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Synopsis

Evaluating the implementation of Electronic Palliative Care Co-ordination Systems (EPaCCS) and optimising future service provision for palliative and end-of-life care: a synopsis of the Optimal Care mixed-method study

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Our work focused on improving the delivery of palliative and end-of-life care. We dedicate this report to Dr Barbara Hibbert, who brought her own experience of living with advanced illness to her role of leading the patient and public involvement work. Barbara was a wonderful, kind and supportive colleague who facilitated inclusive and insightful patient and public involvement meetings and activities and played a crucial role in helping to design and deliver the project.

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Abstract

Background: Electronic Palliative Care Co-ordination Systems are central to end-of-life care policy despite critical gaps in the evidence base underpinning their use. It is unclear how Electronic Palliative Care Co-ordination Systems are being implemented across England and there is a lack of research to understand their use in routine care.

Aim: To understand how Electronic Palliative Care Co-ordination Systems are currently being used in routine care and to guide the development of interventions to support their optimal implementation and maximise patient benefit.

Method: A mixed-method approach was adopted across the five-stage programme of research. Packages of work included: (1) a national online survey of end-of-life care leads at clinical commissioning groups in England; (2) an online survey of community and hospital-based health and care professionals in West Yorkshire and London; (3) semistructured interviews with a sample of survey respondents; (4) focus groups and interviews with patients with progressive chronic illnesses and carers and (5) regional and national Theory of Change workshops.

Results: Two-thirds of surveyed regions have Electronic Palliative Care Co-ordination Systems in place. Where present, there is limited use of Electronic Palliative Care Co-ordination Systems to document patients' wishes and preferences. Low uptake may be explained by challenges experienced by health professionals. This includes limited interoperability across electronic health record systems in which Electronic Palliative Care Co-ordination Systems are typically nested, affecting information sharing across settings. Uncertainty was common across health and care professionals relating to what Electronic Palliative Care Co-ordination Systems are, who they are for and how organisations should monitor them. Mid-range programme theory was generated to guide the development and evaluation of Electronic Palliative Care Co-ordination Systems alongside recommendations for decision-makers and commissioners for palliative and end-of-life care in England.

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Limitations: The project was conducted across England with in-depth health and care professional engagement in two regions of England. This may limit the applicability of findings across England, although the project included large regions with multiple Electronic Palliative Care Coordination Systems operating at different levels of maturity.
Conclusions: Electronic Palliative Care Co-ordination Systems are not working as intended for palliative and end-of-life care delivery in England. The application of the recommendations generated through this project can ensure consideration of the wider ecosystem in which Electronic Palliative Care Co-ordination Systems are being implemented, guiding system development that promotes health and care professional engagement and facilitates patient and carer access to Electronic Palliative Care Co-ordination Systems records.
Future work: Future research is required to develop approaches that seek to improve health professional engagement with digital approaches to advance care planning documentation and sharing. Furthermore, there is a need to develop and evaluate patient and carer access to digital advance care planning records. Lastly, the mid-range programme theory generated through this project requires continued refinement and use to evaluate Electronic Palliative Care Co-ordination Systems' implementation.
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Introduction

Rationale for research and background

Patients with long-term conditions or complex needs who are approaching the end of life should be offered the opportunity to take an active role in planning for their future health and care.[2–5] Advance care planning is defined by the European Association for Palliative Care as a process that 'enables individuals to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family members and health and care providers'.[6] Patients' preferences may be elicited iteratively over multiple discussions and should be available to health and care providers so that they can be accessed at the point of need.[7] Furthermore, preferences can change through the course of their condition, and current information is paramount to provide the care the patient expects. Increasingly, digital systems are being used to support real-time documentation of advance care planning information by patients, which can then be stored directly in their digital health records.[8–10] Digital approaches may capture varying elements of advance care planning information [i.e. advance statements of wishes and preferences, advance decisions to refuse treatment (ADRT) (e.g. cardiopulmonary resuscitation and antibiotics) and details of lasting power of attorney].[11] Such digital advance care planning systems are being developed and implemented internationally in countries that include the USA,[12,13] Australia[14,15] and the UK.[16]

In England, the current national end-of-life care policy promotes digital systems as a way to support the documentation, storage and sharing of advance care planning information across all settings involved in the delivery of palliative care.[7] This is aligned with calls to integrate information technologies in a way that enhances patients' experiences[17] and supports quality care and coordination for people receiving palliative and end-of-life care.[18] In England, the collective term for the most widely used digital advance care planning approaches is Electronic Palliative Care Co-ordination Systems (commonly abbreviated to EPaCCS).[8,19] EPaCCS have been developed across the UK since 2008[20] and multiple variants have arisen. EPaCCS is an umbrella term to describe a range of approaches to recording and sharing advance care planning information that include stand-alone web-based electronic registers, such as Coordinate my Care, which was implemented in London,[21] and template forms integrated into already-existing electronic patient records, such as in Leeds[22] and the Key Information Summary in Scotland.[23] While there is a variation in the structure of systems, the content of EPaCCS is required to align with information standards that were published in 2022,[24] updating earlier standards from 2015.[25]

Since their initial introduction in 2008, there has been variation in how EPaCCS are implemented in the UK.[19] The UK Government initially called for the national roll-out of EPaCCS by 2020 to all areas in line with existing

policy and commitments on end-of-life care.[26–29] This target was extended indefinitely until a clearer understanding of optimal approaches to implementation had been gathered. To date, 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, including the intended impact of EPaCCS.[16] There is a need to understand the perspectives of EPaCCS users, including unreported perspectives of patients and carers, to determine how the use of EPaCCS can be optimised in the complex environment at the interface of different health and care professionals and services.[30,31] EPaCCS are essentially complex health interventions and should be understood and evaluated as such.[32] EPaCCS are central to a key policy on end-of-life care and have been 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 harm.[16] Logical and well-intentioned policy recommendations can do more harm than good.[33] Therefore, this project was developed to inform national EPaCCS roll-out, reduce uncertainty around engagement with EPaCCS and contribute to evidence-based improvements in the quality and efficiency of care of patients with progressive chronic illnesses.

Objectives

The study adopted a mixed-methods design[34] to understand factors influencing EPaCCS implementation in routine care, determine user preferences for its development to optimise engagement and determine how best to evaluate their intended impact following implementation (*Figure 1*). The research objectives were:

1. to examine how EPaCCS are being implemented nationally, their intended impact, cost and existing processes for monitoring their uptake and use
2. to examine community and hospital-based health and care professional perceptions of EPaCCS on advance care planning and the delivery of palliative care for the management of patients with progressive chronic illnesses
3. to explore factors influencing the uptake and use of EPaCCS to support advance care planning in routine clinical practice
4. to explore the perspectives of patients with progressive illness and their carers 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.

Overview of project methodology

The study adopted a multiphase mixed-methods design[34] with sequential, linked work packages.

Work package 1: national survey of end-of-life care Clinical Commissioning Group leads in England (objective 1)

Participants

End-of-life care leads in 135 clinical commissioning groups (CCGs) in England. Participants were expected to be either a clinical lead or a managerial lead working in palliative and end-of-life care.

Methods

The content of the survey was developed by the research team with input from the steering group, including representatives from NHS England. The survey included replication of questions from The Public Health England 2013 survey content,[35] asking about the status of implementation, organisations hosting these systems, who are the intended users and recipients of data, which other providers' electronic systems are involved in information sharing, what is the intended local impact, and what is the annual commissioned spend on EPaCCS. We also requested aggregate data related to the number of patients with EPaCCS records. Additional items included questions about barriers and facilitators experienced in implementation and clinical challenges faced and processes being used for monitoring uptake and health and care professional interaction. The survey also included expressions of interest to participate in a workshop as part of work package 5 activities and to receive a report of benchmarking

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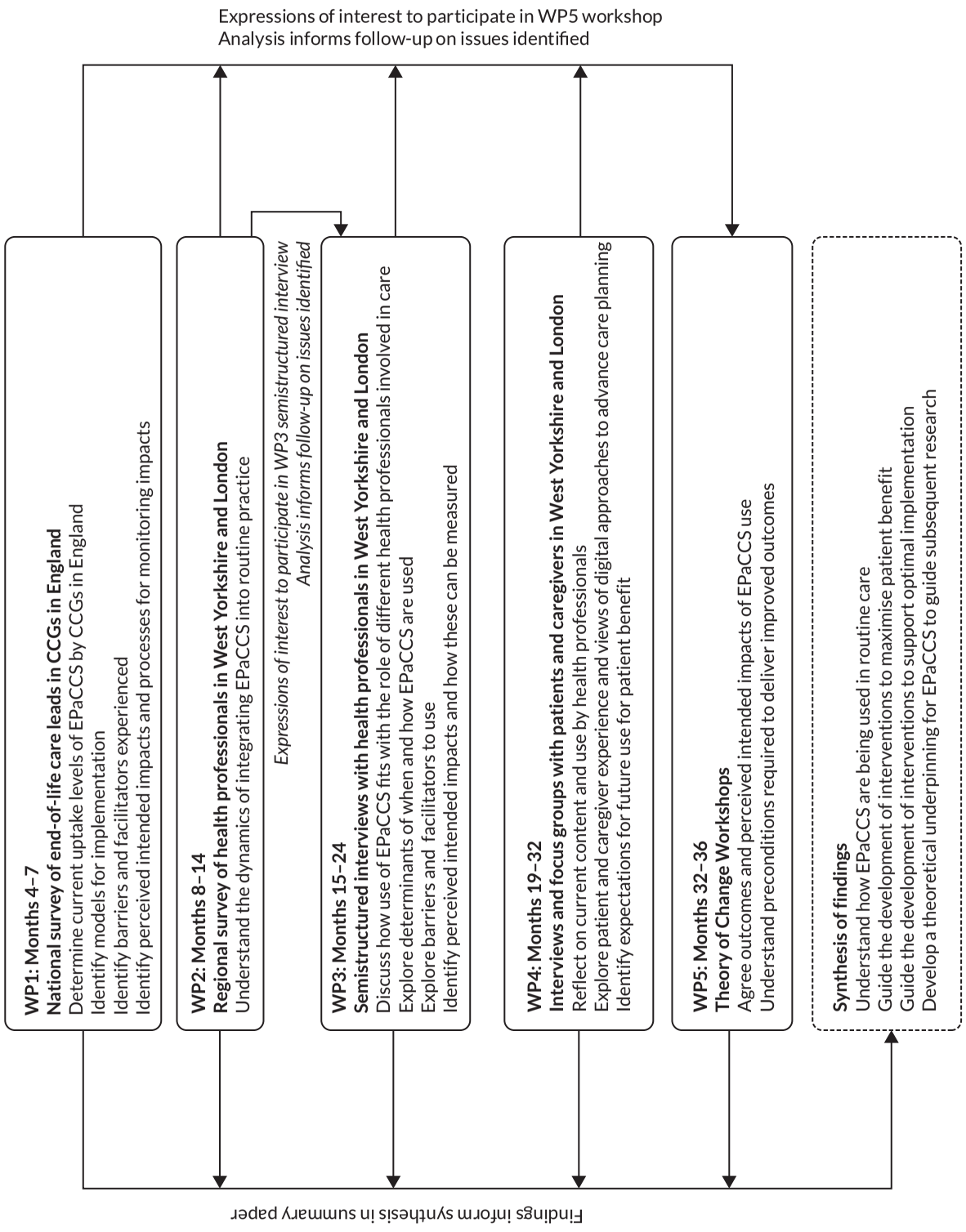

FIGURE 1 An overview of the research pathway for optimal care detailing the research activity across each work package and the associated outputs. WP, work package.

data comparing local data with anonymised data from all survey respondents. The Leeds-based research fellow (JB) oversaw the distribution of the survey, supported by the NHS research and development (R&D) forum and the Professional Records Standards Body. Non-respondents were sent up to two reminders 2 and 4 weeks after the initial approach. A conservative response rate of ≥ 50% was assumed based on a previous estimate of 53% from a meta-analysis of overall survey response rates among health and care professionals.[36]

Analysis

Descriptive statistics using Statistical Product and Service Solutions (SPSS) version 27 (IBM Corporation, Armonk, NY, USA) were used to derive frequencies and proportions of responses from each CCG and the remaining closed questions. A map plotting the registered address of each CCG was generated to depict the status of EPaCCS (operational, in planning and no system) using colour coding. Box plots were also produced, showing the median, interquartile range and upper and lower values for summary statistics relating to: (1) patients with an EPaCCS record at death; (2) records with preferred place of death recorded and (3) proportion of EPaCCS records where a patient had a cancer diagnosis recorded. A directed content analysis was used, including quantification to evaluate free-text responses. The study was reported in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES)[37] guideline for online survey distribution and reporting.

Work package 2: survey of health and care professional users of Electronic Palliative Care Co-ordination Systems in West Yorkshire and London (objective 2)

Methods

The content of the survey included the Normalization MeAsure Development (NoMAD) tool, a set of 23 survey items, grouped into four constructs, based on Normalisation Process Theory (NPT).[38] This is an implementation theory used to explain how complex interventions are embedded in routine practice. The survey utilises 5-point and 11-point scales to gauge levels of agreement to statements assessing implementation processes which the research adapted to fit with EPaCCS use. Additional items included questions about how well EPaCCS support the sharing of advance care planning information for patients, questions about alternative methods used for data-sharing (excluding EPaCCS), and barriers and facilitators to using EPaCCS. Expressions of interest to participants in work packages 2 and 5 and preferences for receiving a newsletter about study findings were also included. The Leeds-based research fellow (JB) oversaw the distribution of the survey supported by research leads in NHS Trusts and hospices, care home managers and the North Thames Clinical Research Network, Noclor (an NHS-based Research Office serving North London) and West Yorkshire R&D. Three reminders were sent at monthly intervals, with a newsletter describing survey response numbers and interim findings based on responses received; this was found to encourage completion. Despite published response rates of 53%[39] we assumed a conservative response rate of 35% across these professional groups, resulting in a recruited sample target of 200 respondents.

Analysis

Frequency distributions using SPSS were used to describe respondent characteristics. We used the poLCA package within R v4.2.0 (The R Foundation for Statistical Computing, Vienna, Austria) to undertake latent class analysis to stratify respondents to find out if different classes of EPaCCS users exist based on the responses of each of the six health professional groups. We did this for the questions about their ratings of familiarity with using EPaCCS and the four constructs of NPT. Free-text responses relating to alternative approaches to advance care planning documentation were analysed using a directed content analysis approach. The CHERRIES[37] guideline for online survey distribution and reporting was followed.

Work package 3: in-depth qualitative interviews with health and care professional survey respondents in West Yorkshire and London (objective 3)

Participants

Health and care professionals who had participated in the work package 2 survey and had agreed to be contacted about participating in an interview were the participants. We sought a total sample size of 60 health professionals (approximately 5 from each setting in each region) with a sampling frame covering general practitioners (GPs), community-based nurses, community-based palliative care doctors and nurses, care home staff, ambulance staff, hospital-based palliative care doctors and nurses.

Methods

Face-to-face or online semistructured interviews were conducted by experienced qualitative interviewers (JB, AB) following a topic guide. The topic guide was informed by findings from the previous surveys (work packages 1 and 2) and centred around NPT to explore the impact of how EPaCCS are delivered (e.g. ease of use, familiarity and

personalisation), types of engagement (e.g. duration of use and frequency) and mechanisms of action influencing use (e.g. skills, motivation and attitudes). Interviews lasted up to 60 minutes, and participants' organisations were offered a reimbursement of £75 for their time.

Analysis

Interviews were audio-recorded, fully transcribed, anonymised and analysed using Framework Analysis.[40] Data analysis was carried out concurrently with data collection to allow the refinement of the interview questions and to enable recruitment to the point of data saturation (the stopping criterion being three interviews completed without new ideas emerging). NVivo (QSR International, Warrington, UK) data analysis software [Lumivero. NVivo (Version 13). www.lumivero.com; 2020; accessed 5 September 2025] was used to aid data management. Analysis was undertaken by four researchers (AB, JB, MA, MT). The initial coding frame was discussed to ensure consistency and rigour in the analysis and was then applied to the remaining transcripts. Comparative analysis in the framework enabled us to identify common themes as well as region-specific and participant group divergences. The coding frame was informed by NPT and was further developed as subthemes emerged. Illustrative codes were reported for each theme. The research was reported in line with the consolidated criteria for reporting qualitative research (COREQ).[41]

Work package 4: workshop and interviews with patients with progressive illness and their carers in West Yorkshire and London (objective 4)

Participants

Participants were patients with a life-limiting chronic condition or terminal illness and carers (current and bereaved) of these patients. Two hospice sites in each region (West Yorkshire and London) identified patients receiving palliative care as well as carers and invited them to attend one of the focus group workshops to explore patients' and carers' perspectives on EPaCCS. To accommodate social distancing needs, participants were offered individual interviews and online options. Caregivers were able to attend with or without the patient they cared for. Patients who were not receiving palliative care and carers of these patients were identified and invited by representatives from community support and advocacy groups representing patients and carers.

Methods

Face-to-face or online focus groups and semistructured interviews were conducted by two experienced qualitative interviewers following a topic guide. The topic guide was informed by findings from the previous surveys and interviews (i.e. work packages 1–3) with health professionals as well as research focused on patients' experience of advance care planning or electronic health records and experiences and views of patient and public involvement (PPI) representatives. The researcher began by presenting an example of how EPaCCS content may be used to inform care for people with progressive chronic conditions. This was followed by focus group discussions regarding existing and future content and use of EPaCCS as well as exploring patients' and carers' perspectives on the EPaCCS approach and anticipated impact from its use, alongside identifying priorities for the development of these systems. Field notes were taken by researchers during the workshops and interviews.

Analysis

Interviews were audio-recorded, fully transcribed and anonymised and analysed using a Thematic Framework Analysis.[42] A set of broad codes relevant to the research questions was developed through iterative team discussions. These categories were based on JB's and MA's familiarity with the data and the research team's previous work. The coding frame was applied to all the transcripts. Field notes were used to contextualise the data and inform interpretation. The research was reported in line with COREQ.[41]

Work package 5: theory of change workshops in West Yorkshire and London (objective 5)

Participants

Health professionals, patients and carers who participated in work packages 1–4 and had agreed to be contacted about participating in a Theory of Change Workshop. We supplemented the health professional group with additional participants working in the sites that had participated in the previous work packages. We sought a total sample size of 15–20 participants (palliative and end-of-life care leads, health professionals, patients and carers) to attend an in-person workshop in each region (West Yorkshire and London). We aimed for a sample of three to six end-of-life care leads to attend an online workshop.

Methods

Exploratory qualitative research design was conducted using Theory of Change Workshops[43] exploring technological, infrastructure and human factor influences on EPaCCS implementation.

Two in-person workshops were held, for patients, carers and health and care professionals. These took place in West Yorkshire and London and were led by an experienced Theory of Change Workshop facilitator, supported by six members of the research team and one PPI group member. Each workshop lasted 4 hours and the structure included: (1) informed consent via paper or online form; (2) a brief introduction to the project; (3) group work where participants were divided into three mixed groups (patients, carers, health and care professionals) and completed four activities [discuss intended impacts and outcomes of EPaCCS, prioritise impacts and outcomes, develop a theory of change map (sequentially working backwards from identified outcomes to consider the preconditions required to achieve them) and circulate between groups to discuss the emergent theory of change maps] and (4) a whole group discussion at the end of the session.

An online regional meeting took place using Microsoft Teams (Microsoft Corporation, Redmond, WA, USA) and lasted for 90 minutes. The structure included (1) informed consent via paper or online form; (2) introduction to the project and report of findings from work packages 1–4; (3) two smaller breakout groups facilitated by members of the research team {discussing the purpose and intended outcomes of EPaCCS (e.g. with whom EPaCCS should be used), how EPaCCS differ from other end-of-life care plans [e.g. Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)][44] and the relevance of EPaCCS to end-of-life policy and commissioning priorities, challenges experienced when implementing EPaCCS and future research priorities} and (4) a whole group discussion at the end of the session.

Analysis

We adopted a pluralistic approach to data analysis.[45,46] We identified the Non-adoption, Abandonment, Scale-up, Spread and Sustainability (NASSS) framework[47] as offering explanatory power that supported the development of a rich and situated narrative. The NASSS framework consists of seven domains (health condition, the technology, the value proposition, the adopter system, the organisation(s), the wider system and changes over time). It was used deductively to categorise and explain the nuances and divergences in views regarding different elements of the conceptual model. The conceptual model evolved, combining findings aligned to the NASSS framework, leading to the development of an initial programme theory. This sought to convey the influencing conditions and contexts alongside processes through which EPaCCS are expected to lead to different outcomes.[48,49] Study findings were reviewed and discussed with a subsample (n = 5) of patient and carer participants to ensure the representation of participants' perspectives.

Results summary

A summary of key findings derived from each work package is outlined in *Table 1*. Research papers derived from the project were each aligned with and reported specific findings from each of the work packages. The research papers in which the methods and findings are outlined in further detail are summarised in *Table 2*.

Discussion

The project sought to generate insights that could be used to optimise EPaCCS implementation and evaluate their future use. We produced evidence to inform three areas that can directly contribute to the future development of EPaCCS:

1. generating foundation knowledge required to understand the role of EPaCCS in supporting patients with progressive chronic illnesses
2. clarifying the intended impact of existing EPaCCS
3. guide the development of the necessary underpinning theory for EPaCCS.

Main findings

Below we summarise key findings from the study alongside outlining how we have contributed to the research literature across each area.

At the commencement of the project, the development and implementation of EPaCCS had largely been pragmatic, with no underlying theoretical basis guiding its design and the anticipated mechanisms of action. Furthermore, there were calls for further research to understand the benefits of advance care planning and incorporating patients' preferences,[60] alongside determining the best ways to ensure continuity in care for patients at the end of life.[61] This

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TABLE 1 Summary of key findings generated from each work package in the project

WP (publication)	Summary of key findings
WP1[19]	• In a national survey, only two-thirds of palliative and end-of-life care leads indicated that there was an operational system in place to support advance care planning in the region in which they were based. The remaining one-third of CCGs (which was the commissioning structure in place at the time of the project) either were at the planning stage of implementation or had no digital systems for advance care plans • Critical gaps in information sharing were reported by respondents, with most digital advance care planning systems not facilitating access for key providers of palliative care, including care homes and social care staff • The intended impacts of existing approaches to digital advance care planning reported by leads aligned with national policy goals. These were grouped under the broad classifications of enhancing co-ordination of care, early identification and recording of people approaching the end of life and reducing avoidable hospital admissions[51] • More than half of respondents reported that they did not undertake any monitoring of impact, or they used measures that did not align with the intended impact of digital advance care planning approaches • Common implementation challenges included difficulties with engaging health professionals involved in the initiation and review of patients' EPaCCS records and issues with access to and sharing of information • From routine data provided by respondents for the clinical commissioning region in which they were based, we determined that one-third of patients had an EPaCCS record in place at death. Where an EPaCCS record was in place, fewer than one-third of the records had key information relating to care preferences recorded (e.g. preferences around place of death) and nearly half of patients with a record had a diagnosis of cancer. There was an increase in the initiation of records following the start of the COVID-19 pandemic
WP2[52]	• Using a national online survey with health and social professionals, we identified latent classes (groupings of participants based on their responses to the survey) relating to familiarity with and the role of EPaCCS in supporting advance care planning and the delivery of palliative care • There is a variation in the way in which EPaCCS are perceived and used across both the two geographical regions surveyed and the professional groups involved in palliative care delivery • Health professionals in London were more likely to report being familiar with EPaCCS; however, health professionals in West Yorkshire rated EPaCCS more highly in terms of them being a legitimate part of their role and that people work together to appraise the system and its components • There was low to moderate agreement of EPaCCS being worthwhile and of value among respondents from ambulance trusts, community nursing teams, hospital teams and most GP practice teams. Respondents from both hospice and care home teams were most likely to view them as worthwhile and of value • While there was broad agreement that these systems do not disrupt working relationships, most were ambivalent about the skills and confidence of colleagues to use them • EPaCCS were viewed as supporting people to communicate advance care plans across NHS settings, but there was less certainty about their ability to share information with social care services • Commonly reported barriers to the use included not having access to electronic devices, lack of training and lack of knowledge relating to advance care plans. *These experiences may have influenced perceptions of the ability of these systems to share information* • Multiple alternative approaches to documenting advance care plans were reported, which were running in parallel to EPaCCS, including similar advance care planning initiatives using both paper and digital formats
WP3[53]	• Findings from semistructured interviews with health and social care professionals suggest that EPaCCS are not working as intended for facilitating person-centred care • Challenges which resulted in missed opportunities to deliver care in line with recorded patient wishes sometimes led to a loss of trust and confidence in EPaCCS; instead, staff opted for more traditional means of communication, such as direct communication verbally or via e-mail or fax • Challenges around implementation include problems with access and inconsistent use and engagement across settings. A key issue was technological limitations, with separate electronic health records often operating in parallel systems or failing to provide sufficient documentation or access • Health professionals' experiences resonate with previously documented challenges related to advance care planning such as lack of time, hesitancy in initiating conversations and lack of care continuity.[54–56] Lack of clarity over who contributed to records and the timing of these contributions often resulted in poor-quality data • Care home staff reported having detailed discussions regarding residents' wishes and preferences for care and documenting these within their own electronic systems. While these systems were used and engaged across care homes, the information contained within them was mostly inaccessible to external services. Care homes were also unable to access or provide helpful and detailed information from the EPaCCS used by NHS services

TABLE 1 Summary of key findings generated from each work package in the project (*continued*)

WP (publication)	Summary of key findings
WP4[1]	• Semistructured interviews and focus groups with patients and their carers highlighted requirements for digital advance care planning systems • Patients' engagement with discussions and subsequent documentation of advance care planning wishes and preferences were varied. Some participants actively pursued this via online resources, while others were unaware that it was available or indicated that this was not wanted • Experiences involving digital health records in any aspect of prior care influenced participants' views on how digital advance care planning would support their future care. Situations where health information had not been shared between services when expected and instances of incorrect information about them that had been recorded led to concerns around the accuracy of advance care planning information, not knowing what information, if any, was already held about them and who could see it • There was a recognition of the need for a skilled discussion to support advance care planning decision-making and documentation. However, it was often unclear which health professional could be approached to support this discussion. Patients indicated hesitating to approach a GP for this type of discussion due to perceived difficulty in obtaining a face-to-face appointment • The impact of digital advance care planning, important to the participants, included improved outcomes of quality-of-life aspects such as upholding personal autonomy and emotional, social and spiritual factors. Commonly, digital advance care planning systems are not evaluated using metrics that indicate care quality of the patient's experience,[57] but rather focus is on service outcomes, e.g. the location where a person is cared for and dies[9]
WP5[50]	• Through a series of theory of change workshops, a conceptual model drawing upon the NASSS framework[58] was generated, depicting EPaCCS in five distinct components relating to their use in practice (*Figure 2*) 1. Sociocultural, technical and structural prerequisites 2. Recognition of the clinical need for conversation and digital documentation 3. Having conversations and documenting decisions 4. Accessing, actioning and amending 5. Using data to support evaluation, use and implementation • The theory facilitated the capture of granular and divergent views to enrich an understanding of implementation, including the technological infrastructure and human factor influences • There were differences, divergence and uncertainty relating to what these systems are, who they are for and how organisations should evaluate them • Participants across professional groups understood the value of EPaCCS primarily in terms of service delivery and clinical decision-making, including achieving the preferred place of care and death, reflecting existing research and policy[10] • Patients and carers considered additional information that could be captured and shared through digital advance care planning approaches. This included broader aspects of care such as symptom management, not receiving unwanted medical interventions, family and carer support (including through bereavement), maintaining social ties and achieving a 'good death' • The five components of implementation presented in the conceptual model can support the development of defined outcomes and indicators of success that are important to EPaCCS implementation and amenable to quantification • Proximal, process-related outcomes may be straightforward to quantify (e.g. whether a record is documented or updated and how many times a record is accessed), but it is not currently possible to establish causal links between proximal process-related outcomes and more distal outcomes related to care quality (e.g. achieving a preferred place of care or death, delivering care in line with wishes and preferences and avoidance of hospital admissions)

WP, work package.

project generated a novel understanding of the perspectives of a wide range of health and care providers across England. We also explored patient and carer perspectives on the use of EPaCCS and how their future development could align with their needs and preferences.

We determined that EPaCCS are commonly hosted across multiple electronic clinical record software products, creating a complex informatics landscape within which data are stored and shared. Implementation of EPaCCS at the individual, team and organisational levels was affected by wider technological challenges. The inability of many EPaCCS to share advance care planning across settings involved in a patient's care was a major shortcoming that was reported by all stakeholders. Interoperability is an enduring challenge and remains a priority for health and social care delivery in the UK.[62] In particular, care homes and ambulance trusts were commonly unable to access the information stored on EPaCCS. Ongoing initiatives such as GP Connect may help to overcome some barriers, with the ambition to improve information sharing across primary and secondary care settings and provide support to more care homes and home care providers to take up this capability.[63]

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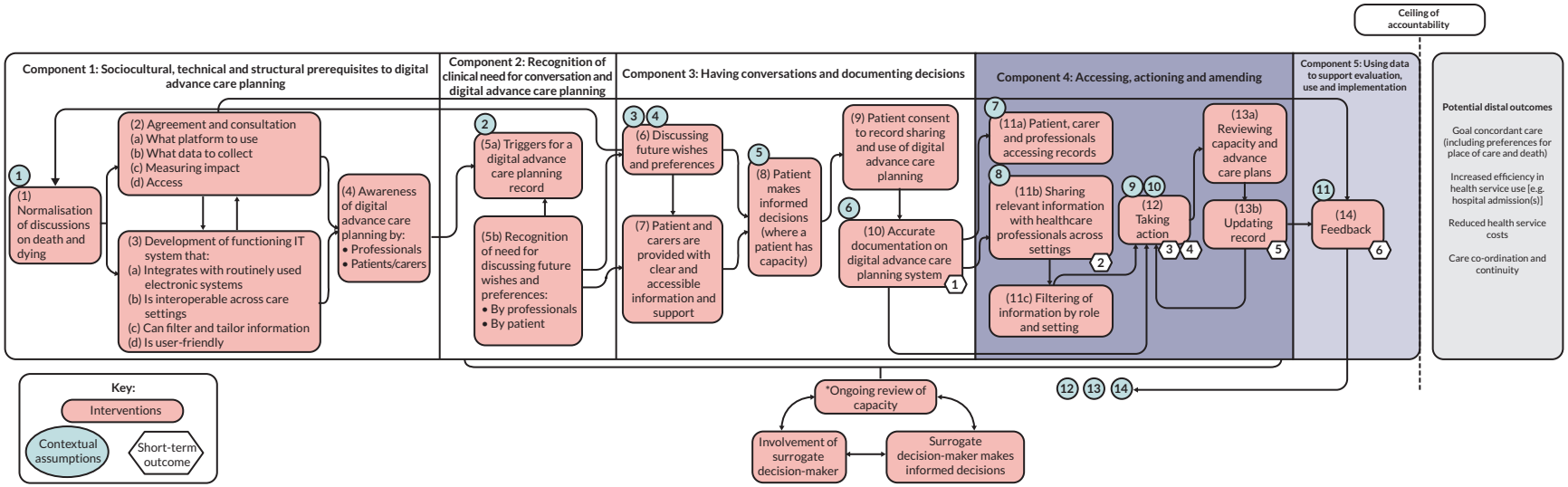

Interventions

1. Efforts, campaigns, and approaches that promote discussions of death and dying for patients and the public (i.e., Dying Matters Awareness Week, support from non-governmental and charity organisations) and healthcare professionals.
2. Across geographical locations, different digital advance care planning platforms are used [**2a**]. Commissioners decide what to measure (performance indicators) and collect relevant data within records [**2b**] and decide how to measure impact (if at all) [**2c**]. Different digital advance care planning systems have access to records for professionals and patients (e.g., editorial permissions vs. only being able to view information) [**2d**].
3. Electronic functionality of digital advance care planning systems varies regarding: [**3a**] How they integrate with routinely used electronic health and social care records and their ability to exchange information from digital advance care planning templates to local records (and vice versa); [**3b**] The extent of interoperability with other local electronic health record systems (i.e., able to share information across settings of care within a defined region); [**3c**] Their ability to filter information by role; [3d] How user-friendly digital advance care planning systems are (e.g., how easily they can be accessed, navigated, and used).
4. Professionals, patients, and carers have varied levels of awareness regarding what digital advance care planning systems are, how they work, how they are accessed, and the impact they may have on patient care and outcomes.
5. Includes [**5a**] a trigger to create a digital advance care planning record (e.g., deterioration in condition, acute hospital admission, or significant conversation), and [**5b**] recognising a need to discuss a patient's future wishes and preferences.
6. A conversation takes place between a patient and a professional. The topic(s) of conversations may vary but might cover: agreeing clear and realistic goals, managing expectations, understanding support services available, implications of treatment and care options, treatment escalation, finances, identification and inclusion of carers and individuals with Lasting Power of Attorney, and having culturally congruent conversations. Where appropriate, family and carers are involved in these conversations.
7. Patients and carers have relevant, clear, and accessible information to support their decisions e.g. leaflets and short videos.
8. Patient reflects on the conversation and makes an informed decision about their future wishes and preferences.
9. Patient gives consent for a professional to complete and share a digital advance care planning record with other professionals across care settings.
10. A professional accurately documents a conversation on a digital advance care planning system to create a quality record.
11. Digital advance care planning records [**11a**] should be available to all professionals involved in a patient's care and the information [**11b**] shared effectively where needed with other professionals, the patient, and their carers. This may be electronic (through digital advance care planning systems), printed on paper, or verbal forms; [**11c**] Information can be filtered by role, for example, ambulance trusts need to see emergency plans and contact information for other professionals involved in a person's care.
12. Information stored in digital advance care planning system records supports taking action e.g. informs decision-making, referrals (to palliative care, social prescribers, co-carer support, bereavement review), contacting specific teams for review or input, and identifying appropriate resources.
13. [**13a-c**] Where appropriate, have repeat conversations with patients to review wishes and preferences, and update records and care planning.
14. Regular feedback of outcomes to professionals (e.g., number of records created, number of times records are accessed or updated, avoiding unnecessary hospital admissions, achieving preferred places of care and death, carer bereavement outcomes, patient, and carer feedback) to highlight the impact of digital advance care planning systems on patient care and care delivery.

Short-term outcomes

1. Aspects of a person's advance care planning wishes and preferences documented.
2. Information sharing between health and care professionals across settings of care.
3. Information in records that could be used in ways to deliver care in line with patient wishes and preferences.
4. Information in records used in ways that could support family and carers.
5. Information in records reviewed and updated in ways that could reflect patients' current wishes and preferences.
6. Identifying potential contributory influences on distal outcomes, including avoidance of hospital admissions and the receipt of care that aligns with wishes irrespective of location.

Contextual assumptions

15. Differing levels of death literacy (i.e., awareness of and confidence in discussing death and dying)
16. Different understandings and views on *who* digital advance care planning systems are for (i.e., are they for everybody? Are they only for people with life-limiting illnesses? Should they include any person with multi-morbidity or people thinking about the end of life?)
17. Variations in the skills and confidence of different professionals in initiating conversations, having conversations about people's future wishes and preferences, knowing, and explaining likely options and outcomes based on patients' condition, prognosis, and awareness of available resources and support.
18. Variation in people's willingness and confidence in talking about and deciding their future care wishes.
19. Sometimes family and carers do not agree with the choices and decisions made by a patient.
20. Variation in documented levels of detail on patients' wishes and preferences. Too much or too little information can impede documentation review and decision-making.
21. Different digital advance care planning systems provide different professionals and patients with varying levels of access (e.g., read-only vs. the ability to edit records).
22. The digital infrastructure underpinning the sharing of information across care settings and professional roles varies.
23. Geographical variation in health services' resources to meet patient and carer preferences, e.g. in the clinical workforce, symptom guidance support, care and clinical infrastructure, facilities to meet cultural needs, 24/7 GPs, hospice and community nurses, drugs, and hospice capacity. There is also variable professional awareness of available resources and how they can help meet patient and carer preferences.
24. Variations in the skills and confidence of professionals in interpreting information in records, confidence in the accuracy of record content, and perceiving they have the authority to make decisions on available information.
25. Incentives in place based on the quality of records to support the creation and review of records. These may include key performance indicators and feedback that patients are benefitting from the routine use of digital advance care planning systems.
26. The amount of time that professionals have is often limited. Time is needed to have high-quality conversations that are electronically documented, alongside the ability to revisit and revise documented preferences where necessary, engage in training on advance care planning and digital systems to support the process, and collect, reflect on, and use feedback to improve processes.
27. There is often a lack of clarity over which professionals are responsible for which activities at different stages of generating and using documentation stored within digital advance care planning systems. Shared responsibility across healthcare settings (i.e., GPs, care homes, hospice, hospital, community, paramedics) is needed to have and document conversations and to make use of information stored within digital advance care planning systems.
28. Engagements and implementation efforts require buy-in, motivation, and incentivisation to input, access and review records.

Context

1. Differing levels of death literacy (i.e., awareness of and confidence in discussing death and dying).
2. Different understandings and views on *who* EPaCCS are for (i.e., are they for everybody? Are they only for people with life-limiting illnesses? Should they include any person with multi-morbidity or people thinking about the end of life?)
3. Variations in the skills and confidence of different professionals in initiating conversations, having conversations about people's future wishes and preferences, knowing, and explaining likely options and outcomes based on patients' condition, prognosis, and awareness of available resources and support.
4. Variation in people's willingness and confidence in talking about and deciding their future care wishes.
5. Sometimes family and carers do not agree with the choices and decisions made by a patient.
6. Variation in documented levels of detail on patients' wishes and preferences. Too much or too little information can impede documentation review and decision-making.
7. Different EPaCCS provide different professionals and patients with varying levels of access (e.g., read-only vs. the ability to edit records).
8. The digital infrastructure underpinning the sharing of information across care settings and professional roles varies.
9. Geographical variation in health services' resources to meet patient and carer preferences, e.g. in the clinical workforce, symptom guidance support, care and clinical infrastructure, facilities to meet cultural needs, 24/7 GPs, hospice and community nurses, drugs, and hospice capacity. There is also variable professional awareness of available resources and how they can help meet patient and carer preferences.
10. Variations in the skills and confidence of professionals in interpreting information in records, confidence in the accuracy of record content, and perceiving they have the authority to make decisions on available information.
11. Incentives in place based on the quality of records to support the creation and review of records. These may include key performance indicators and feedback that patients are benefitting from the routine use of EPaCCS.
12. The amount of time that professionals have is often limited. Time is needed to have high-quality conversations that are electronically documented, alongside the ability to revisit and revise documented preferences where necessary, engage in EPaCCS and advance care planning training, and collect, reflect on, and use feedback to improve processes.
13. There is often a lack of clarity over which professionals are responsible for which activities at different stages of generating and using documentation stored within EPaCCS. Shared responsibility across healthcare settings (i.e., GPs, care homes, hospice, hospital, community, paramedics) is needed to have and document conversations and to make use of information stored within EPaCCS.
14. Engagements and implementation efforts require buy-in, motivation, and incentivisation to input, access and review records.

FIGURE 2 Mid-range programme theory depicting the contextual assumptions, interventions and outcomes influencing digital advance care planning implementation. Reproduced from Bradshaw *et al.*[49] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The figure above includes minor additions and formatting changes to the original text.

TABLE 2 Summary of research papers synthesised in the synopsis

Research paper	WP details reported in the paper
Birtwistle J, Millares-Martin P, Evans CJ, Foy R, Relton S, Richards S, *et al*. Mapping and characterising electronic palliative care coordination systems and their intended impact: a national survey of end-of-life care commissioners. *PLOS ONE* **17**:e0275991.[19]	WP1
Birtwistle J, Williamson G, Relton SD, Bradshaw A, Sleeman KE, Twiddy M, *et al*. Community and hospital-based healthcare professionals perceptions of digital advance care planning for palliative and end-of-life care: a latent class analysis [published online ahead of print June 25 2025]. *Health Soc Care Deliv Res* 2025.[52]	WP2
Bradshaw A, Birtwistle J, Evans CJ, Sleeman KE, Richards S, Foy R, *et al*. Factors influencing the implementation of digital advance care planning: a qualitative interview study. *J Med Internet Res* **26**:e50217.[53]	WP3
Birtwistle J, Allsop MJ, Bradshaw A, Millares Martin P, Sleeman KE, Twiddy M, Evans CJ. Views of patients with progressive illness and carers about the role of digital advance care planning systems to record and share information: a qualitative study. *Palliat Med* **38**:711–24.[1]	WP4
Bradshaw A, Allsop MJ, Birtwistle J, Evans CJ, Relton SD, Richards S, *et al*. Exploring the contexts, processes and outcomes of digital advance care planning systems: a theory of change approach to understand implementation and evaluation. *Palliat Med* **38**:1144–55.[50]	WP5
Allsop MJ, Birtwistle J, Bennett MI, Bradshaw A, Carder P, Evans CJ, *et al*. Optimising digital advance care planning implementation in palliative and end-of-life care: a multi-phase mixed-methods national research programme and recommendations. *BMC Med* **23**:291.[59]	WPs 1–5

WP, work package.

Health professionals, who are intended users of EPaCCS, reported widespread confusion about who EPaCCS are meant for and who is responsible for creating and updating records. This lack of clarity may contribute to the low uptake; in their current form, EPaCCS records are only being created for one-third of all people who die. The current number of EPaCCS records is much lower than even conservative population-based estimates of palliative need despite continued policy ambitions for EPaCCS to support early identification of patients.[7,64] Alongside interoperability challenges, many EPaCCS currently in use are not tailored to meet the diverse information needs of various health and care professionals across settings; for example, ambulance teams often reported requiring quick access to accurate information about people who may not be known to them, while palliative care teams, GPs and care homes need systems that allow them to document, update and share detailed advance care planning information.

At the start of the project, there had been no reported engagement with patients and carers to understand their perspectives on the use and content of EPaCCS. This project provided novel insights into digital advance care planning and its perceived importance to patients and carers, including the ability of systems to document quality-of-life aspects such as personal autonomy and emotional, social and spiritual factors. Commonly, EPaCCS are evaluated using outcomes, including the location where a person is cared for and dies;[9] metrics that do not indicate care quality or the experience of the patient.[57] The findings can inform the refinement of outcomes for assessing digital advance care planning system use to include, for example, the presence of iterative discussions over time that are needed to ensure that patients are fully informed about the decisions that are documented and shared. Aligned with existing research outside the UK, patients and carers also highlight a greater role that health professionals could play in ensuring patients are informed about the subsequent storage and sharing of their information.[65,66]

The project highlights the limited way in which the intended impact of systems is currently being measured. There was commonly misalignment between the intended impact of EPaCCS and measures in place to assess the intended impact. Assessment of whether EPaCCS are supporting the delivery of care may require a range of indicators to capture the process of implementation and clinical outcomes.[67] To guide this process, this project developed a mid-range programme theory of digital advance care planning. We outlined the contexts, processes and outcomes influencing the implementation and impacts of EPaCCS, from the perspectives of patients, carers, health and care professionals, and commissioners. This programme theory establishes a foundation for subsequent research and can guide the further development and evaluation of EPaCCS. The programme theory identified contextual assumptions, interventions and outcomes influencing EPaCCS implementation. This is partly presented as a conceptual model that can support the development of defined outcomes and indicators of success that are important to EPaCCS implementation and are amenable to quantification. Proximal, process measures may be simpler to quantify

(e.g. whether a record is documented or updated, and how many times a record is accessed) compared to outcomes of importance to services, health professionals and patients and carers. However, it is not currently possible to establish causal links between proximal process measures and more distal outcomes related to care quality (e.g. achieving a preferred place of care or death, delivering care in line with wishes and preferences and avoidance of hospital admissions). This is critical to consider in future studies that seek to determine the impact of EPaCCS on the quality and delivery of palliative and end-of-life care.

Strengths and weaknesses of the study

This study was the first to undertake a large-scale, in-depth exploration to understand how EPaCCS are used to support advance care planning in palliative and end-of-life care in England. A mixed-methods design was used, and multistakeholder views were explored to understand how EPaCCS are used, which patients they are for and their intended impact.

In work package 1, a comprehensive study was conducted, mapping the diversity, geographical variation and intended impact of EPaCCS. This was achieved by recruiting end-of-life care leads to a national survey across England. A notable strength of this study was its extensive coverage, spanning a large part of England and surpassing the response rate of a previous national survey by Public Health England in 2013[35] and the minimum recruitment target set by the project. We expanded upon the 2013 national survey to obtain more nuanced in-depth information about the intended purpose and impacts of EPaCCS alongside methods used for monitoring these impacts. However, we acknowledge that the survey undertaken in work package 1 may have had a potential response bias, with those with more established and operating EPaCCS more likely to respond, although reports from CCGs with no EPaCCS or systems in planning were gathered. Additionally, it was assumed that respondents accurately recalled information relating to EPaCCS. It was also acknowledged that routine clinical data were limited to 60% of respondents, with data access issues arising for some respondents resulting from planned reorganisation and merging of CCGs into integrated care systems.

In work package 2, we used NPT[68,69] to explore the views of health professionals most likely to use EPaCCS. We recruited from a range of community and hospital settings and focused on two regions of England, known to have mature systems encompassing multiple models and approaches to EPaCCS. Work package 2 was the first study to undertake a latent class analysis[70] to identify emergent subgroups across a study population. This novel application provided a deeper understanding of subgroups in terms of their familiarity with EPaCCS, and for the 465 respondents who used an EPaCCS, the four domains via the NoMAD questionnaire.[38] The survey relied on self-reported responses to items, and response bias is possible. It may have also included respondents more engaged with or interested in EPaCCS, therefore representing a skewed positive perspective of the systems and how they are being used in practice.

In work package 3, the design and analysis of in-depth semistructured interviews were informed by NPT. Previous research has typically focused on demonstrating whether EPaCCS records have been created, alongside the average number of days from initiation to death;[22,71] there has been less clarity on who initiates the records and the factors that influence this.[8] We recruited staff from diverse professional backgrounds and our findings reflect the personal experiences of health and care professionals who use EPaCCS and similar health information technologies across end-of-life settings. Work package 3 built on initial classifications of health and care professionals around their perceptions of EPaCCS in work package 2.[70] Weaknesses included limited representation of community nurses in London, and there may be limited generalisability of findings to areas where EPaCCS have not been implemented. We drew on NPT to guide data collection and analysis, although other implementation theories may have provided different, yet equally valuable insights into answering the research question.

Work package 4 was the first qualitative research study that we know of to explore patient and carer experiences and views of digital approaches to advance care planning. Previous research on patient experience has been conducted using brief surveys[72] or patient health records,[12] or evaluations where EPaCCS was not the main focus.[73,74] A major strength was the involvement of patients using different health services, support and advocacy organisations and the inclusion of both current and bereaved carers who could report on their experiences and views

of digitally documented wishes. Limitations included that ethnic diversity was limited, with participants mainly identifying as White. Furthermore, only a limited number of participants could report their experiences of digital documentation of advance care plans.

In work package 5, the programme theory provides a novel conceptual and theoretical understanding of digital advance care planning alongside the complexities, nuances and conflicts regarding their implementation. The depth and detail of the study findings provide a strong foundation for generalisations to be made to other contexts in which digital advance care planning approaches are being used (e.g. MyHealthRecord in Australia and online patient portals in the USA[75]). Member checking was undertaken with a subsample of patient and carer participants (n = 5). It should be acknowledged that we presented a mid-range programme theory that will require further refinement and testing in future work. Future research should explore developing the theory of change conceptual map to include additional elements, such as indicators and rationale, and greater linkage of intervention activities and outcomes.

Protocol changes that occurred during the project

Minor changes to the original protocol

Recruitment and data collection challenges, in addition to responding to COVID-19-related research restrictions, occurred in most work packages. We overcame these issues by adapting the study processes outlined in our protocol plans to ensure recruitment targets were met while accommodating safety protocols in operation post-pandemic. Protocol changes are outlined, below.

In work package 1, we planned to recruit participants via registers provided by NHS England and Public Health England. Public Health England was decommissioned during the study, and instead, we used palliative and end-of-life care networks (clinical, management and digital) to reach clinical leads. We also stated there were 195 CCGS, but mergers during the recruitment period reduced this to 135 CCGs. We also enlisted support with recruitment from the National Institute for Health and Care Research (NIHR) Clinical Research Networks, in particular North Thames, North West London, Thames Valley, Wessex, East Midlands and the affiliated organisations, West Yorkshire R&D and Noclor.

In work package 2, care home recruitment was not possible via direct contact using Care Quality Commission registers as intended; issues mainly related to COVID-19 (such as increases in resident deaths, staff sickness and staff retention). Additionally, the survey was launched when research unrelated to COVID-19 was paused or deprioritised by clinicians due to workload pressures during the post-pandemic period. To maximise the recruitment of community nurses, we widened recruitment from our named sites to all NHS Acute Trusts and Community Trusts in both regions that employ community nurses. To maximise the recruitment of care home workers in West Yorkshire, a research nurse based in Mid Yorkshire Teaching NHS Trust was assigned to us to support recruitment, and this input was invaluable in supporting recruitment. The study also deviated from earlier planned activities where the online survey was initially planned to explore health professional perceptions of EPaCCS, alongside understanding the role of EPaCCS in supporting the management of people living with progressive, chronic illnesses. This study reports limited data relating to the role of EPaCCS in supporting the management of patients. Although originally planned in work package 2, this focus was pursued in more detail in subsequent interviews with a subsample of survey respondents as part of work package 3 and is reported elsewhere.[53]

In work package 3, we planned to recruit participants for semistructured interviews from the pool of work package 2 respondents, but this was not sufficient to achieve recruitment targets. To maximise recruitment, research leads at existing sites and clinical research networks were asked to circulate invitations to health professionals who did not participate in work package 2. We also offered the opportunity to participate online via Microsoft Teams rather than in person.

In work package 4, we planned to recruit from two hospices in West Yorkshire and one hospice in London; however, while there had previously been research nurses in post at these sites, there were none in post at the time of the study. In each hospice, clinical staff offered to commit a limited amount of time to support recruitment, so we could meet our target. In addition, we included the option for participants to take part in individual or dyad interviews; we also offered an online alternative, as well as the opportunity to participate online. We also recruited a further hospice in London. Final recruitment took place across four hospices (two each in West Yorkshire and London) alongside Victoria House Care home in Wakefield, AGE UK, Compassion in Dying and PPI groups at the Royal Marsden NHS Foundation Trust, Kings College Hospital NHS Foundation Trust and Leeds Teaching Hospitals Trust.

In work package 5, we planned to recruit from the previous work packages 1–4. We augmented recruitment to the regional workshops with health professionals from sites where previous participants could not attend or did not respond to invitations. To maximise participation, we conducted the final workshop (for end-of-life care leads) online instead of in person.

Overcoming challenges to data collection and analysis

In work package 2, a large proportion of respondents were unable to access an EPaCCS (104/569), including respondents from the ambulance service in West Yorkshire (n = 21). These participants were able to answer questions about the perceived impact of EPaCCS but were unable to reflect on their experiences as users. There was a dominance of responses from participants based in GP practices, which resulted in the need to extend the survey period when we recruited further sites and increased research nurse support later in the planned data collection period.

In work package 3, several participants had no access to EPaCCS that were typically used by NHS or hospice services. These included participants based in care homes and the ambulance trust operating in the West Yorkshire region. Both groups provided valuable data about other means of digital and non-digital planning and so their data were included in the analysis.

In work package 5, we planned to use a Theory of Change approach to conduct and analyse the data. While we were able to incorporate the Theory of Change approach into data collection, we found that NASSS better explained the data, and it was subsequently used to develop a mid-range programme theory and generate a conceptual model depicting contextual assumptions, interventions and outcomes influencing implementation.

Challenges faced in project delivery

The key challenges faced were related to delays in approvals as a consequence of the COVID-19 pandemic. This included the prioritisation of COVID-19 studies, delaying governance and ethical reviews by the University of Leeds School of Medicine Research Ethics Committee, which delayed the application for NHS Research Ethics Committee and Health Research Authority (HRA) approvals. There were also delays in NHS Trust R&D approvals and recruitment via research nurses, where clinical staff were redeployed to patient care.

In work package 1, recruitment to the national survey (December 2020–April 2021) was affected by refusals to participate, given demands on capacity relating to the COVID-19 pandemic. Recent CCG mergers meant that the number of CCGs had reduced to 135 from around 195 in the previous months. The resulting reorganisations meant that there were difficulties in identifying appropriate leads to complete the survey. Routine clinical data, requested as part of participation in the work package 1 survey, were limited to 60% of respondents, with data access issues arising for some respondents resulting from the recent and planned reorganisation of CCGs.

In work package 2, a large proportion of the sample could not access an EPaCCS (104/569), including the entire ambulance service in West Yorkshire (n = 21). However, these participants could still answer questions about the perceived impact of EPaCCS. Care home recruitment was very challenging via direct contact using Care Quality Commission registers as intended; issues mainly related to COVID-19 (including resident deaths, staff sickness and staff retention). Additionally, the survey was launched when research unrelated to immediate patient care was not considered to be a priority. The invaluable assistance of a research nurse assigned to us later in recruitment enabled us to overcome this hurdle. However, it also necessitated extending the survey period by 4 months, and we also received a dominance of responses from participants based in GP practices.

In work package 3, there were difficulties experienced with recruiting community nurses across London.

In work package 4, access to hospice services was limited by protective measures related to COVID-19, which had an impact on capacity at sites to run focus groups and recruit participants.

In work package 5, we experienced recruitment issues due to organisational staffing changes in the interim period between participants registering expressions of interest in work packages 1–3 and inviting participants to the in-person, half-day regional workshops for work package 5.

Individual training and capacity-strengthening activities

The project provided the opportunity to provide development support for two early career researchers who were the research fellows: one based at the University of Leeds and one at King's College London. Both research fellows were supported in leading the development and writing of the research manuscripts that reported research activities from work packages 1–5. This included the close involvement and support of the Chief Investigator, alongside respective leads for each work package.

The Chief Investigator was deemed eligible to apply for the Future-Focused Leadership Programme as part of the NIHR Leaders Support and Development Programme. This enabled the Chief Investigator to benefit from the training and development focused on management and leadership in health research, focusing on the individual, team, institution and system levels to enhance leadership and management capability.

Patient and public involvement

Barbara Hibbert and Nick Plant, PPI co-applicants, were recruited via the Yorkshire Cancer Patient Forum and the Cardiology PPI group at Leeds Teaching Hospitals Trust, respectively. Working with the Leeds-based research fellow, Barbara Hibbert supported the formation of and led the PPI group for the project, organising and chairing 6-monthly online meetings and circulating documents to the group. Barbara recruited nine members from both Yorkshire and London with various cultural backgrounds and with different health conditions. Members included patients and carers.

Barbara Hibbert's diagnosis of stage 4 bowel cancer meant that her experience was highly relevant to the project. Barbara supported the development of project plans, formed our patient involvement group and facilitated inclusive and insightful PPI group meetings. Barbara was a much-admired colleague, highly skilled at facilitating PPI group meetings and a critical member of the project team. In January 2022, Barbara died, having made a significant impact on the conception and delivery of the project. Barbara was always very inclusive and ensured all voices were heard, and she effortlessly shared her insights into how the project could be improved and adapted. Barbara was always very frank about her prognosis – and pragmatic in planning for it too. Barbara had arranged continuation of the PPI work should her condition have worsened. The project team were fortunate to have the support of Christina Stokes, an existing member of the PPI group formed by Barbara, who took on the role of lead PPI member during 2022 and attended one of the workshops held for work package 5.

The PPI members were involved throughout the delivery of the project. The PPI group supported the review of documentation submitted for ethical review, including providing feedback on patient information and consent form information and processes. Specific involvement within work packages also included providing a lay summary for the write-up of findings from work package 2, supporting the development of engaging materials for patients and carers in work package 4, alongside reviewing the content and overview of study findings in the research manuscript and providing input on the conceptual model derived from work package 5.

The PPI co-applicants and public contributors were reimbursed based on individual needs (e.g. time to attend meetings and workshops, travel and access requirements) in line with the NIHR public contributor payment policy.

Dissemination to participants and related patients and public communities

Throughout the project, project findings were shared with the PPI group, exploring opportunities to share lay summaries of project findings across patient and public networks. The research team have also actively sought to participate in patient- and public-facing dissemination activities. This has included two online events. In September 2021, the Chief Investigator was an invited to be a presenter for a webinar hosted by the Digital Health Section of the Royal Society of Medicine. The webinar, 'Life and Death in a Digital World', featured the research arising from work package 1 of the project. The event was attended by ~100 participants and was also made available online after the event. In August 2024, findings from the project were presented as part of a webinar cohosted by Compassion in Dying and the University of Leeds research team. The webinar, 'Digital end-of-life records: what's needed, what's likely, what's possible' was chaired by Dr Anushka Aubeelak, Vice-chair of Compassion in Dying. The webinar, attended by ~150 people, featured members of the research team providing key findings from the project. Other presenters featured during the webinar included Miranda Ashitey (a person living with stage 4 breast cancer who spoke about her experience of making end-of-life decisions and ensuring they are known about across different health and care settings), Usha Grieve (Director of Partnerships and Services at Compassion in Dying, sharing findings from work with people the organisation supports to explore what matters to them when sharing their end-of-life wishes), Dr Karen Chumbley (Chief Clinical Officer at St Helena Hospice who shared experiences in Suffolk and Northeast Essex to ensure as many people as possible have their wishes recorded digitally) and Dr Ian McNichol (a health informatician and former GP supporting initiatives to develop shared end-of-life care digital records).

Equality, diversity and inclusion

Language and terminology

We developed participant information sheets, consent forms and advertising information with the project PPI

group. The PPI group comprised people from a range of different educational and social backgrounds, with people who identified with ethnic groups of Asian (*n* = 2), Southeast Asian (*n* = 1) and White (*n* = 6). There was also a mix of people living with cancer and non-cancer conditions (including dementia) and carers. Information for health professionals was reviewed by hospice nurses involved in research, who advised on acceptable language, taking into consideration the range of backgrounds of the workforce. Information for patients was piloted with a group of current and bereaved carers from White, mixed Asian and Asian backgrounds, and changes were made where possible while also taking into consideration the required content of patient information sheets.

Generalisability and transferability of evidence

To ensure that we investigated which patients typically have a digital advance care plan and their experience of it, we targeted:

- clinical leads from each CCG, who could report on how they monitor uptake and provide aggregate patient data
- health professionals who were able to report on their work with patients and carers from diverse backgrounds
- patients and carers from diverse backgrounds, with different health conditions (e.g. cancer, non-cancer) and attending different services (known and not known to specialist palliative care).

In work package 1, we recruited commissioners across England, ensuring a widespread representation of the types of EPaCCS being implemented nationally. In work packages 2–4, we focused on two regions of England with diverse populations. London is more ethnically diverse than England as a whole.[76] There is also diversity in terms of deprivation, gender identity and disability. Across West Yorkshire,[77] there is variation in ethnicity by area. While we are unable to generalise evidence from patient and carer participants, we consider that evidence from health professionals who work with diverse patient groups across these two areas will be transferrable to the national population.

Enrol and retain diverse participants

The methods of data collection were planned to minimise inconvenience to health professional participants working with palliative care patients and their carers. We offered online or face-to-face interviews. Participants working in health services preferred an online method, whereas participants working in care homes often did not have the equipment available to participate in online interviews. Care home staff also needed to remain available to answer questions from other care home staff, residents and their families throughout the interviews. Consequently, interviews were often held in their working environment rather than the care home office. We offered interview appointments on evenings and weekends to accommodate health professionals working out of core hours.

We were flexible with data collection from patients and carers. This was especially important for recruitment taking place while COVID-19 was a risk, and there was a requirement to adhere to social distancing in public places. We offered the choice of an interview or a focus group that could take place in one of the following settings: participant's home, hospice, community venue, university venue or online via a platform of their choice [e.g. Zoom (Zoom Video Communications, San Jose, CA, USA) and Microsoft Teams]. Careful recruitment and consideration of participants enabled us to retain their input throughout the work packages.

Participant data

We collected data on ethnicity, gender and age in work packages 3–5. In the online surveys in work packages 1 and 2, we sought to develop comprehensive but brief questionnaires for a range of health professional roles. We refrained from requesting detailed personal information about respondents. In work package 3, most health professionals from West Yorkshire identified as White. In London, there was some diversity in the groups in terms of ethnicity with one-third each, White English, other White and non-White. In both regions, there were more females than males, reflecting the female predominance in current palliative care workforce data.[78]

In work package 4, in both regions, most patients (93.1%) and carers (73.3%) identified as White, and while most of the sample were aged 65–74 years (62.1% of patients, and 60.0% of carers), we had representation from people aged 64 years or younger (24.1% of patients, and 33.3% of carers). Two-thirds of the sample were female. Characteristics of participants attending the work package 5 workshop reflected the two previous studies with health professionals, patients and carers.

Reflections on your research team and wider involvement

We ensured an equitable approach to authorship with distribution across male and female research fellows in leading the first drafts of manuscripts. The research team and steering group membership were evenly distributed in age and gender. We also carefully considered the professional background and skill set required to deliver the

project, ensuring that we have the right mix of expertise and experience.

Impact and learning

What difference has been made already?

Throughout the project, the team explored ways of ensuring emerging findings were being used to guide care delivery in England. During 2020–2, information standards used nationally to guide the content of EPaCCS underwent revision, updating the previous revision by Public Health England in 2015.[79] Led by the Professional Record Standards Body, the latest revision was published in 2023.[24] Members of the research team (Matthew J Allsop, Katherine E Sleeman) were part of the Palliative and End of Life Working Group which led the review and development of the information standards. Other organisations represented in the Group included NHS England and Improvement, NHS Digital, Compassion in Dying, Hospice UK and Together for Shorter Lives. Findings from work packages 1–3 were fed into the development process. The revised standard is UK-wide for use across the whole of health and social care relevant to anyone requiring palliative and end-of-life care, including children, and is accompanied by implementation guidance and a minimum viability information standard.

Findings from the project have been shared with organisations that are designing and refining digital advance care planning systems. Throughout the project, findings were shared via online meetings with partners, including the Programme Director and management team of a new digital advance care planning system implemented across London (Urgent Care Plan, now called Universal Care Plan). The team members have continued to share key findings and their relevance for the development of the system with palliative and end-of-life care commissioners for London to guide continued system development. Findings from the project have also been shared internationally, including with the Institute for International Socio-Economic Studies in Japan, which has been using the findings from the project to design a digital advance care planning system for use in Japan.

We have also ensured that we have maintained an impact on academic research and practice relating to digital advance care planning research. We have presented at multiple international conferences alongside engaging research groups across the UK through regularly participating in research seminars (see *Additional outputs*). This included findings from the project being presented by the Chief Investigator as an invited speaker to a national webinar hosted by the Royal Society of Medicine in September 2021 called 'Life and Death in a Digital World'. This activity is detailed in *Additional outputs*.

Collaborations

The project has formed the foundation for multiple related research. In 2023, the Chief Investigator was awarded funding as a joint principal investigator from the British Medical Association to undertake a retrospective observation cohort study exploring the association of social determinants of health in decision-making at the end of life. The project Chief Investigator is also a coinvestigator on a project funded through the Royal Marsden Charity and Royal Marsden Biomedical Research Centre to undertake an evaluation of EPaCCS to support advance care planning for people living with life-limiting conditions. Both projects draw on routine data sets to understand how and when EPaCCS are being used in practice. Both projects involve leading statisticians and health economists and seek to advance the analysis of EPaCCS data sets. A detailed protocol outlining the planned analyses has been published.[80]

During the project, the team has worked closely with the third-sector organisation, Compassion in Dying, who advocate for patient involvement in decision-making for people at the end of life. As part of their PhD studies, a research fellow from the project (Birtwistle) worked with the organisation in 2022 to seek external funding to support the analysis of data collected by Compassion in Dying to explore patient and public experiences of and priorities for the use of shared patient health records for advance care planning. The data set analysed included responses from 1728 participants in 103 UK counties, including people with a terminal condition (n = 33), long-term condition (n = 442), who provide or have provided care to a person with a long-term or terminal illness (n = 229), and who identified as healthy and interested in planning for the future (n = 1024). The findings have been published.[81]

Implications for decision-makers

In England, EPaCCS encompass multiple approaches to supporting the creation, sharing and updating of key palliative and end-of-life care information (e.g. advance care plans, preferences for care, resuscitation decisions, key clinical information). The project derived insights across multiple key stakeholders to guide the development of what we broadly term digital advance care planning (DACP) approaches for England. Key findings are detailed in *Table 3* alongside a rationale and recommendations for decision-makers to enhance and develop existing and new DACP approaches in England.

This synopsis should be referenced as follows:
Allsop MJ, Birtwistle J, Bradshaw A, Carder P, Evans CJ, Foy R, *et al*. Evaluating the implementation of Electronic Palliative Care Co-ordination Systems (EPaCCS) and optimising future service provision for palliative and end-of-life care: a synopsis of the Optimal Care mixed-method study. *Health Soc Care Deliv Res* 2026;**14**(24):1–32. https://doi.org/10.3310/HSDA7175

TABLE 3 Recommendations and rationale for decision-makers to guide the development of new and existing EPaCCS

Phase 1: sociocultural, technical and structural prerequisites
Description: aspects that need to be considered and established ahead of a system being in place and used as part of routine care

Recommendation 1. Digital advance care planning (DACP) systems should accommodate patient diversity – including varying disease trajectories and patient and carer backgrounds
Health professionals (WP3), patient and carer interviews (WP4) and **workshop (WP5)** data revealed that current DACP systems are more suited to people with a diagnosis of cancer. Systems design needs to ensure relevance for people with conditions other than cancer, and those with multiple conditions, such as ensuring access for all relevant health services, integration across care pathways and the potential greater carer and proxy involvement in discussions and decision-making documented on DACP systems
Patient and carer (WP4) and **workshop (WP5)** participants suggested exploring the possibility of involving patients and carers from a range of backgrounds to inform culturally congruent content of DACP systems
Aligned with NASSS *Domain 1 – health condition*

Recommendation 2. Engagement with key stakeholders (i.e. health and care professionals, patients and carers) is essential to guide the content of DACP systems, alongside ensuring that expectations, requirements, procedures and impact of the documentation and sharing of digital advance care plans are clear
Health professionals (WP3) reported the constant burden of training new staff, including the increasing use of agency staff. GPs stated a need for guidance on roles and responsibilities of DACP in primary care and suggested that this should be as brief and focused as feasible

Patient and carers (WP4) indicated that information should provide any health professional with enough knowledge about who they are as a person to treat them in a way that aligns with their wishes. Information should include:
- holistic information about the person
- information about preferred medical treatments
- information about usual and preferred places of residence and preferred places of death.

They emphasised the need for different electronic formats (Android, computer) and printed information *Aligned with* NASSS *Domain 2 – technology*

Recommendation 3. Organisations should prioritise and build DACP systems using platforms that support interconnectivity. This should ensure that authorised health and social care workers across all relevant care settings can access digitally stored advance care planning documentation
Commissioner survey (WP1) data indicated that the implementation of digital systems for storing and sharing advance care plans varied significantly across services and geographical regions. The ability to view electronic advance care plans is limited, and most areas cannot share data with care homes or ambulance teams
Health professional survey (WP2) respondents reported that while digital systems supported the documentation of advance care plans, they were less helpful in sharing them
Health professional interviewees (WP3) stated critical gaps that exist with some DACP systems, including systems that do not share advance care planning information with ambulance teams or enabling access and sharing by care homes. Care home teams reported regularly engaging in and documenting advance care planning conversations with residents, but they could not view and access health services digital systems. If this were possible, it would have allowed care home teams to check that information about their residents was accurate. Care home teams considered the content of care home systems to be superior and said that NHS health professionals would benefit from viewing it. They were aware of software that would join up with records in primary care and that procurement was the responsibility of the general practice team or NHS service
Aligned with NASSS *Domain 2 – technology*

Recommendation 4. Agreement on the purpose and intended impact of DACP systems should be established through consultation with all stakeholders involved in the care of patients with life-limiting illnesses, alongside patients and carers themselves. This engagement should guide the selection and measurement of DACP outcomes, which must be developed locally to account for geographical variations and differing approaches to DACP
Commissioner survey (WP1) respondents cited multiple intended impacts of DACP systems. Despite variation across geographical regions, there was broad agreement that these systems should facilitate the delivery of care following patient wishes and priorities
Health professional survey (WP2) data showed variation between health professional groups on the purpose of DACP systems. Respondents from care homes, hospices and ambulance teams were more likely than other groups to consider digital solutions to be distinct from other ways of working and were clear about their purpose
Health professional interview (WP3) data highlighted that palliative care teams, care homes and GPs need to be able to document, update and share quality advance care planning information; however, they also reported using verbal communication if situations are urgent and e-mail or letters if they are not
Patient and carer interview (WP4) data indicated that patients valued aspects of planning, documenting and sharing their information. Patients with a digital advance care plan valued the documentation process even though they were unsure if it would be used to inform their care
Patient and carer interview (WP4) and **workshop data (WP5)** highlighted the role of non-governmental organisations (e.g. Compassion in Dying, AGE UK and Macmillan) in supporting people to make advance care plans, therefore these organisations should be involved in discussions about intended impacts and patient outcomes
Workshop data (WP5) also revealed multiple perspectives on which types of patients were eligible to have a shared digital advance care plan and what information the plan should contain. Variations in perspectives occurred between health professionals as well as patients and carers
Aligned with NASSS *Domain 3 – value proposition*

TABLE 3 Recommendations and rationale for decision-makers to guide the development of new and existing EPaCCS (*continued*)

Recommendation 5. The limitations of sharing information between services and regions should be clear to health professionals should this need to be communicated to patients **Health professional interview (WP3)** participants indicated that it was not always known which other services could access shared information and in what format **Patient and carer interview (WP4)** participants reported that they were not sure who could see their data; some had presumed that other services could access it at the point of need and then found this was not the case *Aligned with* NASSS *Domain 4 – adopters*
Recommendation 6. Organisations should learn from others who have developed activities to promote uptake and use (such as strengthening engagement or leadership and development of training). There is scope to identify and learn from creative solutions to promote uptake and use **Commissioner survey (WP1)** respondents described the use of dashboard functionality to help stakeholders make informed decisions about patient care as well as to share learning across different organisations. Other activities reported included the development of a range of training resources, collaboration between regional care settings, engagement of senior management, strong clinical and IT leadership and having an active communication strategy **Health professional interview (WP3)** participants described how the integration of shared digital records with single point-of-access telephone line facilitated fast access to advance care planning information for both patients and other health professionals involved in patient care at the point of need. These data also revealed areas of good practice where the use of standard operating procedures in one hospital department had been rolled out to another *Aligned with* NASSS *Domain 5 – organisations*
Recommendation 7. Organisations should consider ways of embedding DACP into routine structures and processes (e.g. at admission, at discharge, multidisciplinary team meetings and handovers) **Health professional survey (WP2)** data indicated a lower level of commitment to working together to build and sustain a community of practice around DACP systems among health professionals who did not work in hospice or ambulance teams **Health professional interview (WP3)** data revealed that while high staff turnover can be a barrier to creating participation networks, this could be ameliorated by having key health professionals or managers in the organisation who drive forward engagement with digital systems for advance care planning as part of their designated role *Aligned with* NASSS *Domain 5 – organisations*
Recommendation 8. Training delivered within organisations should include data protection and legal or regulatory implications of methods of planning future care **Workshop (WP5)** participants viewed data protection laws and safeguarding as crucial to consider in developing and using DACP systems. Participants, including health professionals, were not always clear on the legal or regulatory implications of different components and types of future planning (e.g. advance care plans, lasting power of attorney, advanced statements, ReSPECT, ADRT, and do not attempt cardiopulmonary resuscitation decisions) *Aligned with* NASSS *Domain 6 – wider system*
Recommendation 9. Initiatives that empower patients and families to engage in discussions about death and planning for end-of-life issues should be pursued. This may include the circulation of accessible resources (pamphlets, videos and website material) that offer guidance, alongside public engagement events such as Dying Matters Week **Patient and carer interview (WP4)** discussions revealed that some patients could not remember if they had been approached about documenting preferences and some believed their health professionals considered it to be too early. Some reported that their cultural background had made discussions about their death difficult, and family members had avoided the topic when the patient wanted to have a conversation **Patient and carer interview (WP4)** participants and **workshop (WP5)** participants talked about non-governmental organisations that had introduced them to thinking about advance care planning. These included AGE UK, Compassion in Dying, Macmillan Cancer Support and University of the Third Age. These organisations also produced a wide range of online resources as well as hosting events and one-to-one sessions *Aligned with* NASSS *Domain 6 – wider system*
Phase 2: Recognition of the clinical need for conversation and DACP (e.g. deterioration in condition, acute hospital admission or significant conversation) and recognising a need to discuss a patient's future wishes and preferences (could be from a professional or patient) *Description: initiating an advance care planning record on the digital system*
Recommendation 10. Patients should be identified and offered the opportunity to document a digital advance care plan irrespective of disease type, with approaches explored to support the identification of non-cancer conditions **Commissioner survey (WP1)** data revealed that only one-third of people who had died had any advance care planning information recorded. However, records for people with diseases other than cancer have increased since the start of the COVID-19 pandemic **Health professional interview (WP3)** data suggested that patients without cancer make up most of the palliative care caseload, yet people with cancer are more likely to have a digital advance care plan **Patient and carer interviews (WP4)** revealed that some participants without a clear clinical need had documented a digital advance care plan, whereas others with a long-term condition did not. Making choices appeared to be more straightforward for people with a short-term prognosis compared with a long-term progressive disease. Domestic life is more easily arranged around a patient for a short period than an unknown one. Patients often base wishes on what is realistic and available closer to death, so options are more likely to be known for cancer patients due to the more predictable nature of the disease *Aligned with* NASSS *Domain 1 – health condition*

continued

TABLE 3 Recommendations and rationale for decision-makers to guide the development of new and existing EPaCCS (*continued*)

Recommendation 11. There is scope to leverage existing community-based assets, including organisations that provide in-person and patient-facing resources designed to support people to develop their own advance care plans. Existing patient-facing resources (including online resources) can be used to support preparation and readiness for advance care planning discussions
Patient and carer interview (WP4) participants spoke about the usefulness of information obtained from community-based organisations or downloaded from websites to inform their advance care planning decisions
Workshop (WP5) participants talked about governmental and charity organisations that are active in raising awareness and supporting advance care planning documentation and these services are useful in helping to prepare people for advance care planning and discussions
Aligned with NASSS *Domain 4 – adopters*

Phase 3: having conversations and documenting decisions
Description: engagement of patients in the discussion of advance care planning information. Digital documentation of preferences

Recommendation 12. Efforts should be made to ensure stored information is accessible through existing electronic medical record systems, for example summary care records in England. Attempts should be made to ensure synchrony of information across record systems to ensure professionals can access exact and up-to-date patient preferences
Patient and carer interview (WP4) participants believed they had different information stored in various services that could not be viewed or cross-checked by each service
Aligned with NASSS *Domain 2 – technology*

Recommendation 13. Health professionals should elicit information from patients regarding any paper or electronic self-completed advance care plans they may hold and consider how to merge this information with the organisation's digital system
Patient and carer interview (WP4) discussions about existing plans and components of plans (e.g. ReSPECT, advance directives) revealed that many had documents stored in different services and at home in electronic and paper formats. They often did not know where to take information stored only in the home so it could be documented and shared with health professionals who need to see it to provide future care
Aligned with NASSS *Domain 4 – adopters*

Recommendation 14. Undertaking a needs assessment of levels of staff competence in conducting advance care planning conversations with patients with life-limiting conditions can identify opportunities for delivering and tailoring training. There may also be scope to link competencies around communication and advance care planning within job descriptions for health and care professionals
Health professional interview (WP3) participants discussed the belief that some palliative care teams were better placed to carry out advance care planning discussions than others. While they were presumed to have more experience and time available than generalists, participants felt that any health or social care worker working with patients could and should undertake advance care planning discussions
Patient and carer interview (WP4) participants said they would prefer to discuss their advance care plan with a person who can dedicate enough time to discussing a range of options and likely outcomes and who can also get to know and understand the patient well. These characteristics were considered to be more important than a health professional's clinical background
Aligned with NASSS *Domain 5 – organisations*

Recommendation 15. There is a need for agreement and clarity on which services and settings can interact with a digitally stored advance care plan as soon as it is ready to share. This includes who can review, update and use the information to inform decision-making
Health professional survey (WP2) ambulance team respondents are more confident in accessing the digital system to view and use patient data than other professionals
Health professional interview (WP3) data indicated a general view that for digital systems to benefit patient care, all health professionals needed to contribute to the process of discussing, documenting and sharing their patients' advance care plans
Aligned with NASSS *Domain 5 – organisations*

Recommendation 16. Processes should be explored to ensure that the content of DACP system records remain up-to-date and accurate. These processes may include, for example options for patient and carer access to review the content of records or through discussion with patients. Different patients have varying preferences and comfort levels with technology, so access should allow flexibility with access and security (e.g. using either biometrics, security keys, social media credentials or passwords)
Patient and carer interview (WP4) and **workshop (WP5)** patient and carer discussions included the recognition that documented wishes and preferences should be contemporaneous to support care delivery. Participants also acknowledged that the timing of subsequent discussions varied according to disease trajectory and patient resources. Patients welcomed the option to access their record to check for accuracy and a function to prompt or request a discussion with a health professional who could update their information
Patient and carer interview (WP4) participants indicated that viewing their records would be helpful for checking the accuracy of content. They would also value being able to check which professionals have accessed and edited their records. Participants did not want to constantly change or remember complex passwords. Logging in should be straightforward to facilitate continued use, and it must also be secure so that unauthorised users cannot access it
Aligned with NASSS *Domain 5 – organisations*

Phase 4: accessing, amending, actioning
Description: this includes the iterative process of reviewing and updating records

TABLE 3 Recommendations and rationale for decision-makers to guide the development of new and existing EPaCCS (*continued*)

Recommendation 17. Health professionals must ensure that the advance care planning information they record is sufficient, but presentation in a summary or succinct form (e.g. highlighting resuscitation preference) may ensure accessibility and utility for different professional groups, enabling them to provide care that aligns with patient wishes **Health professional survey (WP2)** and **interview (WP3)** respondents working in ambulance teams said they valued the skill and input of other health professionals in documenting advance care plans and emphasised the importance of complete and up-to-date information they could find, read and interpret quickly to provide emergency care (such as information about resuscitation preferences). The ability to view the most up-to-date information quickly without the need to scroll or search, especially when using it to provide patient care in an emergency, was shared across other health professional groups **Patient and carer interview (WP4)** participants wanted holistic information to be the most readily available when receiving care from professionals who did not know them personally *Aligned with* NASSS *Domain 2 – technology*
Recommendation 18. Electronic patient record system notifications should flag patients with a digitally recorded advance care plan and prompt clinicians to access and review. This should be across settings, including options for health and social care professionals working in relevant acute hospital specialties (e.g. emergency department, oncology, respiratory and cardiac) to have viewing access to DACP records created externally to the care setting at a minimum **Commissioner survey (WP1)** highlighted most hospital palliative care teams could not share advance care planning information with other teams and services, even within the same hospital **Health professional interviews (WP3)** suggested that indicators on electronic systems were crucial for locating advance care planning information quickly; this was particularly important to ambulance teams **Patient and carers (WP4)** valued information sharing between different hospital services, particularly if seen out of hours by professionals they do not know well. This was particularly key for patients with conditions needing input from different professionals Patients had experienced instances where electronic information documented about them within one health service could not be viewed by another and anticipated similar challenges for DACP systems *Aligned with* NASSS *Domain 2 – technology*
Recommendation 19. While interacting with the digital systems, health professionals should work alongside patients (and their carers, if the patient permits) by offering to share the screen so patients feel part of their own planning **Patient and carer interview (WP4)** participants expressed discomfort and detached from their plans and preferences when health professionals typed information they could not see and did not invite them to view *Aligned with* NASSS *Domain 4 – adopters*
Phase 5: using data to support evaluation and implementation *Description: This could include, e.g. quarterly reporting and also includes providing feedback on outcomes to professionals*
Recommendation 20. The processes associated with the implementation of DACP systems and their effect on patient care should be measured and findings should be reported back to health professionals as well as organisation management. A range of appropriate methods of measurement may be needed to capture how DACP systems influence patient care and clinical decision-making **Commissioner survey (WP1)** data found that measuring the intended impact of DACP systems focused on routinely collected data that counted the number of patients achieving a specific outcome (e.g. number of patients with a DACP system record at death, having a recorded preference for place of care or death). Several areas used feedback from staff, patients and families **Health professional interview (WP3)** data revealed that counts of patient activity helped identify patients' characteristics of who was less likely to have a record and could be used to help reduce inequality. However, wishes about the place of care or death can change quickly and frequently in a patient's last days. Therefore, any outdated, digitally documented advance care planning data were deemed unsuitable for measurement, and additional measures are needed to assess how often records are being reviewed, updated and used to inform care *Aligned with* NASSS *Domain 2 – technology*

Recommendations are organised in alignment with the five components of DACP that are detailed in the mid-range programme theory generated from the project. A paper outlining the process of synthesising project findings and deriving recommendations has been published elsewhere.[59]

Research recommendations

This project has generated research to demonstrate how digital advance care planning is being undertaken in England. Through extensive engagement with key stakeholders, the project generated insights into the experiences and preferences relating to digital advance care planning implementation. Mid-range programme theory was also generated to support the development of defined outcomes and indicators of success that are important to digital advance care planning implementation and amenable to quantification. The recommendations for commissioners and providers (see *Table 3*) require new research to evaluate their impact on practice. Three main research areas are recommended, as explained below.

1. There is a need to develop and test approaches that seek to improve health professional engagement with digital advance care planning systems

The successful implementation of digital interventions into routine care depends on the extent to which they enhance established ways of working with minimal disruption. For complex interventions like digital advance care planning systems to become normalised into everyday practice, they must fit within and enhance established systems of care.[82] Interoperability remains an enduring challenge for users of digital advance care planning, but this should not be prioritised over research at the level of users of digital advance care planning systems. Across patients, carers and health and care professionals (including commissioners), there is a lack of clarity, and divergent views, on the purpose and intended impact of digital advance care planning systems, who they are for and professionals' responsibilities relating to their use. Where there are subsequent changing work practices and evolving technology systems, a context could be created in which unintended consequences (e.g. care delivered that does not align with a person's wishes due to inaccessible, outdated or inaccurate information) arise.[83] Future research is required to focus on approaches that support planning, communication and continued monitoring of health professional roles and responsibilities relating to the use of digital advance care planning systems. Roles and responsibilities can be defined within restrictions to data-sharing and access that exist within specific regions, which may require ongoing monitoring as systems and their capabilities evolve. Alongside working to clarify roles and responsibilities, future research is also required to explore approaches to determining and conveying the benefits of digital advance care planning to patient care and clinical practice compared to traditional ways of working.[84,85,86]

2. Patient and carer access to digital advance care planning records is an emerging and essential focus for future research

Currently, in England, no digital advance care planning systems enable patients and their carers to access and review information documented about them. A system in London, Coordinate My Care,[87] previously enabled patients to access information stored in their records, but the system was decommissioned during the initial phases of the project. Published research from work package 4[1] provides a list of considerations for the future development of digital advance care planning systems that facilitate patient access to their records. As systems evolve with the capability to support patient access to their records through online portals and mobile phone applications, it is crucial to continue to understand the experiences of patients and their carers to refine the design and content of digital advance care planning systems. This will include further exploration of patients' trust in the use of digital systems for end-of-life preference documentation and sharing, processes around access for patients and potentially carers and family members, and exploring how existing online resources and advance care planning documentation generated with the support of community support groups can be accommodated by existing digital advance care planning systems. Examples include patient-facing online resources to guide people through creating an advance care plan without direct input from a health professional[88–91] (MyWishes. MyWishes. 2023. www.mywishes.co.uk/advance-care-plan; accessed 5 September 2025). Such patient-facing platforms have been shown to increase the engagement and documentation of advance care plans,[92] but they typically require the download of a patient-completed paper-based form that needs to be taken to a health professional for adding to and storing in a digital health record.

3. Mid-range programme theory for digital advance care planning should be tested and refined to underpin the future development of systems and their implementation

The project addressed an absence of an underlying theory to guide the development and evaluation of digital advance care planning. A mid-range programme theory was generated that includes a conceptual model depicting defined outcomes and indicators of success important to system implementation (see *Figure 2*). Future research is required to develop the existing mid-range programme theory to incorporate additional elements, including indicators and rationale, and greater linkage of intervention activities and outcomes. This refinement may also draw on routine data to determine the presence and influence of digital advance care planning approaches in the context of routine care. The depth of the data presented provides a strong foundation for naturalistic generalisations to be made to other contexts in which digital advance care planning approaches are being used (e.g. MyHealthRecord in Australia and online patient portals in the USA[75]). Future research is needed to validate the mid-range programme theory in country settings outside England, and subsequently, augment or revise the conceptual model to reflect local country contexts. A key recommendation for future research is the need for a more nuanced evaluation of digital advance care planning. This may include determining pathways of effect from the use of digital advance care planning to distal outcomes, including patient outcomes relating to care co-ordination and care aligned with the wishes and preferences of patients and their carers. This work may benefit from drawing on the emerging field of process science[93] that embraces unfolding and continuous change processes and draws on the perspectives of multiple disciplines. Where more comprehensive and detailed

routine data sets are available, adopting approaches such as quasi-experimental analysis of effectiveness may offer further insights into the impact of digital advance care planning approaches.

Conclusions

This project has generated research to understand how digital advance care planning is being implemented in England. EPaCCS were introduced in 2008. At the start of this project, there was a national policy drive to roll-out EPaCCS across England, but uptake was low. This project identified that only one-third of those who died were reported to have an EPaCCS record. This study has helped elucidate the reasons for low uptake in England and propose solutions. Through extensive engagement with PPI representatives, people receiving palliative care, carers, health and social care professionals, and commissioners of palliative care services, the project generated insights into the experiences and preferences relating to EPaCCS and digital advance care planning implementation. The project highlighted divergence in views among health professionals about the intended use and outcomes of digital advance care planning systems. The project also highlighted the need for EPaCCS that cater to the diverse information needs of various health and care professionals, ensuring that these systems are more user-friendly and effective in information sharing to inform palliative care delivery. Alongside professionals, the project generated novel insights into patient and carer perspectives on the role and development of EPaCCS. This highlighted the importance of digital advance care planning from the perspective of patients and carers, particularly regarding the documentation of quality-of-life aspects and the need for better communication about how their information is stored and shared. However, there remains a need to determine the extent to which digital advance care planning systems align with the needs of people from a range of sociocultural backgrounds.

The project contributed a theoretically informed basis for the future development of EPaCCS and digital advance care planning approaches. Mid-range programme theory, including a conceptual model was generated, defining outcomes and success indicators that are crucial for the implementation of EPaCCS and that are amendable to quantification. Further research is required to test and refine the mid-range programme theory, with a need to establish causal links between process-related outcomes and more distal outcomes related to care quality. To support the application of project findings in practice, the report presents a distillation of findings into recommendations and a supporting rationale for decision-makers to guide the development of new and existing digital advance care planning approaches (see *Table 3*). These recommendations seek to address the implementation challenges and uncertainties reported across participants relating to EPaCCS and digital advance care planning approaches.

This project has generated research publications and conference presentations that outline factors influencing EPaCCS implementation in routine care, user preferences for EPaCCS development to optimise engagement and mid-range programme theory to guide evaluation of their outcomes and success following implementation. Project findings have also informed the development of national information standards for England relating to the information contained in palliative and end-of-life care digital records. Findings have also been used to guide regional and national digital advance care planning system development in the UK and internationally. The pursuit of research aligned with recommended areas of future research will ensure the continued impact of the project. This includes the need to develop and test approaches that seek to improve health professional engagement with digital advance care planning systems, develop and evaluate digital advance care planning systems that enable patient and carer access, and further refine and test mid-range programme theory derived from the project. Taken together, this project and subsequent research may be able to guide the continued evolution of digital advance care planning approaches to ensure optimal implementation that aligns with the needs of their multiple stakeholders; patients, carers, health and social care professionals, and commissioners of palliative and end-of-life care.

Additional information

CRediT contribution statement

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Patient data statement

This report does not use data provided by patients and collected by the NHS as part of their care and support.

Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

Research activities undertaken as part of work package 1 was approved by the University of Leeds on 1 November 2020 (reference number MREC 20-008) and Health Research Authority on 4 December 2020 (reference number 20/HRA/5804). There were no amendments. Research activities undertaken as part of work packages 2–5 were approved by the North of Scotland Research Ethics Service, Aberdeen, on 13 April 2021 (reference number 21/NS/0046) and Health Research Authority on 14 December 2020. A substantial amendment was granted on 6 June 2021. This was to allow the researchers to ask participants at workshops in work packages 4 and 5 for permission to take photographs that would be used to illustrate the dissemination of results at conferences, posters and future research events. Participant information sheets were updated accordingly and consent forms were adapted so that a preference for being photographed or not could be documented. There were 12 non-substantial amendments that required no ethics review covering the addition of new sites and minor changes and corrections to study documents; these changes did not adversely impact sites or participants. Research governance approvals were awarded by 17 participating NHS trusts.

Information governance statement

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For more information about this research please view the award page (www.fundingawards.nihr.ac.uk/award/NIHR129171).

Publications

Birtwistle J, Millares-Martin P, Evans CJ, Foy R, Relton S, Richards S, *et al*. Mapping and characterising electronic palliative care coordination systems and their intended impact: a national survey of end-of-life care commissioners. *PLOS ONE* 2022; **17**:e0275991. https://doi.org/10.1371/journal.pone.0275991

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Birtwistle J, Allsop MJ, Bradshaw A, Millares Martin P, Sleeman KE, Evans CJ. Views of patients with progressive illness and carers about the role of digital advance care planning systems to record and share information: a qualitative study. *Palliat Med* 2024;**38**:711–24. https://doi.org/10.1177/02692163241255511

Bradshaw A, Allsop MJ, Birtwistle J, Evans CJ, Relton SD, Richards S, *et al*. Exploring the contexts, processes and outcomes of digital advance care planning systems: a theory of change approach to understand implementation and evaluation. *Palliat Med* 2024;**38**:1144–55. https://doi.org/10.1177/02692163241280134

Allsop MJ, Birtwistle J, Bennett MI, Bradshaw A, Carder P, Evans CJ, *et al*. Optimising digital advance care planning implementation in palliative and end-of-life care: a multi-phase mixed-methods national research programme and recommendations. *BMC Med* 2025;**23**:291. https://doi.org/10.1186/s12916-025-04114-x

Conference papers

2022

- Multinational Association of Supportive Care in Cancer Annual Meeting (Toronto, Canada):

◦ Electronic palliative care coordination system implementation in England: a national survey of palliative and end-of-life care commissioners.

2023

• European Association for Palliative Care Congress (Rotterdam, Netherlands).

◦ Factors influencing the uptake and implementation of technology-mediated advance care planning: a normalisation process theory approach.

◦ Patient and carer perspectives on electronic systems for recording and sharing advance care plans.

• Multinational Association of Supportive Care in Cancer Annual Meeting (Nara, Japan).

◦ Health professionals' familiarity and perceptions of digital advance care planning: a latent class analysis.

◦ Patient and carer perspectives of digital advance care planning approaches: a qualitative study.

• Oceanic Palliative Care Conference (Sydney, Australia).

◦ Mapping and characterising electronic palliative care coordination systems and their intended impact: a national survey of end-of-life care commissioners.

◦ Health professionals' familiarity and perceptions of digital advance care planning approach: a latent class analysis.

◦ Factors influencing health professionals' uptake and use of digital advance care plans.

◦ Patient and carer perspectives on electronic systems for recording and sharing advance care plans.

2024

• European Association for Palliative Care Congress (Barcelona, Spain).

◦ Characterising community and hospital-based healthcare professionals' perceptions of digital advance care planning for palliative care.

◦ Patient and carer perspectives on the role of digital advance care planning.

• Multinational Association of Supportive Care in Cancer Annual Meeting (Lille, France)

◦ Patient and carer perspectives of digital advance care planning approach: a qualitative study.

◦ A theory of change approach to understand contexts, processes, and outcomes influencing digital advance care planning implementation and evaluation.

Seminars

September 2021: Royal Society of Medicine webinar, Life and Death in a Digital World. Presenting *Will expressing our wishes in a digital system get us the death we want?*

March 2022: Yorkshire Regional Palliative Medicine Learning Group, Leeds, UK. Presenting *Electronic palliative care coordination system implementation in England: a national survey of palliative and end-of-life care commissioners.*

May 2022: Palliative and End of Life Care Research Network South West, University of Bristol, UK. Presenting *Electronic Palliative Care Coordination Systems (EPaCCS): how widely are systems being implemented and what are they trying to achieve.*

June 2023: Institute for International Socio-Economic Studies, Tokyo, Japan. Presenting *Patient wishes and information sharing for palliative and end-of-life.*

February 2024: Yorkshire and Humber Palliative Care Research Network, Hull York Medical School, Hull, UK: Presenting *The challenges of implementing technology to support advance care planning – the story of Electronic Palliative Care Coordination Systems (EPaCCS).*

August 2024: Compassion in Dying, London, UK. Presenting *Electronic end of life records: time for change*.

About this synopsis

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List of abbreviations

ADRT	advance decisions to refuse treatment
CCG	Clinical Commissioning Group
CHERRIES	Checklist for Reporting Results of Internet E-Surveys
COREQ	consolidated criteria for reporting qualitative research
EPaCCS	Electronic Palliative Care Co-ordination Systems
GP	general practitioner
NASSS	Non-adoption, Abandonment, Scale-up, Spread and Sustainability
NIHR	National Institute for Health and Care Research
PPI	patient and public involvement
R&D	research and development
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
SPSS	Statistical Product and Service Solutions

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