progressive chronic illnesses. A more detailed understanding of this complex intervention, operating at the interface of different healthcare providers/organisations, is required to guide engagement with EPaCCS and identify what needs to be in place to maximise benefit and avoid harm.

Our team recently conducted a systematic review to search, evaluate and report the state of the science of EPaCCS. CINAHL, MEDLINE, Embase, the Cochrane Library and grey literature were searched for articles evaluating or discussing electronic systems to facilitate sharing of information about advance care plans. In total, 30 articles and reports were included. Of the 26 articles, 14 were 'expert opinion' articles (editorials, discussion papers or commentaries), 9 were observational studies (cross-sectional, retrospective cohort studies or service evaluations), 2 were qualitative studies and 1 a mixed-methods study. No study had an experimental design. Much of the scientific literature on EPaCCS comprises expert opinion, and there is an absence of experimental studies evaluating the impact of EPaCCS on end-of-life outcomes[10]. We concluded there is an urgent need for qualitative studies to understand what needs to be in place to maximise benefits and avoid harms; in particular, the factors influencing whether and how healthcare professionals interact with and use EPaCCS are not well understood.

Timely coordination of care and treatment in the community is key to ensuring individuals living with progressive chronic illnesses receive the right care in the right place at the right time[11]. Receipt of the right care promotes quality of life and enables individuals to remain in their usual place of care, typically at home or in a care home[11-13]. EPaCCS are central to a key policy on end of life care and are intended for national roll-out, yet there are critical gaps in the evidence base that are hampering their effective use and that may potentially affect safety. Innovation to drive improvements in the quality of care is desirable, but when introducing a complex intervention at the interface of different stakeholders there needs to be an understanding of the potential for unintended consequences and patient harms[10]. Logical and well-intentioned policy recommendations can do more harm than good[14].

Collaborating with NHS England and Public Health England, our project will determine the perspectives and needs of patients, healthcare professionals, and commissioners on using EPaCCS, and understand the potential impact on outcomes of care and patient safety. From these, we will identify recommendations to increase engagement with EPaCCS and subsequently ACP documentation and communication. These findings will inform a national programme on scalability and sustainability to maximise patient benefit and avoid previous criticisms of rollout of palliative and end of life care initiatives where the lack of evidence led to negative consequences[15, 16].

This work is necessary to inform national EPaCCS roll-out, reduce uncertainty around engagement with these systems, and contribute to evidence-based improvements in the quality and efficiency of care of patients with progressive chronic illnesses. The proposed research has been developed in direct collaboration with NHS England and Public Health England and will address key issues that typify current concerns and imperatives regarding coordination and advance planning of care in the Ambitions for End of Life Care national action framework[8]. The proposal also addresses two questions from the

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James Lind Alliance priority setting partnership[17]:(iii) benefits of advance care planning and listening to and incorporating patients' preferences; and (xiii) best ways to make sure there is continuity for patients at the end of life[18].

3. Evidence explaining why this research is needed now

A systematic review of 113 studies produced evidence that discussing, documenting and communicating advance care planning (ACP) is associated with better quality care for people approaching the end of life[19, 20]. A further systematic review also highlights that ACP can enable individuals to remain in their usual place of care in the community and reduce reliance on emergency hospital care[21]. Having a recorded preference for place of death (a key aspect of ACP) is associated with greater odds of both dying at home (OR 6.25; 99% CI 5.56 to 7.14)[22] and of experiencing good pain relief (OR 1.87; 95% CI, 1.47 to 1.53)[23]. Advance care planning may lead to better continuity of care, and has positive impacts on patients, health care professionals, and the health system, especially for vulnerable patients[24, 25]. For those approaching end of life, qualitative studies highlight that patients attribute a pivotal role to GPs in facilitating continuity, including informational continuity i.e. use of information on past events and personal circumstances to provide individualised care, of which important aspects include exchange of information between GPs, specialists and care facilities[26].

While EPaCCS have been proposed for national roll out to support ACP, there is a dearth of high-quality evidence supporting their use. In 2013 an NHS evaluation examining 5,662 patient deaths found that patients with a record on EPaCCS were less likely to die in hospital[27], although causality could not be assumed without accounting for temporal trends and confounding.

EPaCCS draw on existing digital infrastructure to support communication and coordination of advance care plans for patients with progressive chronic illnesses. However, digital approaches are known to be underutilised in supporting ACP[28] and this reflects a wider gap in knowledge regarding to what extent EPaCCS are supporting delivery of end of life care. In 2015, we examined 4,579 deaths from advanced progressive illnesses in Leeds. Only 26.8% of deaths of patients that died from advanced progressive disease had a record on EPaCCS, and these records were initiated a median of 31 days (IQR=78) before death. In addition, 33% of EPaCCS were created within 2 weeks of death, despite the intended use over the last year of life[29]. Wider literature points to consistently low EPaCCS use[6, 7, 29-32] with biases in who is more likely to have an advance care plan recorded and the healthcare professional that is entering data[33]. Notwithstanding this, EPaCCS remain well placed to facilitate continuity and coordinate care across all care settings, as highlighted in the Daffodil Standards[34], which are UK General Practice Core Standards for Advanced Serious Illness and End of Life Care, launched earlier this year. Furthermore, end of life care is planned to become part of the Quality and Outcomes Framework (QoF) contract in the future. Guidance around identifying quality improvement activities and setting improvement goals includes offering *"timely and relevant personalised care and support plan discussions; documented and shared electronically (with appropriate data sharing agreements in place) to support the delivery of coordinated, responsive care in and out of hours with key cross-sector stakeholders"* (page 81). The inclusion of this approach in the QoF contract could drive use across general practice, but research is needed to optimise their implementation, including the involvement of healthcare professionals and services beyond general practice.

To date, the development and implementation of EPaCCS has been mostly pragmatic, with no underlying theoretical basis guiding its design and anticipated mechanisms of action. There is also a lack of empirical research on their development and implementation, including their intended impact by those using EPaCCS. There is a need to understand the perspectives of EPaCCS users (including unreported perspectives of patients) to determine how use of EPaCCS can be optimised in the complex environment at the interface of different healthcare professionals and services (e.g. [35], [36]). EPaCCS are essentially complex healthcare interventions and should be understood and evaluated as such[37]. This proposal is also timely given the increasing application of digital technologies in end of life care[38, 39].

4. Study aims and objectives

Our mixed methods design will aim to understand factors influencing current uptake and use of EPaCCS in routine care, determine user preferences for its development to optimise engagement, and determine how best to evaluate their intended impact following implementation.

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5. To synthesise findings to form a conceptual map underpinning EPaCCS, detailing optimal implementation, linkages with the intended outcomes, monitoring, methods of evaluation and identification of future intervention development to support user engagement.

The outputs will guide development of necessary underpinning theory for EPaCCS and generate consensus on the ultimate intended impact of EPaCCS. This will generate the foundation knowledge required to understand the role of EPaCCS in supporting patients with progressive chronic illnesses and how best to optimise their implementation and evaluate their future use.

5. Research Plan

Design of research and theoretical/conceptual framework

This proposal has been developed in partnership with NHS England and Public Health England and NHS England, with earlier planning discussions reflected in End of Life Care Programme Board for NHS Improvement and NHS England[40]. Working with NHS England and Public Health England, we will seek to understand engagement and implementation of EPaCCS with concurrent, focused regional activities in West Yorkshire (population: 2.3 million) and London (population: 8.1 million). Our proposed sample of 16% of the UK population (10.4 million in West Yorkshire and London) will capture both patient and service diversity. To date, the development and implementation of EPaCCS has been mostly pragmatic, with no underlying theoretical basis guiding its design and anticipated mechanisms of action; there is also a lack of empirical research on their development and implementation. Our work will guide selection of a relevant theoretical underpinning for EPaCCS, enabling subsequent EPaCCS research exploring its clinical- and cost-effectiveness that is consistent with the MRC framework for the development and evaluation of complex interventions [37]. Further aligned with this framework, our study draws on a mix of methods to address research objectives that take place during the development stages of the MRC framework [41]. The study draws these methods together in a multiphase mixed methods design[42] with sequential, linked work packages (see Study Flowchart):

WP1: Online questionnaire survey of end of life care leads at clinical commissioning groups in England. Building on a previous survey by the team and working jointly with Public Health England, we will identify models of EPaCCS implementation, barriers and facilitators experienced, and the extent of information sharing via EPaCCS.

WP2: Online survey of community and hospital-based healthcare professionals in West Yorkshire and London to identify the perceived value and impact of EPaCCS on ACP and the management of patients with progressive chronic illnesses, identifying how EPaCCS are used in routine care delivery and how intended outcomes from EPaCCS use are understood.

WP3: Qualitative interviews with a sample of survey respondents (WP2) to understand use of EPaCCS in routine care, determinants of when and how they are used, and barriers and facilitators to uptake.

WP4: Workshops with patients with progressive chronic illnesses and caregivers to explore perspectives on EPaCCS and anticipated positive and negative impact from their use, alongside identifying expectations around access to their own EPaCCS record.

WP5: Regional and national Theory of Change workshops, presenting and validating a synthesis of findings from WP1 – 4 in a conceptual map. We will agree the ultimate intended impact from EPaCCS, determine preconditions, and identify ways of enhancing or developing new interventions to optimise their implementation.

Our study draws on two theoretical frameworks to guide and inform research activities:

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1) Normalisation Process Theory: We have selected Normalisation Process Theory (NPT)[43, 44] to focus on actual use and implementation of EPaCCS. It is an Action Theory that focuses on what people do around implementing a new practice, examining the factors that promote and inhibit the adoption of a complex intervention into everyday practice. It will be used to identify, characterise and explain key mechanisms that promote and inhibit the implementation, embedding and integration of EPaCCS[45]. There are four main components to NPT: coherence (or sense-making); cognitive participation (or engagement); collective action (work done to enable the intervention to happen); and reflexive monitoring (formal and informal appraisal of the benefits and costs of the intervention). NPT is particularly suited to this research, as EPaCCS have already been implemented in West Yorkshire and London, where focused healthcare professional engagement will occur in WP2 and WP3. We are seeking to understand how individuals have adopted this new technology to inform optimisation in areas where implementation has occurred, alongside understanding what lessons can be drawn for those areas where EPaCCS have not yet been implemented. Our previous research has outlined low engagement (cognitive participation) with EPaCCS. There has been no research to determine relationships with other key factors that may be influencing uptake and use of EPaCCS. Using NPT to understand healthcare professional engagement will determine relationships between use of EPaCCS (collective action) with perceived clinical utility (coherence) and engagement (cognitive participation).

2) Theory of Change: We have selected Theory of Change (ToC) to take a wider approach to understanding the process of EPaCCS implementation by considering organisational and system level factors and strategies. ToC is 'a theory of how and why an initiative works' which can be empirically tested by measuring indicators for every expected step on the hypothesized causal pathway to impact[46]. It is a pragmatic approach that is developed in collaboration with stakeholders and modified throughout the intervention development and evaluation process through an 'ongoing process of reflection to explore change and how it happens'[47]. ToC is suited to understanding EPaCCS as it allows for multiple causal pathways, levels of interventions and feedback loops which better reflect the reality of how EPaCCS may achieve their impact[48]. ToC maps will be generated throughout the project, providing a graphic representation of the causal pathways through which EPaCCS are expected to achieve their impact within the constraints of the setting in which it is implemented (framed both regionally and nationally). This will develop a theoretical understanding of the way in which EPaCCS do and could influence change, alongside clarifying knowledge gaps to generate future research questions to strengthen the design and implementation of EPaCCS. This proposal outlines engagement with key stakeholders with each component informing the development of the ToC maps for presentation in regional and national workshops towards the end of the project (WP5). The workshops will include representation from key stakeholder groups, with a ToC map guiding discussion about the real-world impact wanted from EPaCCS and identifying the causal pathways through which this change can be achieved using available resources. These are articulated as a series of preconditions leading to outcomes, the order of which can be adjusted as the pathway develops[48]. Determining what contextual conditions are necessary to achieve intended outcomes from EPaCCS, what resources are required to implement EPaCCS, and how the program gains the commitment of those resources will be crucial to understand the optimal implementation of EPaCCS across the whole health system.

Health technology under investigation

EPaCCS form a discrete part of the electronic clinical record for patients with progressive chronic illnesses designed to support the documenting and sharing of their care preferences. This electronic record is typically initiated by healthcare professionals in the community and is designed to be shared across healthcare providers to improve coordination of care for patients with progressive chronic illnesses, and in particular for those nearing the end of life. End of life care leads, clinical and managerial, are often expected to commission and guide their implementation. The development and implementation of EPaCCS have been mostly pragmatic, with no underlying theoretical basis guiding their design and anticipated mechanisms of action; there is also a lack of empirical research on their development and implementation. It is not clear what problems healthcare professionals face in using EPaCCS, what views patients and caregivers have on EPaCCS, and how EPaCCS affect patient care. From our own work, we know that only a limited number of patients have their preferences recorded with EPaCCS and for many this occurs in the last few weeks of life.

WP1: National survey of end of life care CCG leads in England (Research objective 1)

DESIGN: We will begin by conducting an online questionnaire survey of end of life care leads at clinical commissioning groups (CCGs) in England. This will target those responsible for the commissioning and implementation of EPaCCS across England. An earlier survey conducted by Public Health England[7] indicated that EPaCCS uptake was limited across the UK. Since the survey, there has been reliable support available for EPaCCS from Public Health England National End of Life Care Intelligence

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Network, NHS Improving Quality and national leads in end of life care. Recently, there has been a reinvigorated policy level interest in EPaCCS[31]. In collaboration with Public Health England, drawing on their previous experience, we will assess the current state of EPaCCS implementation across England. The survey will extend to seek data on the diversity and geographical variation in models of EPaCCS being implemented in England, their intended impact, associated resources required for their implementation, alongside determining current methods for monitoring their uptake and use.

SAMPLING: End of life care leads at the 195 clinical commissioning groups (CCGs) in England. Participants are expected to include either or both: i) a clinical lead, typically a GP, or; ii) a managerial lead in terms of the lead commissioning manager. It is expected that either are likely to be acting as an end of life care champion and helping to ensure engagement with and between clinicians and other stakeholders to assist with the development and improvement of end of life care services.

METHODS: The content of the survey will be developed by the research team with input from the steering group, including representatives from NHS England and Public Health England. We will build on existing work of the research team to better understand how well information is shared between healthcare professionals using EPaCCS[49]. It will also be informed by the Public Health England 2013 online survey content[7] by determining current uptake levels of EPaCCS by CCGs in England, but extended to include mapping models of EPaCCS implementation and their intended impact.

Novel data will be gathered in three areas which will provide foundational knowledge to inform a ToC map in WP5:

- Models used for implementation of EPaCCS being employed and in which contexts (e.g. who are the intended users and recipients of data, which providers' electronic systems are involved in information sharing, and the intended local impact of EPaCCS) alongside their costs (through requesting annual commissioned spend on EPaCCS)
- Barriers and facilitators experienced to implementation and clinical challenges faced.
- Where semantic interoperability (ability of systems to both exchange and use the information that has been transmitted) has been realised. We know from work by our team that having a patient with an EPaCCS in the electronic medical records does not necessarily lead to sharing of information among the different services and staff involved[49].
- Existing processes being used for monitoring uptake and healthcare professional interaction with EPaCCS across the CCG, alongside processes for monitoring outcomes and patient safety.

A mailing list will be created by a research fellow in Leeds with input from NHS England and direct contact with CCGs. We will use the NHS R&D Forum (co-applicant PC is a panel member) to work through R&D managers to identify appropriate end of life care leads, for example where there may have been CCG mergers. Where direct contact with end of life care leads is established, preference will be sought on postal or online survey mode, with an online web approach as a default option. The research fellow in the Leeds team will oversee distribution of the survey.

Whilst the previous response rate was 89% in 2013[7], we will assume a more conservative response rate of $\geq 50\%$ based a previous estimate of 53% from a meta-analysis of overall survey response rates among healthcare professionals[50]. We will however circulate the survey with endorsement from Public Health England with the aim of increasing engagement of target respondents. Non-respondents will be sent up to two reminders 2 and 3 weeks after the initial approach. As an incentive for participation, respondents will be offered a report of benchmarking data describing models of implementation and reported levels of uptake, and comparing local data with anonymised data from CCGs completing the survey.

ANALYSIS: A combination of descriptive statistics using SPSS to outline levels of uptake, descriptive comparisons made between models of implementation and their cost, and the use of ArcGIS to undertake analysis of geographical differences in stages and models of EPaCCS implementation, alongside their intended impact. Where possible, we will draw comparisons with the earlier 2013 Public Health England survey to convey changes to EPaCCS implementation.

ANTICIPATED OUTPUTS: We will describe the diversity and geographical variation in models of EPaCCS being implemented in England, the associated resources and costs required, and barriers and facilitators experienced. We will also identify current processes for monitoring EPaCCS uptake, use, outcomes and patient safety, and their intended impact from implementation. These findings will provide essential foundational knowledge to inform linkages between mechanisms of action and the intended patient outcomes, to be presented in a ToC map during stakeholder workshops in WP5. WP1 will also highlight crossover in EPaCCS models across England to inform dissemination of findings from the project. Engagement of end of life care leads will also create a dissemination channel for study findings and support workshop recruitment in WP5.

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WP2: Survey of healthcare professional users of EPaCCS in West Yorkshire and London (Research objective 2)

DESIGN: Initial engagement with healthcare professionals will adopt a focused exploration of the views of intended users of EPaCCS; healthcare professionals delivering palliative and end of life care (GPs, nurse practitioners, community nursing teams, palliative care clinical nurse specialists, palliative care doctors, care home staff, community social enterprises, ambulance staff and hospital-based palliative care teams). As the main intended end users of EPaCCS, it is crucial to understanding the intended impact and experience of using EPaCCS from this group. Engagement will involve a survey of healthcare professionals in West Yorkshire and London (WP2) with a follow-up interview (WP3) with a subset of respondents. Together they will enable the capture of data on the rationale underlying use of EPaCCS in the delivery of routine care. The survey will explore how EPaCCS are used, identify conditions influencing uptake and use, and the rationale for EPaCCS use based on experience (i.e. intended outcomes, alongside key beliefs that underlie the link between outcomes and the associated preconditions). We will also explore the perceived value and impact of EPaCCS on continuity of care during out of hours care and advance care planning in the management of patients with progressive chronic illnesses.

We will undertake the survey in West Yorkshire and London to gather a detailed range of perspectives referring to multiple models of EPaCCS implementation. As of September 2019, in West Yorkshire 8 of 10 CCGs are using 6 different EPaCCS, launched their systems at a range of different points over the last 10 years and adopting alternative approaches to EPaCCS implementation. In London, one electronic solution acts as the Electronic Palliative Care Coordination System, Coordinate My Care (CMC)[51], which has been implemented in the 32 CCGs in London. Through limiting engagement to healthcare professionals in these two regions, we will obtain an understanding of diversity in EPaCCS implementation models, map multiple causal pathways, levels of interventions and feedback loops to identify how EPaCCS achieve their intended impact.

SAMPLING: The target population for our survey is community-based healthcare professionals and primary care staff supporting patients with chronic progressive illnesses in community settings (i.e. GPs, nurse practitioners assigned to practices, community nursing teams, palliative care clinical nurse specialists, palliative care doctors, care home staff, community social enterprises, ambulance staff) and hospital settings (i.e. palliative care doctors and specialist nurses) in West Yorkshire and London. Recruitment of healthcare professionals will include the predominant groups likely to initiate EPaCCS. We will seek to invite a total sample size of 200 general practitioners (100 in each region), 100 community-based nurses (nurse practitioners and community nursing teams) (50 in each region), and 120 community-based palliative care doctors and nurses (60 in each region). We will supplement these groups by inviting 50 care home staff, 50 ambulance staff, and 50 hospital-based palliative care staff drawn from both regions who are additional users of EPaCCS. This will provide a total sample size of 570. Despite published response rates of 53%[50], we have assumed a conservative response rate of 35% across these professional groups resulting in a recruited sample target of 200 respondents.

GPs and nurse practitioners: We will survey GPs and nurse practitioners via links to the online survey sent to GP practices in 4 Clinical Research Network (CRN) areas: 3 CRNs in the London region and the Yorkshire and Humber CRN. CRN primary care leads will identify research active (Research Sites Initiative) practices for our sample of practices. Practices will then be emailed a link to the survey. Where possible, we will approach locality meetings of practice managers to raise awareness of the study and ask for their help before distributing the survey. To incentivise participation in the survey, we will offer certificates of completion for CPD portfolio and offer feedback of the survey findings. We anticipate this will result in the survey link reaching at least 600 GPs and 200 nurse practitioners, to achieve a sample of at least 200 GPs and 70 nurse practitioners with a response rate of 35%.

Community nursing teams: We will identify community-based healthcare trusts in West Yorkshire (Leeds Community Healthcare Trust, Calderdale Health and Social Care Economy, West Wakefield Health and Wellbeing Ltd) and London (Central London Community Healthcare NHS Trust, Croydon Health Services NHS Trust, Hounslow and Richmond Community Healthcare NHS Trust) who employ community nursing teams with support from local CRNs (e.g. Leeds Community Healthcare Trust, Central London Community Healthcare NHS Trust). The survey link will be distributed to nurses via a local collaborator / service lead identified by the CRNs (e.g. Director of Nursing or Medical Director) in community-based healthcare trusts in West Yorkshire and London. We will work with each local collaborator / service lead to determine the number of community nursing teams' roles to ensure representation of each group. For example, in Leeds Community Healthcare Trust there are 603 whole time equivalent community nursing staff, which includes nursing assistants, staff nurses, senior nurses/District Nurses, Advanced Nurse Practitioners and Community Matrons.

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Palliative care clinical nurse specialists and palliative care doctors: recruitment will be via a link to an online survey distributed to nurse leads and medical directors in all hospices listed in the Hospice UK directory serving adult populations. This will include 10 hospices in West Yorkshire and 16 in London. Community clinical nurse specialist teams with hospices will be identified by a telephone call or email to hospice nurse leads and medical directors by the researchers and a survey link distributed by these contacts to community nursing teams and palliative care doctors. We will ask all nurse leads to cascade this link out to the nurses in their teams. We estimate an average of 8 nurses per team, per hospice, totalling 208 nurses (with a recruited sample of 72 from a response rate of 35%). From previous research, we have determined a median of 6.6 whole time equivalent (WTE) doctors per site for hospices, although more than one doctor can form part of 1 WTE[52]. This will ensure a sample of 156 doctors (providing a recruited sample of 54 with a response rate of 35%).

Care home staff: We will adopt a sampling method developed by colleagues at the University of Leeds[53]. We will first identify eligible care homes (CHs) in West Yorkshire and London through searching a publicly available care directory on the CQC website. This dataset will be filtered to include only CHs providing: a) residential care (with or without additional specialist nursing and/or dementia care) from the local authority areas; b) with 10 or more beds; and c) which are categorised under the 'older people' service user band. Eligible CHs will be sent an information pack by post inviting them to consider participation in the survey. The pack will include an introductory letter, information sheet about the study and a reply slip with which to register interest or to decline participation. On receipt of reply slips registering interest in the study, researchers will re-check CHs are not ineligible and their current status on the CQC website. The CHs will then be telephoned to confirm their eligibility, to discuss the likely resource requirements for participating (CH staff completion of online survey and possible follow-up face-to-face interview) and to confirm they had no current involvement in any other conflicting research trials or studies.

Community social enterprises: The same approach to identification will be adopted as used for care homes. Social enterprises will be identified through a list of independent healthcare services via a publicly available care directory on the CQC website. Once a list is generated, providers will be limited to those interacting with health services in West Yorkshire and London. Providers will only be asked to participate if they outline they interact with services that support patients with progressive chronic illnesses. Eligible providers will be sent an information pack by post and email, where available, inviting them to consider participation in the study, which will also include an introductory letter, information sheet about the study and a reply slip with which to register interest or to decline participation.

Ambulance staff: We will work with the research teams at Yorkshire Ambulance Service (YAS) and London Ambulance Service; both are research active organisations and have confirmed they will support identification and recruitment of staff. All frontline ambulance staff are likely to interact with EPaCCS, which for YAS includes around 3,500 people, including paramedics and other clinical staff (e.g. ambulance technicians), with around 600 people working across West Yorkshire. The research teams at both ambulance services have agreed to advertise the study in weekly staff bulletins, alongside circulating participant information sheets and the survey link to a subset of staff based only in West Yorkshire and London.

Hospital-based staff: With support from local CRNs, we will identify hospital-based palliative care teams across trusts in West Yorkshire and London. We will ask team leads to distribute a link to the survey to both palliative care doctors and specialist nurses.

DATA COLLECTION PROCEDURES: The survey will seek data on healthcare professionals' views on the perceived value and impact of EPaCCS on advance care planning and the management of patients with progressive chronic illnesses. It will consist of three sections i) the respondent and their role; ii) questions about current use of EPaCCS, and the perceived impact on care planning and management; iii) items from the Normalisation MeASURE Development questionnaire (NoMAD) implementation measure [54]. The survey will be piloted on a small sample prior to roll-out.

The NoMAD is a set of 23 survey items utilising both 5-point and 11-point scales to gauge levels of agreement to statements assessing implementation processes from the perspective of professionals directly involved in the work of implementing complex interventions in healthcare. NoMad measures constructs of NPT (Coherence, Cognitive Participation, Collective Action, Reflexive Monitoring) and will be used to understand what people do, how the intervention impacts on their work, and articulate the generative mechanisms by which implementation takes place. A free text box will seek other implementation strategies, and allow us to also identify sites where implementation is not well embedded into practice[55, 56], and where participants indicate EPaCCS is unlikely to become part of routine work. Additional items will be constructed to explore the perceived value and impact of EPaCCS on continuity of care during out of hours care and advance care planning in the management of patients

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with progressive chronic illnesses (how and when they are used) and how the intended outcomes from using EPaCCS are understood. At the end of the survey, respondents will be asked to indicate if they are willing in principle to participate in follow-up in-depth interviews (which will form part of planned research activities in WP3, outlined below).

We will follow design-based approaches to improving response rates to surveys by healthcare professionals[50]. We will approach professional groups iteratively to focus efforts and coordinate follow up. To optimise respondent burden, our questionnaire will remain concise (<30 minutes to complete). We will use predominantly closed questions and structured response options in an online format using Online Surveys (<https://www.onlinesurveys.ac.uk>; formerly Bristol Online Surveys) to increase response rates. Paper copies of questionnaires will also be made available if preferred by respondents, together with stamped addressed return envelopes. To maximise response rates, non-responders will receive up to three reminder e-mails 2, 3 and 4 weeks after the after first distribution. A sample of size 200 will ensure 95% confidence intervals are no wider than +/-7% (based on intervals calculated using the normal approximation).

ANALYSIS: Frequency distributions will be used to describe respondent characteristics and survey responses, which will be conducted using SPSS. We will cross-tabulate respondent characteristics with perceptions of 'intervention fit' and NPT domains. Furthermore, responses will be clustered to look for groups of healthcare professionals with similar response patterns. The key characteristics of these groups will be identified to gain a higher-level overview of the diversity between respondents. Analysis of free-text responses will be conducted with conventional content analysis[57], using a code book comprising the NPT domains. Patterns in the qualitative data will be identified, and explored in relation to the quantitative data, with comparisons made across healthcare professional groups and regions. The research team will also determine the feasibility of charactering 'positive deviants'[58] (i.e. respondents with consistent and exceptionally high performance (e.g. based on EPaCCS uptake and use data provided in WP1) – final criteria to be determined by expert opinion) in use and integration of EPaCCS in their work. Positive deviance may, for example, be reflected by high coherence, cognitive participation and collective action scores on the NoMAD. This, alongside further responses on the survey (e.g. views about the perceived value of EPaCCS) will be used to inform sampling in WP3.

ANTICIPATED OUTPUTS: Novel insight into the perceived utility and benefits of EPaCCS across a wide sample of intended users, identification of facilitators and barriers to use and implementation of EPaCCS in practice, their intended impact, and perceived value in supporting continuity of care in the management of patients with progressive chronic illnesses. Analysis from WP2 will inform sampling for interviews in WP3 alongside topic guide items to enable follow-up on issues identified during the healthcare professional survey in WP2.

WP3: In-depth qualitative interviews with healthcare professional survey respondents (Research objective 3)

DESIGN: In-depth interviews will enable further exploration of how EPaCCS are used (including how they support continuity of care and communication of advance care planning decisions and preferences) in routine clinical practice, identify conditions influencing uptake and use for those reporting high and low levels of engagement and interaction with EPaCCS, and further explore issues identified from responses to the healthcare professional survey (WP2). We will seek to characterise participants reporting both high and low engagement.

SAMPLING: Up to 30 interviews will be conducted with respondents to the survey (WP2) in both West Yorkshire and London (study total = 60, assuming data saturation) who agreed to participate in a follow-up interview. We will purposively sample up to a maximum of 5 of each community-based healthcare professional group (GPs (including those supporting out of hours services), community nursing teams, palliative care doctors, clinical nurse specialists) alongside an additional 5 – 10 interviews representing professionals from care homes, ambulance services, and hospital settings (i.e. palliative care doctors and specialist nurses). We will sample to ensure representation of professionals reporting: 1) high and low understanding and engagement (i.e. coherence and cognitive participation) and reporting high and low familiarity (collective action) with EPaCCS as assessed by the NoMAD (WP2 responses); we will sample different levels of implementation; and if possible, we will identify examples of positive deviants[58, 59] (i.e. those centres or individuals who consistently demonstrate exceptionally high performance).

METHODS: Survey participants (WP2) who agreed to be approached for follow-up face-to-face semi-structured interviews will be contacted by letter and asked to contact the research team by email, phone or post if they would like to participate in an interview. Additional consent will be sought prior to participation in an interview. Face-to-face semi-structured interviews with healthcare professionals will

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be conducted by an experienced qualitative interviewer following a topic guide, with phone interviews offered if more convenient [60]. Interviews will be piloted, take up to an hour and will take place at a time and place of the participants choosing. The content of the topic guide will be informed by findings from the surveys of end of life care leads (WP1) and healthcare professionals in West Yorkshire and London (from WP2), although we anticipate healthcare professionals will be asked to provide a walkthrough of their use of EPaCCS in practice (e.g. discussing and initiating an EPaCCS record for a patient, reviewing and updating EPaCCS records, using EPaCCS to inform decision making), alongside outlining determinants of when and how they are used which will include barriers and facilitators. We will explore how EPaCCS are used in the documentation and communication of advance care planning decisions and preferences with patients and their families. We also plan to explore factors that enable uptake and use of EPaCCS and allow its use to be sustained and embedded, and those which inhibit uptake. An existing framework on direct and indirect influences on engagement with digital interventions [61] together with NPT will inform questions about the impact of how EPaCCS are delivered (e.g. ease of use, familiarity, personalisation), types of engagement (e.g. duration of use, frequency), and mechanisms of action influencing use (e.g. skills, motivation, attitudes). Interviews are expected to last up to 60 minutes and all participants will be reimbursed £75 for their time, based on the average hourly rate for locum doctors [62].

ANALYSIS: Interviews will be audio-recorded, fully transcribed and anonymised, and analysed using Framework Analysis[63]. Data analysis will be carried out concurrently with data collection, to allow the refinement of the interview questions and to enable recruitment to point of data saturation (the stopping criterion being three interviews completed without new ideas emerging [64]). NVivo data analysis software[65] will be used to aid data management and ensure transparency in the analysis process. Analysis will be undertaken by three researchers (MT, MA and research fellow). Initial coding of the first five transcripts will be undertaken independently by two researchers using inductive coding alongside a priori codes informed by NPT (MT and research fellow). The initial coding frame will be discussed to ensure consistency and rigour in the analysis, and then this will be applied to the remaining transcripts by the research fellow. The analysis will be overseen by MT and MA with regular monthly meetings used to share the ongoing analysis with the research team. Comparative analysis in the framework will enable us to identify common themes as well as region-specific and participant group divergences, with attention given to the identification of negative or extreme cases. A model of the coding frame will be developed, and each theme and subtheme given a definition to ensure internal consistency of each code. Illustrative codes will be reported for each theme, with the study ID code to demonstrate reporting from across the sample breadth.

ANTICIPATED OUTPUTS: We will obtain detailed accounts of the use of EPaCCS by healthcare professionals, alongside identifying determinants of when and how they are used, including barriers and facilitators experienced. This richer understanding of processes and mechanisms underpinning EPaCCS will enable modelling of EPaCCS use in the ToC map, including factors influencing uptake and use of EPaCCS, and the rationale for EPaCCS use based on healthcare professional experience (i.e. intended outcomes, key beliefs that underlie the link between outcomes and the associated preconditions). These will be refined and validated when presented in workshops during WP5.

WP4. Facilitated workshop in West Yorkshire and London with patients with progressive illness and their caregivers (Research objective 4)

DESIGN: Focus group discussions will be used to explore patient and caregiver perspectives on EPaCCS. Our research has highlighted a lack of patient and caregiver engagement at all stages of development and implementation of EPaCCS[10]. The UK government commitment of national rollout of EPaCCS includes efforts to enable patients to access and update their own EPaCCS record[3]. It is crucial to gather patient and families' preferences for EPaCCS use to ensure they inform this planned development. Furthermore, patient and caregiver input on intended outcomes from EPaCCS can help to frame priorities around EPaCCS use. To date, many intended benefits of EPaCCS have been framed around structural (e.g. number of patients with an EPaCCS record, updated information about wishes and management plan available to all care providers) and process changes (e.g. reduced hospital admissions, fewer hospital deaths, fewer admissions) rather than specific outcomes for patients and caregivers (e.g. quality of life, family-reported end-of-life care quality).

SAMPLING: Six workshops will be conducted, three held in both London and West Yorkshire. Each region will hold two patient workshops and a separate caregiver workshop. Patients will include those with progressive chronic illnesses, ensuring representation of participants at different disease stages, enabling representation of those who have and have not engaged with palliative and end of life care. Workshops will aim to recruit between 4 – 12 participants which the research team view as an optimum number to generate discussion while remaining manageable. For one patient workshop and the

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caregiver workshop in West Yorkshire and London, participants will be purposively selected from community groups and patient advocacy groups representing patients and caregivers. This approach has been successfully applied in research to understand the views of older people about the home as a place of care during dying and understand of technologies used in end of life care[66]. To ensure a diverse range of participation, multiple community groups will be invited to participate, including groups supporting or advocating for both cancer and non-cancer conditions. These participants may not have an EPaCCS record. For the remaining patient workshop, we will recruit through outpatient clinics of local hospices where patients will have an EPaCCS record. Sampling across all workshops will seek to ensure representation across diagnosis, disease stage, age, and gender.

The following groups and organisations will be used for recruitment of patient and caregiver workshops:

- West Yorkshire: For participants without an EPaCCS record, we will recruit patients and caregivers through organisations including Yorkshire Cancer Community, West Yorkshire and Harrogate Cancer Alliance and the Cardiology PPI group from the Leeds Clinical Research Facility. Out PPI representatives from West Yorkshire are active members of these groups. These organisations are led by patients and advocate for patients and their caregivers, including work to engage harder to reach communities. Participants with an EPaCCS record will be recruited through a research nurse via outpatient clinics at two hospices in Leeds; St Gemma's Hospice and Wheatfields Hospice. The research team has a track record of recruiting through these outpatient clinics across multiple NIHR portfolio studies.
- London: For participants without an EPaCCS record, we will recruit patients and caregivers through the MacMillan Centre at Kings College Hospital, Lambeth Pensioners Action Group, the London branches of Age Concern and Alzheimer's Society, and the Carers Centre in Lambeth. Participants with an EPaCCS record will be recruited through a research nurse via outpatient clinics of Royal Trinity Hospice.

For patient and caregiver groups, we will ask them to share details of the research with their members. Where possible, workshops will be held at centres of existing groups to minimise travel burden for participants, or at university sites of the research team.

METHODS: The workshops will comprise an overview by the research team of current content of EPaCCS and their intended use (incorporating findings from WP1 – WP3). Focus groups held as part of the workshop will be facilitated by our PPI representatives and explore patient and caregiver perspectives on both the existing and future content and use of EPaCCS. Focus group discussions will also explore patient and caregiver perspectives on the EPaCCS approach and anticipated impact from its use, alongside identifying priorities from the evolution of EPaCCS to support continuous services (e.g. enabling patient access to update their wishes for care directly in their own record on EPaCCS, alongside approaches that may not include use of technology by patients). Field notes will also be taken by participating researchers during the workshops.

ANALYSIS: Data from focus groups will be analysed thematically[67]. This approach is appropriate to allow for the exploratory nature of the research[68]. Coding frames will be developed from a patient and caregiver focus group and will be compared and integrated to produce two overall coding frames (for patients and for caregivers), including definitions of themes and sub-themes. The coding frames can be applied to the remaining transcripts using line-by-line coding and findings aggregated in a narrative, paying attention to nonconfirmatory cases and differences between patient and caregiver views and experiences. Field notes will be used to contextualise the data and inform interpretation.

ANTICIPATED OUTPUTS: We will, for the first time, understand patient and caregiver perspectives on the way in which EPaCCS are implemented. Their perceptions of the intended impact of implementation will be identified, alongside future priorities for development, informing futures thinking in health[69] by reflecting on the possibilities of greater patient access to their own EPaCCS record as enabling technology-solutions are emerging (e.g. the NHS app, developed by NHS Digital). The findings from this work package will inform the iterative development of the ToC development running throughout the project and will be presented as part of the ToC map in subsequent workshops (WP5).

WP5. Theory of Change workshops in West Yorkshire and London (Research objective 5)

DESIGN: Theory of Change (ToC) is suited to understanding EPaCCS as it allows for multiple causal pathways, levels of interventions and feedback loops. This will enable exploration of how EPaCCS achieve impact in the real world[48]. A ToC map will be iteratively developed following review of findings on completion of each work package throughout the study. By WP5, we will have iteratively refined a ToC map, providing a graphic representation of causal pathways through which EPaCCS are expected to achieve their impact in the context of the setting in which they are implemented.

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To discuss and refine the ToC map, we will hold three ToC workshops[48]; two regional workshops (one in West Yorkshire (at the University of Leeds) and one in London (at King's College London)) and one national workshop in London. Workshops will seek to: i) validate the ToC map generated by the research team; ii) build consensus across key stakeholder groups about the intended impact of EPaCCS; iii) explore how EPaCCS can be embedded into the context of palliative and end of life care services, and; iv) provide a frame for future evidence generation. Crucially, this will enable realistic expectations of the impact of EPaCCS on specific outcomes to be agreed within the geographical setting, and the context of available resources.

Prior to ToC workshops, the research team, PPI panel and steering group members will hold a one-day meeting to finalise the ToC map. The meeting will reflect on findings to determine what the fundamental changes are that EPaCCS seek to achieve through their implementation. This will also reflect preferences for the future implementation of EPaCCS. The group will also decide how best to frame workshop discussions to explore the long-term outcomes of EPaCCS implementation, which contextual conditions or circumstances are necessary to achieve preconditions (short-term, intermediate and long-term outcomes), and consensus concerning the chronological order of preconditions. Drawing on a diverse set of evidence and experiences is intended to produce a more plausible ToC map ahead of workshops.

SAMPLING: Workshop participants will include those involved in the development, implementation or organisation of EPaCCS, focusing predominantly on delivery of services. Participant groups will differ across the two workshop types:

- Regional workshops (West Yorkshire and London): End of life care commissioning leads who participated in the national survey (WP1) and are based in either West Yorkshire or London. Participants who took part in earlier stages of the research, including community- and hospital-based healthcare professionals (WP2 and WP3) and patients and their caregivers (WP4)).
- National workshop: End of life care leads at CCGs across England (using the distribution list formed in WP1). We will also invite collaborators at NHS England, NHS Improvement, Public Health England, and leading organisations in palliative and end of life care (e.g. National Council for Palliative Care, Hospice UK and Marie Curie Cancer Care). We will purposively sample participants from professional sector bodies across England representing healthcare professional groups who are intended users of EPaCCS. This will include the Royal College of General Practitioners, College of Paramedics, Royal College of Nursing, British Association of Social Workers, British Geriatrics Society, and the British Medical Association. We are also keen to engage IT suppliers involved with medical record systems in England (e.g. EMIS and TPP) and a representative from the NHS Digital Future GP IT Futures Programme, which oversees the supply of clinical IT systems to general practice.

METHODS: Each workshop will be structured as follows:

- A brief introduction of the project, state of the research evidence (synthesising the systematic review by the research team[10] alongside any additional research on EPaCCS published by the time of the workshop), and overview of the ToC approach in a non-technical format
- Presentation of findings from all previous work packages to date (WP1 – WP4): Findings from previous work packages to prompt questions concerning the preconditions found most important to achieve the long-term outcome. This will also be an opportunity to prompt discussion where areas of uncertainty and contention can be explored (e.g. should and could all healthcare professionals have access to edit patient records on EPaCCS or only those responsible for enacting preferences? Can shared decision making between patients and healthcare professionals be facilitated through EPaCCS?).
- Presentation, review and discussion of ToC map, followed by review and refinement of its content and filling in the gaps. This will involve discussion of whether the ToC map: i) is valid, feasible, effective and sustainable; ii) reflects change in a logical manner, and; iii) is missing any elements or aspects that should be considered or discussed.
- Tailored discussions, based on the remit of the workshop (regional or national). Discussions will involve reflection on priorities and future research to support EPaCCS implementation, including possible barriers and enablers of these. Discussions will seek to agree which interventions should be initiated to achieve the preconditions and the long-term outcome, and identify the perceived utility and feasibility of indicators to track the presence of preconditions required to deliver intended impact with EPaCCS. To ensure focus, we will frame discussions in regional and national workshop around macro, meso and micro levels[70]:
 - Regional workshops will focus on the meso (organisation and regulation of services for patients with progressive chronic illnesses, including commissioning) and micro (individual user experiences of patient, caregivers and healthcare professionals, as users of EPaCCS or recipients of care potentially influenced by them) levels, as reflected in participant recruitment.

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- o National workshop will focus on the macro level (governmental priority setting mediated through, and transformed within, regional health authorities and professional regulatory bodies), also reflected through participant recruitment.

Following the workshops, the research team will meet three times to discuss the formulation of the preconditions, their potential causal relationship, and the intervention components depicted in the ToC map. During this step, team members with extensive experience in theory-based intervention development (RF; SR; CE) will review the methods and terms used to ensure correct usage and consistency of pathways. Between the second and third team meeting, the ToC map will be shared with participants of the regional and national workshops for comment to ensure that it reflects discussions held prior to being finalised by the research team. In a third meeting, a final ToC map will be agreed which will be checked against relevant literature proposed by the core research group and the four attributes (plausible, doable, meaningful and testable) for a good theory of change[48].

ANALYSIS: Workshops will be video and audio recorded and photographs taken of the ToC map at the end of each workshop to maintain a visual record. Points that were raised and perceived as important by the majority of stakeholders will be included in the ToC map. The ToC map will be generated using Lucidchart (<http://www.lucidchart.com>).

ANTICIPATED OUTPUTS: A ToC conceptual map will be produced, outlining the essential components of an EPaCCS needed to support optimal implementation to achieve agreed ultimate outcomes from their implementation. This will determine optimal implementation both regionally (West Yorkshire and London) and nationally. We will better understand the preconditions required to deliver improved outcomes with EPaCCS and identify where intervention components are required to ensure these are realised. An understanding of preconditions across the pathway can also support development of indicators to evaluate EPaCCS implementation. This will begin the development of a relevant theoretical underpinning for EPaCCS, enabling subsequent EPaCCS research exploring its clinical- and cost-effectiveness to align with the development stage of the MRC complex intervention guidance.

6. Dissemination and projected outputs

We will build upon strong existing links between the research, practice and policy communities, with the latter already engaged as project collaborators to ensure their dissemination. Our strong track record of working with patients, healthcare professionals and commissioners across West Yorkshire and London to support improvements in provision of end of life care provides an excellent platform for generating research findings relevant to a wide range of audiences, locally and nationally. We will use an explicit framework developed within the Leeds Institute of Health Sciences (LIHS) to guide our knowledge transfer strategy[71, 72], as detailed below.

The most frequently reported barrier to the use of research by decision-makers is the lack of personal contact between researchers and decision makers[73]. The networks and positions of team members will ensure that the findings of the study are written up in formats that are relevant and accessible to commissioning and provider bodies, and cascaded through their existing dissemination networks. Our collaborators include Jo Brooks (Manger of the Personalised Care Group, NHS England and NHS Improvement), Professor Bee Wee (National Clinical Director for End of Life Care at NHS England), and Professor Julia Verne (Clinical Lead for the National End of Life Care Intelligence Network at Public Health England). To inform our dissemination work from within the team, KS works with the Policy Institute at King's College London, drawing on evidence and its expertise to influence practice and policy. RF shares research findings with and advises NICE, particularly via its Implementation Strategy Group, the Healthcare Quality Improvement Partnership and a number of national clinical audits.

We anticipate a number of tangible outputs to be generated from the project. Outputs will target different stakeholder groups utilising existing channels supported by our collaborators and research team:

PATIENTS, CAREGIVERS AND LAY AUDIENCES: The research team will work with PPI representatives and the Cicely Saunders Institute (CSI) PPI group to generate lay summaries of the research. These will be shared both electronically (e.g. podcasts and summaries as pdf files) and through presentation initially to patient and caregiver groups where links exist through PPI representatives and the CSI PPI group. During workshops in WP5 we will also identify CCGs who have EPaCCS in place or plan to, with an interest in disseminating information on EPaCCS to patients and caregivers accessing palliative and end of life care services. We will work with PPI representatives and the CSI PPI group to generate lay summaries that describe common characteristics of EPaCCS, reflecting patient and caregiver perspectives gathered during the study (WP4). These will be developed with support from a design company to ensure they are engaging and aligned to the Clear English Standard, and developed in a pdf format for ease of sharing across interested CCGs.

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Our research team routinely undertakes public engagement in palliative care (e.g. [74]). The Lead PI is a Public Engagement Champion at the University of Leeds and supports organisation of *Be Curious*, the University's annual research open day, and collaborative events with St Gemma's Hospice, Leeds, for *Dying Matters* week. We will actively seek opportunities to participate and present aspects of the study through our annual cycle of public engagement events.

POLICY MAKERS: We are collaborating with partners that can enact findings from our research to steer EPaCCS development locally and nationally. As highlighted in their letter of support, **NHS England** state the national survey (WP1) will actively assist with national adoption and implementation of EPaCCS. Furthermore, **NHS England** are keen to collaborate to understand which metrics (e.g. performance indicators) might be most suited to monitoring the national adoption of EPaCCS (which will be generated from WP5, based on findings from all previous work packages). **Public Health England** too highlight the need for this research (see letter of support); a former national survey of EPaCCS from 2013 is the most downloaded publication on their End of Life Care Intelligence Network.

Our collaborators have provided the opportunity to utilise their communication channels to disseminate findings from across the project that will target End of Life Care Leads and clinical commissioning groups across England. This will facilitate communication with the target audience for research briefs and summary reports generated during the study to highlight key findings. Representation of **NHS England** and **Public Health England** on the study steering group will enable identification of findings to share across collaborator networks for national coverage. **NHS England** have agreed to allow access to multiple channels to support dissemination. These include:

- **NHS England bulletins:** e.g. the CCG bulletin, which is a primary communication channel between NHS England and clinical commissioning groups
- **EPaCCS collaboration platform:** a collaborative online platform for localities to network and share experiences, hosted on the futureNHS collaboration platform (<https://future.nhs.uk>)
- **Annual National EPaCCS meetings:** annual events, hosted by NHS England, bringing together commissioners of palliative and end life care service, End of Life Care Leads, practitioners, informatics expertise, and researchers

Public Health England will further support dissemination of research briefs and findings through their:

- **National End of Life Care Intelligence Network:** a collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. The Network aims to utilise and disseminate existing data sources more effectively for local service planning and driving improvement in standards of end of life care. Furthermore, it provides national co-ordination to bring together a national repository of diverse sources of data related to end of life care which will enable people to create intelligence from data and thereby improve quality and productivity. The former national survey of EPaCCS from 2013[7] still remains the most downloaded report from this platform as outlined in our letter of support from Public Health England, suggesting continuing demand for information on EPaCCS from users of the Network.
- **Webinar series:** Webinars designed for supporting interactive presentations and discussions to highlight new data or findings that can inform provision of palliative and end of life care. Two webinars are currently planned for delivery during the study. The first will take place following completion of the national survey of EPaCCS implementation (WP1) to update End of Life Care Leads and service planners on the national landscape and provide an overview of planned subsequent activities. We will use this opportunity to share a national benchmarking report and gather feedback on models of implementation. The webinar will also be used to gather preferences of end of life care leads for dissemination of subsequent study findings to increase their utility. The second webinar will take place following completion of ToC workshops (WP5), communicating where EPaCCS are intended to have impact and highlighting preconditions for implementers to monitor, alongside highlighting experiences of healthcare professionals (WP2 and WP3) and patient and caregiver preferences (WP4).

Through leveraging communication channels of both collaborators, we hope to maximise reach and impact of our study findings by actively engaging with clinical and managerial leads of end of life services across England. Our collaborators and those accessed through dissemination encompasses those responsible for the management of around 375,000 annual deaths from chronic progressive diseases in England (based on an estimate of 75% of people in high-income countries dying from chronic progressive diseases with evolving and increasing healthcare needs[75], and mortality data for England in 2017[76]). Our planned dissemination will be available within 2 – 3 years and will deliver evidence that can impact on the future implementation of EPaCCS, with benefits realised by year 2023 as findings are adopted in practice.

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PRACTITIONERS: We are keen to engage with practitioners in the regions where the study will take place. Working with support from co-applicant PC, West Yorkshire R&D manager and member of the NHS Research and Development Forum, we will host workshop events supported by NHS research and development teams in West Yorkshire and London. We will invite local managed clinical networks alongside community and hospital-based healthcare professionals. Prior to the workshops we will produce a 1- or 2-page manual for primary care practices on how to get the best out of EPaCCS, supplemented with suggested audit criteria and ensuring it is compatible with the QoF quality improvement scheme. We will discuss and refine the manual during the workshops prior to reviewing and finalising a version for sharing with all attendees. We will also host the final version of the manual on the West Yorkshire R&D website with supporting social media promotion. Co-applicant, PC, is a member of the R&D Forum primary care steering group and also on the R&D Forum commissioning group and will support sharing of the study findings and manual through these national groups.

ACADEMIC BENEFICIARIES: We aim to publish four papers (survey of national EPaCCS implementation, healthcare professional survey and interviews, patient and caregiver engagement, and the conceptual model and logic models linking mechanisms of action with intended outcomes of EPaCCS) in relevant target journals (e.g. BMJ for findings of interest to a general readership alongside discipline specific journals such as Palliative Medicine and BMJ Supportive and Palliative Care). We will prioritise open access publishing as a means of enabling wider access to our findings and therefore potentially faster uptake and implementation. We will also disseminate our findings at two academic conferences, including the annual conferences of the Association for Palliative Medicine of Great Britain and Ireland and the European Association of Palliative Medicine; key conferences for sharing palliative care research with academic and clinical audiences.

The project will further develop collaboration between leading palliative care research groups in Leeds, London and Hull, and national organisations guiding development of palliative care, including Public Health England and NHS England. Whilst research on EPaCCS is at an early stage, we are keen to consolidate emerging interest in EPaCCS research across the UK through establishing an EPaCCS research network. The network will promote discussion, exchange of ideas, and drive advancement of the evidence base underpinning EPaCCS. During the course of the study, we will facilitate interactions through an online seminar series and hold side meetings at the NHS England EPaCCS annual meeting. The EPaCCS research network will also be well placed to explore collaboration through follow-on funding to address gaps in evidence and to develop interventions for optimising engagement with EPaCCS identified during this study.

At the start of the project the research team will work with the PPI co-applicants, the PPI group at CSI and the steering group to generate a social media strategy[77], agreeing offline impacts intended from the research and determine which platforms to target at different points of the study. This will include use of platforms such as Twitter for sharing project updates and outputs, alongside developing a project webpage within the University of Leeds website. Review of the social media activity will occur during scheduled PPI and steering group meetings to accommodate approaches to accessing new and existing stakeholders as project outputs are generated throughout the study.

7. Project timetable

The majority of activities in the project are sequential, but there will be some overlap in relation to the setup of individual work packages and the analysis of qualitative and quantitative data streams, with ethical and governance approvals being requested for all work packages at the start of the project. The key deliverables for the project are as follows:

Research activities:

- Month 1 – ethical and governance approvals submitted
- Month 6 – completion of national online survey of CCG leads
- Month 13 – completion of online survey of health professionals
- Months 22 – completion of in-depth qualitative interviews with healthcare professional survey respondents
- Month 25 – completion Facilitated workshop events with patients and caregivers
- Month 30 – completion Theory of Change workshops in West Yorkshire and London

Dissemination:

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- Work package summaries and write up in months 6, 12, 20, 24, 29 and 30

Project management meetings:

- Programme steering group meeting held in months 1, 6, 12, 20, 25, and 29
- Patient and public involvement panel meetings held in months 1, 5, 12, 19, 24, and 29

8. Project management

The Chief Investigator (CI) (MA) will be overall strategic lead for delivery of the project and co-ordination of activities across work packages, supported by a highly experienced Joint-CI (MB). Each work package has a designated WP lead who will work closely with the CI and local teams to ensure timely delivery of WP-specific milestones. Two research fellows will be responsible for day-to-day project activities and contribute to each objective working closely with WP leads, the CI and Joint-CI. One research fellow will be based at the University of Leeds, supported by MA, alongside a research fellow at King's College London, overseen by CE. Research fellows and the wider programme will be supported by a project administrator, who will also have a role in ensuring regular communications within the team and wider collaborators.

The Project Management Team will include members of the core scientific team (MA, MB, CE, KS, MT, PM, RF, SDR, SR), a PPI co-applicant (BH), and regional research lead for commissioning (PC). The Project Management Team will meet every two months face-to-face or by teleconference to discuss scientific and operational issues. There will be parallel monthly meetings held between researchers at the University of Leeds (MA, MB) and Kings College London (CE, KS) and WP leads (where relevant according to project timelines) to coordinate the day-to-day research activities across the two sites, ensuring alignment of research activities, and progress of the research fellows at each site. Individual team members will lead on specific work packages according to their skills and experience:

WP1 (National survey of end of life care CCG leads in England): WP lead PM. MA, MB and PM contributing to the design and conduct of the online survey. PC advising on approaches to recruitment and dissemination. Uploading and creation of the online survey overseen by MA and associated research fellow in Leeds. Quantitative analysis and geographical mapping will be overseen by SDR.

WP2 (Survey of healthcare professional users of EPaCCS in West Yorkshire and London): WP lead MA. Online survey content to be developed by MA, MB, PM, KS, CE, RF, SDR, and SR. Recruitment will be guided by PC. The Leeds-based research fellow will lead distribution and analysis, with guidance from MA, MB, PM, KS, CE, RF, SDR, and MT (to identify findings to raise in WP3 interviews).

WP3 (In-depth qualitative interviews with healthcare professional survey respondents): WP lead MT. Topic guide development will be supported by CE, MA and PPI co-applicants (BH, NP), with input from PM, MB, RF, and SR to ensure linkage with WP2. Interviews conducted by research fellows in Leeds and London. Analysis will be carried out by the research fellow in Leeds, with guidance from MT.

WP4 (Facilitated workshop in West Yorkshire and London with patients with progressive illness and their caregivers): WP lead CE. Topic guide development by PPI co-applicants (BH, NP) alongside CE, MT, and MA. Focus groups will be conducted in West Yorkshire and London by the research fellows. Analysis will be undertaken by the research fellow in London, with oversight from CE and KS.

WP5 (Theory of Change workshops in West Yorkshire and London): WP lead KS. ToC development and validation following each iteration from WP1-4 will be led by RF, SR, CE, MA and KS. Overview of engagement with end of life care leads and policymakers will be led by KS. Regional workshops will be organised by the research fellows in Leeds and London. The national workshop will be led by the London team (research fellow; KS; CE) with input from MA, MB, RF and SR.

We will convene a Project Steering Group which will meet six times over the course of the programme to ensure the quality of ongoing work, maintain our focus on healthcare and commissioning needs, monitor progress against objectives, and guide planned dissemination. This group will comprise a senior independent academic, representatives from NHS England and Public Health England, PPI representatives, a health economist (to guide collection and future use of cost data gathered in WP1 (e.g. cost-effectiveness modelling of different EPaCCS models and intended outcomes), and two clinical academic general practitioners (one from Leeds, one from Hull) who utilise EPaCCS and also have expertise in access to hard to reach populations, including people who experience homelessness.

9. Ethics and Regulatory Approvals

We will require NHS ethical approval for research activities across WP1 – WP5, involving recruitment of patients, caregivers and healthcare professionals which will take place within NHS bodies. We will be identifying CCG leads for end of life care, who are typically general practitioners, through their role within CCG organisations (WP1). Identification and recruitment of healthcare professionals for participation in a survey and subsequent in-depth interview (WP2 and WP3) will occur through clinical research networks and distribution of survey links through service leads. For patient and caregiver workshops (WP4), participants will be recruited from both outside NHS bodies (e.g. existing community support and advocacy organisations) and through NHS organisations (i.e. hospices in Leeds and London). We will apply for NHS ethical approval covering all activities across the programme three months before the project start date.

The main ethical issues of this study relate to informed consent, anonymity, and information provided to participants:

- All patients, caregivers and health care professionals invited to take part will be free to decline and this will be made clear before and during their participation. All participants will be given an information sheet detailing the study procedures to allow them to make an informed decision about their participation. In addition, for in-depth interviews and workshops, a verbal explanation of the study will be offered ahead of the beginning of each interview, and consent will be checked again at the end. All participants involved in any stage of the study will be reminded of their right to withdraw at any point without giving an explanation.
- To ensure anonymity, all participants will be given a unique ID number which will be noted on survey logs and interview transcripts, thus preventing participants from being identified. In addition, any identifiable details, such as names of people, places or institutions will be removed from logs and interview transcripts. Digital recordings and research data will be held on a dedicated secure University server and will only be accessible to those directly involved in the interviews and analysis. All quotations in reports, publications and presentations will be presented in an anonymous format. The contact details of participants will be held securely on a dedicated University server for the duration of the study. Data generated from the project (e.g. interview transcripts, NVivo files) will be stored for 5 years after the project, enabling use for dissemination from the project. Deidentified data generated from the project will be evaluated at the end of the study to determine suitability for wider sharing through the University of Leeds data repository. Data not deemed suitable for longer-term storage in the data repository will be deleted after 5 years from project completion. This will be communicated to participants as part of the consent process.
- For information provided to patients and caregivers, content discussing palliative care can be potentially emotional and will be developed with input and feedback from our PPI co-applicants and members of the PPI group at the Cicely Saunders Institute, King's College London. Patients receiving palliative care and recruited through hospices are potentially emotionally, physically and psychologically vulnerable. During WP4, recruitment of patients by research nurses will include a capacity to consent checklist and only patients who have sufficient mental capacity to understand the research process, and who are deemed to have capacity to undertake the requisite elements of data collection for the study will be included. We will re-confirm capacity and consent prior to participation in workshops.

10. Patient and Public Involvement

PROPOSAL DEVELOPMENT

During project development, team members (MA/MB) presented a draft proposal to over 40 members of the Yorkshire Cancer Patient Forum (YCPF). Members expressed support for having their care preferences shared through EPaCCS alongside a sense that ACP facilitated by EPaCCS should be available for all patients. We subsequently increased the scale of patient and caregiver engagement, ensuring exploration of their views and expectations around access to their own EPaCCS record. This aligns with emerging initiatives around increasing patient access to their own health and care record. One example, in Leeds, is developing a single and consistent way for individuals to prove who they are and access digital health and care services (<https://myhelm.org/>). This work is part of a wider programme of work by NHS Digital with five selected partners to develop services for future users.

During the YCPF meeting, BH, a YCPF member, approached the team about involvement following presentation of the proposal. The proposal was also shared by email with the Cardiology PPI group at Leeds Teaching Hospitals Trust, through which a second PPI co-applicant, NP, was identified. Both PPI representatives will act as conduits for their respective PPI groups. Both PPI co-applicants belong

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to groups that advocate for healthcare initiatives, such as EPaCCS, to deliver outcomes that matter to patients. Our earlier discussions with PPI co-applicants for this proposed programme suggest a similar set of expectations and there was surprise at the lack of evidence and notably patient and caregiver engagement in the development of EPaCCS to date. For this proposal, the PPI co-applicants provided feedback on the focus of patient and caregiver engagement and helped us refine the plain English summary.

As part of the proposal development, team members at Kings College London (CE, KS) identified how they can facilitate links to PPI infrastructure supported through the Cicely Saunders Institute (CSI) during the project. This will ensure representations of patients and caregivers who are predominantly London-based in London, involving those with experience of a range of chronic progressive illnesses.

The PPI group is led by a co-applicant (CE), and has won NIHR CLAHRC South London awards, including Most Innovative PPI Activity, in 2016 and 2018. We will engage with the PPI group through:

- Inclusion of a summary of the project during a bi-yearly webinar to identify PPI group members interested in the study and willing to support related PPI activities
- An award-winning online forum that will be created specifically for the project, sharing and asking for feedback on documents and to prompt discussions on topics specifically related to the research project and EPaCCS

INVOLVEMENT DURING THE PROJECT

In general terms, involvement of our PPI co-applicants and the PPI group at the CSI will benefit the research by promoting accountability (ensuring that we work in the public interest and make proper use of resources); appropriateness (ensuring that our work focuses on patient and population benefit), advocacy (for making research a routine part of healthcare planning and delivery), and; alerting networks to findings (participation in dissemination activities). Our team in Leeds has also recently started a formal consensus process with PPI panels for research programmes in primary care to work through how PPI can enhance implementation research, where interventions often primarily target organisations and professionals rather than patients (led by co-applicant, RF). Outputs of this consultation will also influence our overall approach.

In specific terms, our PPI co-applicants (BH and NP) and the PPI group at CSI will contribute by:

- Highlighting public and patient support for research to professionals and organisations considering participation
- Provide feedback on study documents, including study information sheets and planned survey content and topic guides
- Facilitating patient and caregiver workshops to understand the perceived impact of EPaCCS and preferences for their use in delivery of care in WP4
- Participating in discussions as part of Theory of Change workshops in WP5
- Commenting and advising on the relevance of findings from the study for patients
- Identifying dissemination opportunities via PPI and commissioning channels. Our programme will aim to generate findings and lessons applicable across England. We will work with our PPI co-applicants and PPI group at CSI throughout to consider the types of generalisable messages we can produce.
- Holding the research team accountable by reviewing and commenting on progress. Six meetings will be held over the course of the programme and contributing to the Steering Group membership (BH).

The Lead Applicant (MA) will oversee PPI activities across the programme. A PPI co-applicant (BH) will lead PPI activities and chair bi-yearly meetings, with the Lead Applicant supporting distribution of the agenda and circulation of papers ahead of meetings. A London-based co-applicant (CE) will coordinate and organise involvement of the CSI PPI group and infrastructure during the project. This governance structure is designed to support coherence across management of other groups, including the steering group. A PPI co-applicant (BH) will also be a member of the steering group. For PPI meetings, virtual approaches such as Skype will be offered to minimise travel and facilitate participation of PPI co-applicants in PPI activities led by the CSI group.

We will align our PPI activities to the National Standards for Public Involvement developed by a Public Involvement Standards Development Partnership and released in February 2019. The standards will guide evaluation of the impact of our PPI work and identify opportunities for improvement across organisations in which the research team are based. In line with standards, PPI co-applicants and public contributors will be reimbursed based on individual need (e.g. travel, accommodation, and access

Electronic Palliative Care Co-ordination Systems (EPaCCS) in end of life care. Reference: NIHR129171; Protocol version 0.1, pending ethical approval requirements) which is reflected in the justification of costs. Costs for training on group and workshop facilitation has been included for two PPI representatives ahead of WP4.

11. Project expertise

The team comprises researchers from three excellent academic teams, bringing together expertise in mixed methods research, complex intervention development and evaluation, advance care planning, healthcare technology development in palliative care, implementation science, and health policy. It will be led by an early career researcher (MA) with a track record of high-quality applied health research, including grant capture and publications, involving user-centred design of technologies for palliative care. MA is also a member of the NHS England EPaCCS expert reference group. The joint PI (MB) is an active clinician in palliative medicine and has an established track record in delivering large-scale research programmes in palliative care and will provide mentorship and guidance to the Lead PI.

The wider team will ensure our research is applied, relevant and transferable to other settings, providing expertise in:

- Experience of advance care planning as a patient, living with stage III bowel cancer (BH) and heart failure (NP)
- Evaluating complex interventions for health and well-being of older people across care settings (SR)
- Palliative care policy and use of routinely collected data in palliative and end of life care (KS)
- Qualitative research in palliative and end of life care service delivery, public and patient involvement in research, and leading patient and public involvement activities at the Cicely Saunders Institute (CE)
- Qualitative and mixed methods research (MT)
- Implementation research, complex intervention design and evaluation, and general practice (RF)
- Technical infrastructure, interoperability and data sharing within EPaCCS, and former GP Lead for End of Life Care in Leeds (PM)
- Coordination and dissemination of research and development with healthcare commissioners (PC)
- Statistical analysis of primary care healthcare datasets, including EPaCCS and frailty data, and online surveys (SDR)

We have collaborators who can facilitate change and implement project outcomes, including National Clinical Director for End of Life Care (Prof Bee Wee), Manager of Personalised Care at NHS England (Jo Brooks) and National End of Life Care Intelligence Network Clinical Lead (Prof Julia Verne) at Public Health England. We will also have an expert steering group, consisting of 3 independent experts with experience in palliative and end of life care across different regions of the UK. Scheduled meetings to inform key decision-making points in the research project will be held via teleconference or Skype.

Ill health of PPI representatives: We will work closely with our PPI networks to ensure we are able to maintain PPI in the design and delivery of the student in the event of ill health of our PPI representatives.

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