NIHR | National Institute for Health and Care Research

Health and Social Care Delivery Research

Research Article

Community and hospital-based healthcare professionals perceptions of digital advance care planning for palliative and end-of-life care: a latent class analysis

Jacqueline Birtwistle,[1] Gabriella Williamson,[1] Samuel D Relton,[1] Andy Bradshaw,[2] Katherine E Sleeman,[2] Maureen Twiddy,[3] Pablo Millares-Martin,[4] Suzanne Richards,[1] Matthew J Allsop[1*] and on behalf of the OPTIMAL CARE project

[1]Leeds Institute of Health Sciences, University of Leeds, Leeds, UK
[2]Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London, London, UK
[3]Hull York Medical School, University of Hull, Kingston upon Hull, UK
[4]Whitehall Surgery, Leeds, UK

[*]Corresponding author m.j.allsop@leeds.ac.uk

Published June 2025
DOI: 10.3310/XCGE3294

Abstract

Introduction: Numerous digital approaches are being explored internationally to support the elicitation, documentation and sharing of advance care planning information. In England, Electronic Palliative Care Coordination Systems have been developed for this purpose, often as a template stored as part of an electronic clinical record system. Despite Electronic Palliative Care Coordination Systems being central to the end-of-life care policy, there has been a lack of exploration of the perspectives of healthcare professionals who use Electronic Palliative Care Coordination Systems and are critical to their implementation.
Objective: This study addresses this gap aiming to examine community and hospital-based healthcare professionals' perceptions of Electronic Palliative Care Coordination Systems on advance care planning and the delivery of palliative care.
Design and methods: A cross-sectional online survey.
Setting and participants: The target sample comprised health professionals from the main professional groups supporting patients with chronic progressive illnesses in West Yorkshire and London. The survey included items adapted from the Normalisation MeAsure Development questionnaire implementation measure. Survey responses were analysed using descriptive statistics and latent class analysis. Free-text responses relating to alternative approaches to advance care planning documentation were analysed using a directed content analysis approach.
Results: Five hundred and sixty-nine health professionals responded to the survey from West Yorkshire (*n* = 189; 33.2%) and London (*n* = 380; 66.8%). The largest proportion of respondents came from general practice teams (*n* = 254; 44.6%). There were prominent differences in responses, with respondents in London more likely to report being familiar with Electronic Palliative Care Coordination Systems. However, West Yorkshire respondents rated Electronic Palliative Care Coordination Systems more highly in terms of being a legitimate part of their role. Across professional groups, respondents from both hospice and care home teams were more likely to view Electronic Palliative Care Coordination Systems as being worthwhile. Commonly reported barriers to the use of Electronic Palliative Care Coordination Systems included not having access to electronic devices, lack of training and lack of knowledge relating to advance care plans.
Limitations: There was a dominance of responses from participants based on primary care practices, which may reflect general practitioners being largely responsible for initiating an Electronic Palliative Care Coordination Systems record in one region of the survey (West Yorkshire). This survey is reliant on self-reported responses to items and may

This article should be referenced as follows:
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. https://doi.org/10.3310/XCGE3294

have also included respondents more engaged with or interested in Electronic Palliative Care Coordination Systems, representing a skewed positive perspective of the systems and how they are being used in practice.
Discussion: Variation exists in the way in which Electronic Palliative Care Coordination Systems are perceived and used across both geographical regions surveyed and the professional groups involved in palliative care delivery. There continue to be challenges experienced by those using Electronic Palliative Care Coordination Systems, including not having access to electronic devices, lack of training and lack of knowledge relating to advance care plans.
Future work: Future research to identify the preferences of health professionals and patients as potential users of Electronic Palliative Care Coordination Systems could guide the development of ergonomic systems that account for the multiple challenges (i.e. physical, cognitive and organisational aspects) involved in their implementation.
Funding: This article presents independent research funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme as award number NIHR129171.
A plain language summary of this research article is available on the NIHR Journals Library Website https://doi.org/10.3310/XCGE3294.

Introduction

Palliative care aims to improve the quality of life in people with life-limiting illnesses. This is sought through working across different settings (e.g. hospice, hospital, community, general practice, care home and ambulatory) to deliver holistic, multidisciplinary and person-centred care.[1] A focus on person-centred care is embedded in UK national healthcare policy,[2] including ensuring each person is seen as an individual, access to care is equitable and that care is co-ordinated.[3] A central element of delivering person-centred care is advance care planning (ACP),[4] which is developed through a multiphase process, beginning with planned conversations between healthcare and social care practitioners, patients and their families. This process guides the exploration of a person's goals, wishes, and preferences of care, alongside identifying which treatments would align with those goals in hypothetical future scenarios.[5] Crucial subsequent stages include both the documentation of wishes and preferences for care and ensuring that such directives are available to guide clinical decisions.[5]

Increasingly, technology-mediated approaches are being used to support the recording and sharing of ACP documentation across different healthcare providers and settings.[6] These systems have been developed and are being used both internationally in the USA,[7,8] Australia[9] and nationally within the UK. In the UK, the systems used for this purpose are referred to as Electronic Palliative Care Coordination Systems (EPaCCS), which form part of an electronic clinical record system, either within a patient medical record system or a stand-alone system, where information relevant to the delivery of a patient's care can be recorded. Records are typically created within palliative care, community and general practice settings to be accessible to healthcare professionals working across all other settings. This type of data-sharing is referred to as Health Information Exchange, and it is integral to visions to transform and modernise health care, yielding a more effective, efficient and personalised service.[10] However, in the UK, EPaCCS coexist alongside other paper-based and digital processes for documenting advance care plans. This includes, for example, the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process, now implemented in more than one-quarter of acute hospitals,[11] with increasing coverage across geographical regions.[12] Initially, a paper-based process, ReSPECT is increasingly being embedded alongside EPaCCS in electronic health record (EHR) systems generating routine data to support the analysis of its uptake and use.[13]

The EPaCCS were first proposed by the Department of Health in the UK in 2008, with more recent calls for their national roll-out[14] that align with policy commitments within palliative and end-of-life care.[3,15] EPaCCS have been developed in a supportive policy environment, yet there is widespread variation in the extent to which healthcare practitioners across different care settings access, edit, use and share records, with many social care and care home staff reporting having no access.[16–18] Across regional commissioning bodies in England, EPaCCS are at different stages of implementation, with one in five reporting not having one in place.[16] In areas where EPaCCS are being used, reported challenges include a lack of interoperability across electronic record systems, which hinders documentation and access to ACP information, alongside variation in the intended purpose and implementation of EPaCCS.[16,19] These factors may, in part, explain the low levels of use of EPaCCS; only a quarter of all patients have an EPaCCS record in place at death[16,20] which is well below even conservative population-based estimates of palliative need of 63%.[21] Furthermore, when records are present, they are often initiated near the end of life (i.e. a median of 31 days before death).[20]

Despite EPaCCS being central to end-of-life care policy, there are critical gaps in the evidence base underpinning their use and implementation. There is a need for research that helps to optimise the implementation and impact of EPaCCS through a better understanding of differences in the perceptions of and use by health practitioners across different settings of care.[22] 'Adopters' (i.e. healthcare professionals who are the primary intended users of EPaCCS) are a critical element influencing the uptake and success of implementation.[23]

Aim and objectives

This study aims to examine community and hospital-based healthcare professionals' perceptions of EPaCCS on ACP and the delivery of palliative care. This study sought to address the research question: what are community and hospital-based healthcare professionals' perceptions of EPaCCS on ACP and the delivery of palliative care? Specifically, we sought to (1) explore patterns in the perceived familiarity and role of EPaCCS in supporting ACP and the delivery of palliative care and (2) identify facilitators and barriers to the use of EPaCCS in practice.

Method

Study design

A cross-sectional open online survey was designed. The Checklist for Reporting Results of Internet E-Surveys[24] guideline for online survey distribution and reporting was followed.

Recruitment and sample

The target sample comprised health professionals from the main profession groups supporting patients with chronic progressive illnesses in two regions in England – West Yorkshire and London (serving adult populations of 6,904,100 and 1,822,400, respectively) – where EPaCCS were embedded in services. This included general practitioners (GPs), nurse practitioners assigned to practices, community nurses, palliative care clinical nurse specialists and palliative care doctors working in the community (hospices), palliative care clinical nurse specialists and palliative care doctors working in the hospitals, care home teams and ambulance teams. In West Yorkshire, EPaCCS are templates within a patient medical record that contain items that need to be recorded in alignment with existing information standards[25] (e.g. preferred place of care, preferred place of death). In London, at the time of the survey, EPaCCS were aligned with existing information standards and implemented using a stand-alone system that was partly integrated into existing medical record systems and called as 'Coordinate My Care'.[26]

Distribution

The survey website link was distributed to GPs in research-ready general practices in four clinical research networks (CRNs) in England (three in London and one in West Yorkshire), where support teams targeted a diverse range of postcode areas. Distribution to community nurse teams, hospital-based palliative care teams and community palliative care teams employed by the NHS community and acute trusts (i.e. organisations within the NHS of England serving a geographical area) occurred via local collaborators in 13 NHS trusts (London $n = 8$; West Yorkshire $n = 5$), who cascaded the link to health professionals in these teams (where employed by each respective trust). Clinical leads for hospices delivering community-based palliative care (London $n = 12/15$; West Yorkshire $n = 6/8$) cascaded the survey link to palliative care clinical nurse specialists and palliative care doctors. The survey website link was distributed via research leads in ambulance trusts ($n = 2$ trusts) with a request to cascade to paramedic and ambulance staff. Care home managers were contacted by research staff provided by the area CRNs (London $n = 3$; West Yorkshire $n = 1$), and additional care homes were approached individually by the research team (London $n = 7$; West Yorkshire $n = 3$) by direct e-mail with the study information and invitation to distribute the survey website link to staff in their organisation.

Our initial sampling frame of 570 participants was selected to ensure regional diversity in service provision and sought to recruit: GPs and nurse practitioners assigned to research-ready practices (200), community nurses band 5–8 nurses (100), palliative care clinical nurse specialists and palliative care doctors working in the community (120), palliative care teams working in hospitals (50), ambulance teams (50) and care home workers (50). We aimed for a target response rate of at least 35% (200 out of the initial target of 570 health professionals approached) based on a previous estimate from a meta-analysis of overall survey response rates among healthcare professionals.[27]

Data collection

Data were collected from April to October 2021. To maximise the response rate, research or clinical leads (as appropriate to each site) were asked to cascade a monthly reminder over a series of 3 months to the target group.

Questionnaire

The online survey was developed using Online Surveys© (www.onlinesurveys.ac.uk). The platform supports encrypted web connections and manages data in conformance with international standards for managing information security. The survey was designed in

This article should be referenced as follows:
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. https://doi.org/10.3310/XCGE3294

consultation with health professionals who work with patients in palliative care. Paper and online versions of the survey were piloted in January 2021 with health professionals ($n = 9$) inclusive of target groups (GPs, specialist palliative care clinical nurse specialists and consultants and ambulance team). Minor changes were made in light of feedback, such as automatic routing to questions asking about other methods of documentation and sharing ACP information, for respondents with no access to EPaCCS.

Piloting the final survey suggested around 5–10 minutes' completion time. The final online survey comprised five sections (see *Report Supplementary Material 1* for the survey content) displayed over 11 pages. Sections B and C were adapted from the Normalisation MeAsure Development questionnaire (NoMAD) implementation measure,[24] a set of 22 survey items utilising both 5-point and 11-point scales to gauge levels of agreement to statements assessing implementation processes from the perspective of professionals directly involved in the work of implementing complex interventions in health care. NoMAD measures constructs of Normalisation Process Theory (NPT) (coherence, cognitive participation, collective action and reflexive monitoring; *Table 1*) and was used to understand what people do, how the intervention has an impact on their work and articulate the generative mechanisms by which implementation takes place.[28]

1. About the respondent (including their professional role), typical EPaCCS level of access (i.e. document and view information, view only, use for reporting or do not access). Respondents with no access to an EPaCCS were routed to section E to complete questions about other methods they use to document advance care plans.
2. Items from the NoMAD implementation measure which measure the level of familiarity with EPaCCS items (11-point scale: where 0 = not familiar at all, 10 = very familiar) from the NoMAD implementation measure.
3. Items from the NoMAD implementation measure that measure constructs of NPT: coherence, cognitive participation, collective action and reflexive monitoring (Likert 5-point rating scale, from strongly agree to strongly disagree).
4. Items developed by the research team to explore the perceived impact of EPaCCS on patient care (Likert 5-point rating scale, from strongly agree to strongly disagree) of statements about how EPaCCS supports sharing between different health professionals and services.
5. Other methods respondents use to document advance care plans aside from EPaCCS (multiple direct responses and a free text option). A free text box for respondents to provide other information they consider relevant to the survey.

At the end of the survey, participants could review their responses and make any required amendments ahead of submitting their data.

Analysis

Quantitative data for completed surveys relating to respondents and their role were summarised using descriptive statistics using IBM SPSS Statistics 28 (IBM Corporation, Armonk, NY, USA) and R v4.2.0 (The R Foundation for Statistical Computing, Vienna, Austria). Respondent characteristics are reported as the number of responses, expressed as a percentage (%). Latent class analysis (LCA)[29] was used to identify emergent subgroups (classes) across the study population, in terms of the health professional's ratings of familiarity with EPaCCS, and the four domains of the NPT captured via NoMAD (coherence, cognitive participation, collective action and reflexive monitoring). The LCA methodology clusters respondents into groups with similar responses (referred to as 'classes') and is a popular approach to survey analysis, but, to our knowledge, has not been used in conjunction with the NoMAD tool. The NoMAD tool itself does not have any formal guidance on how the results should be analysed. This novel application of LCA provides a deeper understanding of the underlying groups that make up our sample population, as opposed to descriptive statistics that average across all these underlying groups of respondents. LCA assumes that responses are mutually exclusive to a class.

Within each section of the NoMAD tool, a LCA model was used to uncover groups of similar respondents, taking into account their geographical region and role within the healthcare system. These two factors were chosen because they control each participant's access to EPaCCS. The number of classes was chosen by selecting the elbow of the Akaike information criterion[30] on an elbow plot between two and five classes (over multiple restarts). To understand the composition of the emergent classes, descriptive statistics of each class were produced. This analysis is in line with best practice guidance.[31] LCA analysis was performed using the Polytomous Variable Latent Class Analysis package within R v4.2.0.

To visualise the classes, the median and interquartile range (IQR) of responses were plotted within each class across the survey items outlined in *Table 1*. These plots

TABLE 1 Overview of NPT constructs mapped against the items included in the online survey

Item category	Scale items	(Question number) Item stems of included in the survey
Familiarity (i.e. how familiar EPaCCS feel and whether they could become a normal part of work)	1 (not at all), 2, 3, 4, 5 (somewhat), 6, 7, 8, 9, 10 (completely)	1. When you use the EPaCCS how familiar does it feel? 2. Do you feel that using the EPaCCS is currently a normal part of your work? 3. Do you feel that using the EPaCCS will become a normal part of your work?
Coherence ('sense-making work') (i.e. how do people work together in everyday settings to understand and plan the activities that need to be accomplished to put an intervention and its components into practice?)	1–5, with responses of strongly agree, agree, neither agree nor disagree, disagree, strongly disagree. There was also an option for 'not relevant'	4. I can see how using the EPaCCS for advance care plans differs from usual/previous ways of working 5. Staff in this organisation have a shared understanding of the purpose of using the EPaCCS for advance care plans 6. I understand how using the EPaCCS for advance care plans affects the nature of my own work 7. I can see the potential value of using the EPaCCS for advance care plans for my work
Cognitive participation ('relational work') (i.e. how do people work together to create networks of participation and communities of practice around interventions and their components?)	1–5, with responses of strongly agree, agree, neither agree nor disagree, disagree, strongly disagree. There was also an option for 'not relevant'	8. There are key people who drive use of the EPaCCS for advance care plans forward and get others involved 9. I believe that using the EPaCCS for advance care plans is a legitimate part of my role 10. I am open to working with colleagues in new ways to use the EPaCCS for advance care plans 11. I will continue to support use of the EPaCCS for advance care plans
Collective action ('operational work') (i.e. how do people work together to enact interventions and their components?)	1–5, with responses of strongly agree, agree, neither agree nor disagree, disagree, strongly disagree. There was also an option for 'not relevant'	12. I can easily integrate using the EPaCCS for advance care plans into my existing work 13. The EPaCCS for advance care plans disrupts working relationships 14. I have confidence in other people's ability to use EPaCCS for advance care plans 15. Work is assigned to those with skills appropriate to the EPaCCS for advance care plans 16. Sufficient training is provided to enable staff to implement the EPaCCS for advance care plans 17. Sufficient resources are available to support use of the EPaCCS for advance care plans 18. Management adequately supports use of the EPaCCS for advance care plans
Reflexive monitoring ('appraisal work') (i.e. how do people work together to appraise interventions and their components?)	1–5, with responses of strongly agree, agree, neither agree nor disagree, disagree, strongly disagree. There was also an option for 'not relevant'	19. I am aware of what other staff say about the effects of using the EPaCCS for advance care plans 20. The staff agree that using the EPaCCS for advance care plans is worthwhile 21. I value the effects that using the EPaCCS for advance care plans has had on my work 22. Feedback about using the EPaCCS for advance care plans can be used to improve it in the future 23. I can modify how I work with the EPaCCS for advance care plans

were produced using Matplotlib in Python. Categorical data from questions relating to the perceived impact of using EPaCCS for the patient and alternative methods of documenting advance care plans were summarised as the number of responses, expressed as a percentage (%) of the respondents to each question. Responses were reported for the full cohort and by health professional type and their healthcare setting. Free-text responses relating to alternative approaches to ACP documentation were analysed using a directed content analysis approach[32] undertaken by members of the research team (Gabriella Williamson, Jacqueline Birtwistle and Matthew J Allsop), including quantification.

Patient and public involvement

The study research questions were informed through consultation with local groups of palliative care patients. The study investigator team (see *Members of the OPTIMAL CARE project* for a list of all team members) included a patient and public involvement (PPI) co-applicant who was involved from the proposal design phase, and the Project Oversight Group included two PPI members, whose views and experiences helped to inform the survey questions. In November 2020, the PPI co-applicant facilitated two meetings with a total of six people receiving palliative care or their carers. Attendees provided feedback on the study documents (information sheet, survey content and dissemination plans) guiding where text could be simplified or clearer. One attendee also subsequently supported the review and refinement of the plain language summary for the manuscript.

Results

Section A: study population

In total, 569 health professionals responded to the survey (*Table 2*) from West Yorkshire ($n = 189$; 33.2%) and London ($n = 380$; 66.8%). The largest proportion of respondents came from general practice teams ($n = 254$; 44.6%) and included GPs, practice nurses and allied health professionals (AHPs). Respondents included those from hospice teams (85; 15.0%), ambulance workers (68; 12.0%), care homes (64; 11.2%), hospital teams, including doctors, nurses and AHPs (50; 8.8%) and community nurses (48; 8.4%).

Section B: familiarity

Latent classes were detected for the three items (items 1–3, *Table 1*) relating to respondent familiarity with EPaCCS, plotting the median and IQR of responses within each class across the various survey items. Three distinct classes were identified within the familiarity construct (*Figure 1*). Class A (EPaCCS are very familiar) included 43% of participants and included respondents reporting a high degree of familiarity with EPaCCS, who strongly agreed that it was a normal part of their work. Class B (EPaCCS are familiar) included 33% of respondents, representing those with a greater sense of familiarity and who consider EPaCCS to be a normal part of their work, or feel that it will become a normal part of their work in the future. Class C (EPaCCS are somewhat familiar) included 25% of respondents who gave neutral answers in the middle of the scale in response to how familiar they are with EPaCCS and whether it is currently a normal part of their work.

To explore the latent classes (see *Appendix 1* for coefficients relating to latent classes), the effect of region and setting were explored descriptively. At the level of region, health professionals working in West Yorkshire were more likely to be in Class A (EPaCCS are very familiar) compared to those working in London, who were more likely to be in Class B (EPaCCS are familiar) and C (EPaCCS are somewhat familiar). At the level of health professional role (see *Appendix 2* for distribution of responses by health professional role), hospice team respondents were more likely to be in Class A (EPaCCS are very familiar). Care home respondents, community nursing teams and hospital teams were marginally more likely to be in Class B (EPaCCS are familiar). London-based ambulance teams were mostly included in Class A (EPaCCS are very familiar) and Class B (EPaCCS are familiar). GP practice teams were more likely to report lower levels of familiarity and align with Class C (EPaCCS as somewhat familiar). Respondents in Class C neither agree nor disagree that EPaCCS are currently a normal part of their work and are unsure or have neutral feelings towards its role in their normal work currently or in the future.

Section C: Normalisation Process Theory domains

Coherence ('sense-making work')

Two latent classes were detected for the four items (items 4–7, *Table 1*) relating to the NPT construct, coherence (*Figure 2*). Class A (moderate distinctiveness and purpose of EPaCCS) included 67.3% of respondents who agreed to the four items relating to coherence and where there was predominantly strong agreement to items, notably for items 6 (relating to understanding how using EPaCCS for advance care plans affects the nature of their work) and 7 (seeing the potential value of using the EPaCCS for advance care plans in their work). Class B (EPaCCS as having a distinct and agreed-upon purpose) included 32.7% of respondents, with some convergence with class

TABLE 2 Overview of health professional survey respondents by region

	All		West Yorkshire		London	
Health professional group	*N*	%	*N*	%	*N*	%
Primary care general practice team	254	44.6	68	36	186	48.9
Hospice team	85	14.9	27	14.3	58	15.3
Ambulance	68	12	21	11.1	47	12.4
Care home team	64	11.2	27	14.3	37	9.7
Hospital team	50	8.8	15	7.9	35	9.2
Community nurse	48	8.4	31	16.4	17	4.5
Total	569	100	189	100	380	100

A for item 7 (i.e. 'I can see the potential value of using the EPaCCS for advance care plans for my work').

At the level of region, there were no distinctive differences in responses across the two classes (see *Appendix 1*) for coefficients relating to latent classes. In terms of health professional role, GP practice teams, hospital teams and community nursing teams were more likely to be part of class A (moderate distinctiveness and purpose of EPaCCS) when compared to class B (EPaCCS as having a distinct and agreed upon purpose). Ambulance team respondents were evenly spread across the two classes.

Cognitive participation ('relational work')

Three latent classes were detected for the four items (items 8–11, *Table 1*) relating to the NPT construct, cognitive participation, indicating differing levels of agreement relating to the role of EPaCCS supporting advance care plans (*Figure 3*). Class A (collaborative working and support around EPaCCS as a legitimate part of the role) comprised 42.5% of the respondents, who responded mostly with strongly agree to statements for cognitive participation. Class B (moderate support for EPaCCS within the role) accounted for the majority of respondents (50.6%), which included respondents who mostly agreed with the statements. A minority of the respondents (6.8%) were in class C (neutral stance on collaboration around and support for EPaCCS for ACP), providing largely neutral responses, neither agreeing nor disagreeing.

In terms of regional differences in responses (see *Appendix 1* for coefficients relating to latent classes), respondents from London were more likely to be in class B (moderate support for EPaCCS within the role) and respondents from West Yorkshire in class C (neutral stance on collaboration around and support for EPaCCS for ACP). For the health professional role, class A (high agreement to statements for cognitive participation) contained more respondents from hospice and ambulance teams when compared to class B (moderate support for

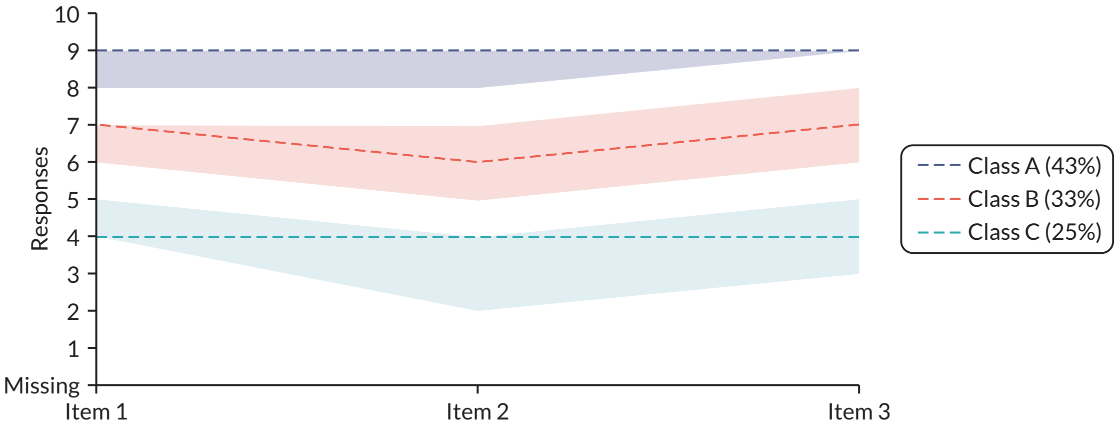

FIGURE 1 Latent classes detected for familiarity, derived from items 1–3 and the scale items for responses as outlined in *Table 1*. Class A – EPaCCS are very familiar: respondents were likely to be from West Yorkshire. Class B – EPaCCS are familiar: respondents were likely to be from London and in care homes, community nursing and hospital teams. Class C – EPaCCS are somewhat familiar: respondents were likely to be from London and GP practice teams.

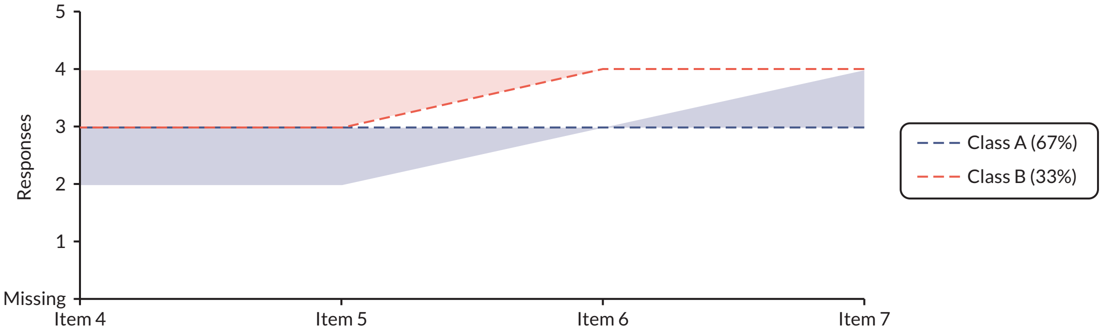

FIGURE 2 Latent classes detected for NoMAD items assessing the construct of coherence, derived from items 4–7 and the scale items for responses as outlined in *Table 1*. Class A – moderate distinctiveness and purpose of EPaCCS: respondents providing slightly lower values in responses were likely to include GP practice teams, hospital teams and community nursing teams. Class B – EPaCCS as having a distinct and agreed-upon purpose: this class comprised the majority of respondents from the care home, community nurse, GP team and hospice team respondents.

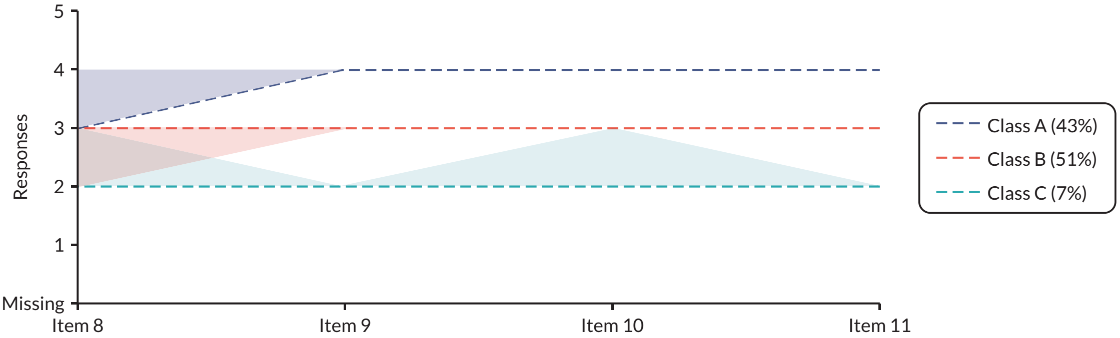

FIGURE 3 Latent classes detected for NoMAD items assessing the construct of cognitive participation, derived from items 8–11 and the scale items for responses as outlined in *Table 1*. Class A – collaborative working and support around EPaCCS as a legitimate part of the role: respondents were likely to include respondents from hospice and ambulance teams. Class B – moderate support for EPaCCS within the role: respondents included over half of all respondents from ambulance, hospice and hospital teams. Class C – neutral stance on collaboration around and support for EPaCCS for ACP: respondents were likely to include respondents from care homes, community nursing teams, GP practice teams and hospital teams.

EPaCCS within the role) and class C (neutral stance). Class C (neutral stance) had lower levels of agreement with statements relating to cognitive participation and were significantly more likely to include respondents from care homes, community nursing teams, GP practice teams and hospital teams.

Collective action (‘operational work’)

For collective action, responses sought to determine how people view that they work together to enact EPaCCS and its components (e.g. confidence in others’ ability to use EPaCCS and sufficient training and resources being available to support EPaCCS use for ACP). Three latent classes were detected for the seven items (items 12–18, *Table 1*) relating to the NPT construct, collective action (*Figure 4*). Class B (lower agreement that EPaCCS are integrated into existing work) comprised most of the respondents (i.e. 47.9%). Class A (high confidence, training and resources to support EPaCCS for ACP) included responses from 14.1% of respondents, with responses that were strongly supportive of statements relating to collective action. Class B (lower agreement that EPaCCS are integrated into existing work with skills and support in its use across colleagues) included 36.4% of respondents.

There were no distinctive differences in responses by region (see *Appendix 1* for coefficients relating to latent classes). In terms of health professional role, when compared to class A (high confidence, training and resources to support EPaCCS), class B (lower agreement that EPaCCS are integrated into existing work) was more likely to include responses from community nurses, hospital teams and GP practice teams. Compared to class A, class C (ambivalence around confidence and skills of colleagues) was more likely to include responses from care homes and hospice teams. Across all classes, participants disagreed or strongly disagreed that EPaCCS for advance care plans disrupts working relationships (i.e. item 13), particularly for class A (high confidence, training and resources to support EPaCCS for ACP).

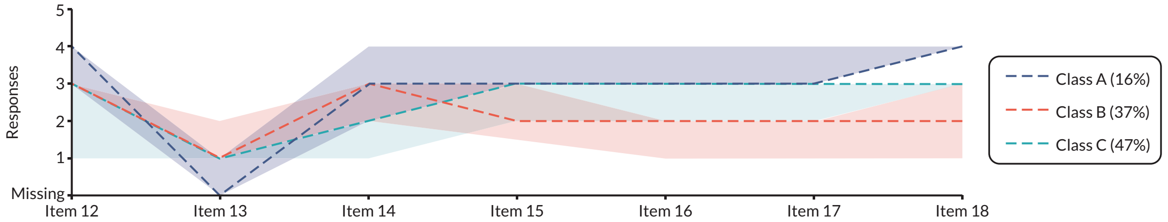

FIGURE 4 Latent classes detected for NoMAD items assessing the construct of collective action participation, derived from items 12–18 and the scale items for responses as outlined in *Table 1*. Class A – high confidence, training and resources to support EPaCCS for ACP: respondents included around a third of ambulance and hospice team respondents. Class B – lower agreement that EPaCCS are integrated into existing work with skills and support in its use across colleagues: respondents included more than half of all ambulance and community team respondents and more than two-thirds of hospital and GP team respondents. Class C – ambivalence around confidence and skills of colleagues in EPaCCS use for ACP: respondents were likely to include care homes and hospice teams.

Reflexive monitoring ('appraisal work')

For reflexive monitoring items, responses sought to explore how people work together to appraise interventions and their components. Three latent classes were detected for the four items (items 19–23, *Table 1*) relating to the NPT construct, reflexive monitoring (*Figure 5*). Class A (low-to-moderate agreement of EPaCCS being worthwhile and of value) included a majority of respondents (74.1%). Class B (strong agreement of EPaCCS being worthwhile and of value) included around a quarter of respondents (i.e. 17.0%). Class C (moderate view of EPaCCS being worthwhile and of value) included the smallest proportion of respondents (8.8%).

In terms of region, respondents from West Yorkshire were more likely to be in class B (strong agreement) and class C (moderate view) than class A (low-to-moderate agreement) (see *Appendix 1* for coefficients relating to latent classes). Class A included all respondents from ambulance trusts, community nursing teams, hospital teams and most GP practice team respondents. Class B was more likely to include respondents from hospice and care home teams when compared to class A (low-to-moderate agreement). Class C was very likely to contain respondents from care home settings.

Section D: perceived impact of Electronic Palliative Care Coordination Systems on advance care planning

The majority of respondents (*n* = 449; 96.5%) reported that EPaCCS 'somewhat' or 'completely' support documentation of advance care plans (*Table 3*). There was broad agreement among respondents that EPaCCS support the sharing of advance care plans between NHS staff, can support people to communicate advance care plans with existing and new health professionals and support the establishment of therapeutic relationships with health professionals known and unknown to people. There was, however, less certainty relating to EPaCCS supporting access to and sharing of advance care plans with social care services.

Section E: challenges to access and additional approaches to documentation

Around one-quarter of respondents (*n* = 104; 18.3%) reported not having access to EPaCCS. Of participants (*n* = 465; 81.7%) who accessed EPaCCS, commonly reported issues that prevented EPaCCS use included issues relating to access to electronic devices (*n* = 112; 24.1%), lack of training (*n* = 108; 23.2%) and a lack of knowledge relating to ACP (*n* = 89; 19.14%). Other issues

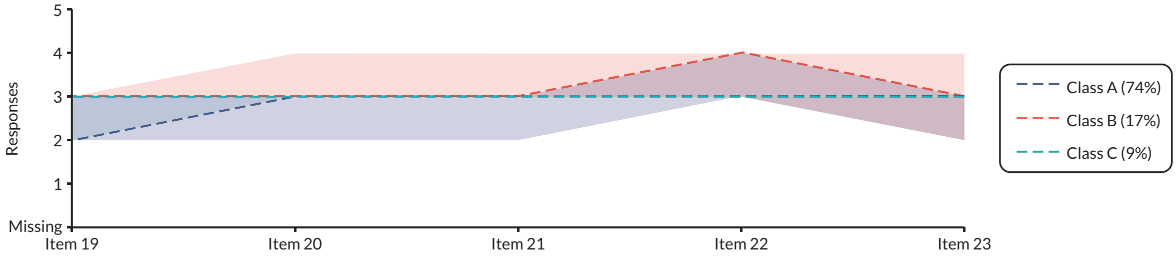

FIGURE 5 Latent classes detected for NoMAD items assessing the construct of reflexive monitoring action participation, derived from items 19–23 and the scale items for responses as outlined in *Table 1*. Class A – low-to-moderate agreement of EPaCCS being worthwhile and of value: this included all respondents from ambulance trusts, community nursing teams, hospital teams and most GP practice teams. Class B – strong agreement of EPaCCS being worthwhile and of value: respondents were likely to be from West Yorkshire and likely to include hospice and care home teams. Class C – moderate view of EPaCCS being worthwhile and of value: respondents were likely to be from London, alongside being from care homes and hospice teams.

This article should be referenced as follows:
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. https://doi.org/10.3310/XCGE3294

TABLE 3 Summary of responses relating to the extent to which EPaCCS facilitate access and sharing of advance care plans across care settings

Survey items relating to perceived impact of EPaCCS	Completely	Somewhat	Not at all	Do not know	Missing data
EPaCCS support documentation of advance care plans	260 (55.9%)	189 (40.6%)	3 (0.6%)	11 (2.4%)	2 (0.4%)
EPaCCS support sharing of advance care plans I have created with NHS teams	211 (45.4%)	186 (40%)	25 (5.4%)	40 (8.6%)	3 (0.6%)
EPaCCS support access to advance care plans created by NHS teams	228 (49%)	192 (41.3%)	15 (3.2%)	23 (4.9%)	7 (1.5%)
EPaCCS support sharing of advance care plans I have created with social care services	77 (16.6%)	108 (23.2%)	109 (23.4%)	167 (35.9%)	4 (0.9%)
EPaCCS support access to advance care plans created by social care services	86 (18.5%)	106 (22.8%)	114 (24.5%)	156 (33.5%)	3 (0.6%)
EPaCCS support ACP for out of hours NHS services (e.g. weekends and overnight)	269 (57.8%)	165 (35.5%)	8 (1.7%)	18 (3.9%)	5 (1.1%)
EPaCCS support communication of advance care plans with someone's usual health service	188 (40.4%)	196 (42.2%)	33 (7.1%)	46 (9.9%)	2 (0.4%)
EPaCCS support communication of advance care plans with health services that are new to a person	158 (34%)	219 (47.1%)	17 (3.7%)	62 (13.3%)	9 (1.9%)
EPaCCS support patients in establishing therapeutic relationships with their usual health professionals	155 (33.3%)	208 (44.7%)	39 (8.4%)	57 (12.3%)	6 (1.3%)
EPaCCS support people in establishing therapeutic relationships with health professionals which are unknown to a patient	140 (30.1%)	228 (49%)	28 (6%)	63 (13.5%)	6 (1.3%)
Understand the intended benefits for people using EPaCCS for advance care plans	339 (72.9%)	106 (22.8%)	5 (1.1%)	8 (1.7%)	7 (1.5%)
GP practice team (*n* = 217)	144 (66.4%)	65 (30.0%)	2 (0.9%)	4 (1.8%)	2 (0.9%)
Hospice team (*n* = 85)	75 (88.2%)	8 (9.4%)	–	–	2 (2.4%)
Ambulance (*n* = 47)	39 (83.0%)	7 (14.9%)	–	1 (2.1%)	–
Hospital team (*n* = 47)	32 (68.1%)	12 (25.5%)	1 (2.1%)	2 (4.3%)	–
Community nursing team (*n* = 43)	34 (79.1%)	8 (18.6%)	–	–	1 (2.3%)
Care home team (*n* = 26)	15 (57.7%)	6 (23.1%)	2 (7.7%)	1 (3.8%)	2 (7.7%)

were also identified (*n* = 178; 38.3%), commonly including time constraints, duplication of data entry and concerns around the quality of data held in records (see *Table 1*).

Of participants who accessed EPaCCS (*n* = 465; 81.7%), multiple additional approaches to documenting advance care plans were reported (*Table 4*). The most common approach was documentation in a different electronic patient record system (*n* = 174; 37.4%) such as in organisation-specific planning templates or summary care records. Another common approach was the use of paper-based advance care plans or Do Not Attempt CardioPulmonary Resuscitation (DNACPR) documents that were held by a patient in their home or usual place of residence, or by an organisation (e.g. care home) and were stored outside an electronic system in which EPaCCS were hosted (*n* = 64; 13.8%). Other common approaches included documenting advance care plans as part of ReSPECT forms (*n* = 26; 5.6%) in both paper and electronic formats and via e-mail (*n* = 24; 5.2%).

Discussion

Our study identified latent classes relating to familiarity with and the role of EPaCCS in supporting ACP and the delivery of palliative care. There is 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. There were prominent differences in responses, with those in London more likely to report being familiar with EPaCCS. However, West Yorkshire respondents rated EPaCCS more highly in terms of them being a legitimate part of their role and people working together to appraise EPaCCS and their components. Across the majority of respondents, there was

TABLE 4 Summary of key findings from section E relating to access to EPaCCS, summarised by health professional group

	Issues with access to EPaCCS				
Health professional group	Access to electronic devices	Lack of EPaCCS training	Lack of knowledge relating to ACP	Other	Examples of other
Primary care general practice team (*n* = 217)	42 (19.4%)	51 (23.5%)	39 (18%)	96 (44.2%)	Time constraints, repetition of information across systems, limited and variable use by providers outside primary care, not useful for documenting an incomplete ACP discussion, complexity and extent of content required, usability issues, including slow system interface alongside remembering passwords and forms having multiple tabs, patients and family may not want to engage in ACP discussion, not being primary clinician for a patient
Hospice team (*n* = 85)	20 (23.5%)	18 (21.2%)	13 (15.3%)	30 (35.3%)	Duplicating effort (with lack of auto-population) when already recorded in other electronic medical records, complexity of forms for ACP, time constraints and pressures, perception that forms are not completed by others
Ambulance (*n* = 47)	7 (14.9%)	3 (6.4%)	9 (19.1%)	18 (38.3%)	For London only: can only view records, records having limited data or not being up to date or relevant, logging takes time, data entry errors preventing record retrieval, perceive few patients as having a record
Care home team (*n* = 26)	9 (34.6%)	7 (26.9%)	6 (23.1%)	8 (30.8%)	Having a stable patient base, care plans not accessible from care home site, time-consuming and repetitive
Hospital team (*n* = 47)	19 (40.4%)	10 (21.3%)	9 (19.1%)	17 (36.2%)	Time constraints and workload, prioritise completion of ReSPECT form over EPaCCS, administrative teams complete on their behalf, limited confidence in governance around documentation and communication of the creation and updating of advance care plans
Community nurse (*n* = 43)	15 (34.9%)	19 (44.2%)	13 (30.2%)	9 (20.9%)	Insufficient data often in records, not having direct access, time restrictions with workload
Total	112	108	89	178	

low-to-moderate agreement of EPaCCS being worthwhile and of value (within reflexive monitoring items), which accounted for all respondents from ambulance trusts, community nursing teams, hospital teams and most GP practice teams. Across professional groups, respondents from both hospice and care home teams were most likely to view EPaCCS as worthwhile and of value. Furthermore, while there was broad agreement that EPaCCS do not disrupt working relationships, most respondents were ambivalent about the skills and confidence of colleagues to use EPaCCS. 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 of EPaCCS 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 EPaCCS to share information. Furthermore, multiple alternative approaches to documenting advance care plans were reported, which are running in parallel to EPaCCS, including similar ACP initiatives using both paper and digital formats.

Context of existing literature

Electronic Palliative Care Coordination Systems were first proposed in England in 2008 and have since evolved with multiple variants, often adapted and tailored for implementation in local commissioning regions.[16] At the time of this survey, the system in use in London was a stand-alone web-based electronic register that was not integrated with existing EHR systems.[33] In West Yorkshire, the systems in use were typically templates embedded in already-existing electronic patient records.[20] Irrespective of the format, the core content of both systems will have been aligned with existing information standards specifying information that should be recorded and shared (e.g. demographic information, diagnosis, medication, ACP information, DNACPR decisions and preferred places of care and death).[25,34] Despite similar content, the ways of accessing, interacting with and documenting systems were likely to differ across regions. This may have affected the levels of perceived familiarity with EPaCCS by respondents, including the extent to which EPaCCS were perceived as being or having the potential to be a normal part of their work. Further differences in systems may have been around their implementation. Coordinate My Care,[33] a web-based platform in London, was integrated within end-of-life care clinical pathways across the city, supported by a clinical teaching and training package for users. In West Yorkshire, however, the integration of EPaCCS as a template with existing EHRs[20] was intended to support improved information-sharing mediated by EPaCCS, alongside aligning EPaCCS use with existing EHR systems.[35] While it is suggested that having an EHR can improve ACP documentation (but may also lead to increased workload),[22] the impact of different system formations on the uptake and engagement of EPaCCS is not currently known. Better understanding the perspectives of end users or system adopters is crucial to understanding the likely success in the implementation of digital health approaches.[23] Without improvements in the use and engagement with EPaCCS, the variable and inconsistent use across regions and health professional groups may continue. This may lead to unintended consequences,[36] including exacerbating existing inequalities in palliative care. Acknowledging these risks alongside mapping disparities in EPaCCS implementation[37] provides a starting point for exploring digital health disparities arising from EPaCCS implementation.

Lesson learnt

Earlier work by the research team identified that EPaCCS are not being implemented across all settings in many areas of England. In particular, very few EPaCCS currently enable access across settings, including care homes, social care and community social enterprises.[16] Where accessed by care home team respondents in this survey, EPaCCS were likely to be viewed as worthwhile and of value. These findings are encouraging, given the UK government's commitment to provide secure access to appropriate and proportionate information from a person's GP record via GP Connect (a service that allows the GP Patient Record to be shared between different IT systems in distinct settings, in primary and secondary care) and provide support to more care homes and home care providers to take up this capability.[38] While access across the settings may increase, most respondents to the survey were ambivalent about the skills and confidence of colleagues to use EPaCCS, with a lack of training being reported as a barrier to EPaCCS use across a quarter of respondents. EPaCCS aim to provide platforms for facilitating the documentation and sharing of advance care plans. However, for some professionals, there remains uncertainty around the value of ACP, whether services can meet patient wishes, and the legalities of the process (e.g. understanding of relevant legal guidance around capacity).[39] This may reflect an increasing acknowledgement of evidence indicating that the process of ACP can have a limited impact on aligning care with patients' wishes, reducing healthcare costs or changing patients' physical or mental health.[40] ACP is complex and intricate, with a need for positive communication between patients, carers and health professionals, alongside enabling patients to discuss ACP with health professionals with whom they feel comfortable.[41] Added to the requisite skills required at the professional level, there is an increasing number of both patient- and professional-facing resources to support ACP approaches, with few that integrated seamlessly with a digital interface or healthcare provider workflows.[42] With such a landscape, there is likely to be a crossover in resources being used, reflected in respondents reporting the need to document advance care plans across different EHR systems, such as organisation-specific planning templates, alongside using paper-based forms that could be held by a patient in their home or usual place of residence.

Our study presents methodological novelty in the application of LCA as a way of interpreting and understanding the differences in responses to NoMAD[28] survey items, organised around the NPT constructs. Suggestions for analysing data include summarising the frequency of responses to items that can indicate where participants are providing positive or negative responses.[43] However, our approach enabled the exploration of positive and negative responses alongside commonality in responses by professional groups and the region of respondents. In sharing our approach, we are responding to calls to disseminate experience and knowledge in the application of NoMAD to a real problem of implementation of complex health interventions in diverse settings alongside the analysis and use of the data generated by the tool.[44]

Equality, diversity and inclusion

The survey questionnaire and participant information were reviewed for inclusive language and terminology by staff at a single hospice. The participant information was also reviewed by the PPI group. To support the generalisability and transferability of evidence, we selected health services from two areas of England, where health professionals were from main professional groups that support patients with chronic progressive illness and where EPaCCS were embedded in services. Our findings are unlikely to reflect practice in areas of England where EPaCCS are less embedded but may help guide the implementation of these systems in those areas. For representation, the research aimed to serve health professionals who work within services used by patients with palliative and end-of-life care needs. We were aware of disparities among minority and socioeconomic groups in both access to palliative care services and palliative care as a research area. We specifically aimed to approach and include areas of mixed ethnicity services in low socioeconomic areas. We did not collect data on the ethnicity of the survey respondents or their typical caseloads. In our subsequent interview study with a sample of respondents, we collected these data, indicating we had recruited from various ethnic backgrounds and geographical areas. We also explored the diversity of caseloads in these interviews. The survey and the interview studies helped us target diverse groups to recruit for further research with patients. To support the enrolment and retention of diverse participants, our sample resulted in the recruitment of health professionals working in hospitals, hospices, care homes, ambulance teams, general practice and the community from Greater London and West Yorkshire. The CRNs supported us with the recruitment of care homes and GP practices to ensure that we enrolled participants from diverse backgrounds and health professionals who serve diverse patient groups. We further explored this through disaggregating the data to explore differences in the use of digital systems among different health professional groups and regions, and we report our findings. In terms of our wider research team, we comprise researchers and health professionals from various professional backgrounds and different levels of experience. Senior research team members supported early career researchers in presenting this work at international conferences. We enlisted the help of Barbara Hibbert, a patient co-applicant who led on public involvement. We recruited a group of patients with terminal or life-limiting conditions or bereaved or current carers of patients with these conditions. The group was from various ethnic and socioeconomic backgrounds and different geographical areas. This group met regularly from the start of the project to the discussion of emerging findings. A bereaved carer reviewed the findings and was involved in writing the plain language summary.

Limitations

We obtained a wide range of perspectives across health professional groups and regions, with all target respondents represented. The target number of 570 health professionals was determined using a sampling frame that reflected the whole-time equivalent (WTE) employment of health professionals typically employed at each site. Since WTE figures represent aggregated full-time hours rather than the actual headcount, the number of health professionals approached may be underestimated. There was also a dominance of responses from participants based on GP practices, albeit those based on research-ready practices, who were recruited for this study and may not be representative of all GP practices. This might reflect that GPs are largely responsible for initiating an EPaCCS record in one region of the survey (West Yorkshire).[20] There was more proportional representation across other professional groups. However, it was not possible to determine the extent of reach of the survey to determine rates of responses across each health professional group. Furthermore, while a wide range of health professional groups responded, palliative care is delivered across multiple settings and important perspectives may have been missed (e.g. professionals working in accident and

This article should be referenced as follows:
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. https://doi.org/10.3310/XCGE3294

emergency settings and geriatric services) who were not directly targeted during recruitment. This survey was also reliant on self-reported responses to items and may have also included respondents more engaged with or interested in EPaCCS, so may represent a skewed positive perspective of the systems and how they are being used in practice. Although the survey was conducted over two large regions of England, covering a population of around 9 million people, perspectives on the use and value of EPaCCS may differ from other regions, particularly where systems have been in place for < 10 years. The study also deviated from earlier planned activities where the online survey was initially planned to explore health professionals' 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, which was pursued in more detail in subsequent interviews with a subsample of survey respondents and is reported elsewhere.[45]

Conclusions

Key learning points

Variation exists in the way in which EPaCCS are perceived and used across both geographical regions surveyed and the professional groups involved in palliative care delivery. There also continue to be challenges experienced by those using EPaCCS, including not having access to electronic devices, lack of training and lack of knowledge relating to advance care plans.

What this adds to existing knowledge

There is a need to further understand the impact and causes of geographical and health professional group variation in the perception and use of EPaCCS in care delivery. This should include an exploration of the low levels of agreement relating to the value and importance of EPaCCS. Future research to identify the preferences of health professionals and patients as potential users of EPaCCS could guide the development of ergonomic systems that account for the multiple challenges (i.e. physical, cognitive and organisational aspects) involved in the implementation of digital systems.

Additional information

CRediT contribution statement

Jacqueline Birtwistle (https://orcid.org/0000-0002-6083-589X): Data curation, Formal analysis, Investigation, Methodology, Project administration, Validation, Visualisation, Writing – original draft, Writing – reviewing and editing.

Gabriella Williamson (https://orcid.org/0009-0007-9508-4946): Data curation, Formal analysis, Investigation, Methodology, Project administration, Validation, Visualisation, Writing – original draft, Writing – reviewing and editing.

Samuel D Relton (https://orcid.org/0000-0003-0634-4587): Formal analysis, Investigation, Funding acquisition, Methodology, Supervision, Validation, Writing – reviewing and editing.

Andy Bradshaw (https://orcid.org/0000-0003-1717-1546): Validation, Writing – reviewing and editing.

Katherine E Sleeman (https://orcid.org/0000-0002-9777-4373): Funding acquisition, Methodology, Validation, Writing – reviewing and editing.

Maureen Twiddy (https://orcid.org/0000-0002-3794-1598): Funding acquisition, Methodology, Validation, Writing – reviewing and editing.

Pablo Millares-Martin (https://orcid.org/0000-0001-7262-1592): Validation, Writing – reviewing and editing.

Suzanne Richards (https://orcid.org/0000-0003-1416-0569): Funding acquisition, Methodology, Supervision, Validation, Writing – reviewing and editing.

Matthew J Allsop (https://orcid.org/0000-0002-7399-0194): Conceptualisation, Data curation, Formal analysis, Investigation, Funding acquisition, Methodology, Project administration, Supervision, Validation, Writing – reviewing and editing.

Members of the OPTIMAL CARE project

Dr Matthew J Allsop, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK.

Professor Michael Bennett, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK.

Mrs Jacqueline Birtwistle, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK.

Mrs Barbara Hibbert, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK.

Dr Andy Bradshaw, King's College London, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, London, UK.

Mr Paul Carder, West Yorkshire Research and Development, NHS West Yorkshire Integrated Care Board, Bradford, UK.

Professor Catherine J Evans, King's College London, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, London, UK.

Professor Robbie Foy, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK.

Dr Pablo Millares Martin, Whitehall Surgery, Leeds, UK.

Dr Samuel Relton, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK.

Professor Suzanne Richards, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK.

Professor Katherine Sleeman, King's College London, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, London, UK.

Dr Maureen Twiddy, Hull York Medical School, University of Hull, UK.

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

Ethics approval was received on 22 April 2021 from the North of Scotland Research Ethics Committee (research ethics committee reference: 21/NS/0046). This study was conducted in accordance with the relevant guidelines and regulations. All participants gave their written informed consent to participate.

Information governance statement

The University of Leeds is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, the University of Leeds is the Data Controller, and you can find out more about how they handle personal data, including how to exercise your individual rights and the contact details for the Data Protection Officer here: https://dataprotection.leeds.ac.uk/data-protection-code-of-practice/

Disclosure of interest statement

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/XCGE3294.

Primary conflicts of interest: Samuel D Relton is an NIHR HSDR Funding Committee member since 1 September 2018. Suzanne Richards is a member of the NIHR HTA CET Funding Committee since March 2024 and was an NIHR In-Practice Fellowship Panel member from 1 January 2019 to 30 June 2023. All other authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Department of Health and Social Care disclaimer

Funding

This article presents independent research funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme as award number NIHR129171.

This article reports on one component of the research award Electronic Palliative Care Co-ordination Systems (EPaCCS) in end of life care: evaluating their implementation and optimising future service provision. For other articles from this thread and for more information about this research, please view the award page (www.fundingawards.nihr.ac.uk/award/NIHR129171).

About this article

The contractual start date for this research was in September 2020. This article began editorial review in March 2024 and was accepted for publication in March 2025. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The Health and Social Care Delivery Research editors and publisher have tried to ensure the accuracy of the authors' article and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

Copyright

List of abbreviations

ACP	advance care planning
AHP	allied health professional
CRN	clinical research network
DNACPR	Do Not Attempt CardioPulmonary Resuscitation
EHR	electronic health record
EPaCCS	Electronic Palliative Care Coordination Systems
GP	general practitioner
LCA	latent class analysis
NoMAD	Normalisation MeAsure Development questionnaire
NPT	Normalisation Process Theory
PPI	patient and public involvement
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
WTE	whole-time equivalent

List of supplementary material

Report Supplementary Material 1

Content of the survey used to collect data from respondents

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/XCGE3294).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

References

1. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, *et al.*; Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *Lancet* 2018;**391**:1391–454.
2. National Health Service. *The NHS Long Term Plan*. 2019. URL: www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf (accessed 12 May 2025).
3. National Palliative and End of Life Care Partnership. *Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021–2026*. 2021. URL: www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf (accessed 11 May 2025).
4. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, *et al.* Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage* 2017;**53**:821–32.e1.
5. Morrison RS, Meier DE, Arnold RM. What's wrong with advance care planning? *JAMA* 2021;**326**:1575–6.
6. Allsop MJ, Chumbley K, Birtwistle J, Bennett MI, Pocock L. Building on sand: digital technologies for care coordination and advance care planning. *BMJ Support Palliat Care* 2021;**12**:194–7.
7. Huber MT, Highland JD, Krishnamoorthi VR, Tang JW. Utilizing the electronic health record to improve advance care planning: a systematic review. *Am J Hosp Palliat Care* 2018;**35**:532–41.
8. Lamas D, Panariello N, Henrich N, Hammes B, Hanson LC, Meier DE, *et al.* Advance care planning documentation in electronic health records: current challenges and recommendations for change. *J Palliat Med* 2018;**21**:522–8.
9. McCarthy S, Meredith J, Bryant L, Hemsley B. Legal and ethical issues surrounding advance care directives in Australia: implications for the advance care planning document in the Australian my health record. *J Law Med* 2017;**25**:136–49.
10. Adler-Milstein J, Bates DW, Jha AK. Operational health information exchanges show substantial growth, but long-term funding remains a concern. *Health Aff (Millwood)* 2013;**32**:1486–92.
11. Perkins GD, Hawkes CA, Eli K, Griffin J, Jacques C, Huxley CJ, *et al.* *Health and Social Care Delivery Research. Recommended Summary Plan for Emergency Care and Treatment: ReSPECT a Mixed-methods Study*. Southampton, UK: National Institute for Health and Care Research; 2022.

12. Resuscitation Council UK. *ReSPECT*. 2023. URL: www.resus.org.uk/respect (accessed 3 January 2025).

13. Anik E, Hurlow A, Azizoddin D, West R, Muehlensiepen F, Clarke G, *et al*. Characterising trends in the initiation, timing, and completion of recommended summary plan for emergency care and treatment (ReSPECT) plans: retrospective analysis of routine data from a large UK hospital trust. *Resuscitation* 2024;**200**:110168.

14. Department of Health. *Our Commitment to You for End of Life CARE: the Government Response to the Review of Choice in End of Life Care*. London: Department of Health; 2016.

15. The Choice in End of Life Care Programme Board. *What's Important to Me. A Review of Choice in End of Life Care*. London: National Council for Palliative Care; 2015.

16. 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.

17. Patterson R, Standing H, Lee M, Dalkin S, Lhussier M, Exley C, Brittain K. Paramedic information needs in end-of-life care: a qualitative interview study exploring access to a shared electronic record as a potential solution. *BMC Palliative Care* 2019;**18**:108.

18. Standing H, Patterson R, Lee M, Dalkin SM, Lhussier M, Bate A, *et al*. Information sharing challenges in end-of-life care: a qualitative study of patient, family and professional perspectives on the potential of an Electronic Palliative Care Co-ordination System. *BMJ Open* 2020;**10**:e037483.

19. Millares Martin P. Electronic palliative care coordination system (EPaCCS): Interoperability is a problem. *BMJ Support Palliat Care* 2018;**8**:358–9.

20. Allsop MJ, Kite S, McDermott S, Penn N, Millares-Martin P, Bennett MI. Electronic palliative care coordination systems: devising and testing a methodology for evaluating documentation. *Palliat Med* 2017;**31**:475–82.

21. Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med* 2014;**28**:49–58.

22. Leniz J, Weil A, Higginson IJ, Sleeman KE. Electronic palliative care coordination systems (EPaCCS): a systematic review. *BMJ Support Palliat Care* 2020;**10**:68–78.

23. Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, *et al*. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. *J Med Internet Res* 2017;**19**:e367.

24. Eysenbach G. Correction: improving the quality of web surveys: the checklist for reporting results of internet E-surveys (CHERRIES). *J Med Internet Res* 2012;**14**:e8.

25. Professional Record Standards Body. *Palliative and End of Life Care Information Standard (Version V1.1b)*. URL: https://prsb2.vercel.app/page/palliative-and-end-of-life-care-information-standard?hsCtaTracking=f03fff77-1ecb-44e3-955b-a56f038c83dd%7C52d83f23-deb4-48a6-99ef-5bd893ec26b62022 (accessed 3 January 2025).

26. Riley J, Madill D. Coordinate my care: a clinical approach underpinned by an electronic solution. *Prog Palliat Care* 2013;**21**:214–9.

27. Cho YI, Johnson TP, Vangeest JB. Enhancing surveys of health care professionals: a meta-analysis of techniques to improve response. *Eval Health Prof* 2013;**36**:382–407.

28. Finch TL, Girling M, May CR, Mair FS, Murray E, Treweek S, *et al*. Improving the normalization of complex interventions: part 2 – validation of the NoMAD instrument for assessing implementation work based on normalization process theory (NPT). *BMC Med Res Methodol* 2018;**18**:135.

29. Weller BE, Bowen NK, Faubert SJ. Latent class analysis: a guide to best practice. *J Black Psychol* 2020;**46**:287–311.

30. Vrieze SI. Model selection and psychological theory: a discussion of the differences between the Akaike information criterion (AIC) and the Bayesian information criterion (BIC). *Psychol Methods* 2012;**17**:228–43.

31. Sinha P, Calfee CS, Delucchi KL. Practitioner's guide to latent class analysis: methodological considerations and common pitfalls. *Crit Care Med* 2021;**49**:e63–79.

32. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;**15**:1277–88.

33. Smith C, Hough L, Cheung CC, Millington-Sanders C, Sutton E, Ross JR, *et al*. Coordinate my care: a clinical service that coordinates care, giving patients choice and improving quality of life. *BMJ Support Palliat Care* 2012;**2**:301–7.

34. Public Health England. *Palliative Care Co-ordination: Core Content. Requirements specification. National Information Standard (SCCI1580)*. London: Public Health England; 2015.

35. Karen H, McDermott S, Suzanne K, Naomi P, Paul W. Developing an electronic palliative care coordination system (EPaCCS) within a large city with multiple clinical IT systems. *BMJ Support Palliat Care* 2014;**4**:A66.

This article should be referenced as follows:
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. https://doi.org/10.3310/XCGE3294

36. Coiera E, Ash J, Berg M. The unintended consequences of health information technology revisited. *Yearb Med Inform* 2016:163–9.

37. Badr J, Motulsky A, Denis JL. Digital health technologies and inequalities: a scoping review of potential impacts and policy recommendations. *Health Policy* 2024;**146**:105122.

38. Department of Health and Social Care. *A Plan for Digital Health and Social Care*. London: Department of Health and Social Care; 2022.

39. Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'. *Palliat Med* 2012;**27**:401–8.

40. Malhotra C. Advance care planning: it is time to rethink our goals. *J Am Geriatr Soc* 2023;**71**:3963–6.

41. Hendry A, Pottle J, Johnstone R, Poolman M, Hiscock J. The intricacy of interactions: qualitative exploration of preferences and perceptions of advance care planning among healthcare professionals, patients and those close to them. *Palliat Care Soc Pract* 2022;**16**:26323524221139879.

42. Ramirez-Valdez EA, Leong C, Wu F, Ball S, Maistrello G, Martin G, Fritz Z. Towards cataloguing and characterising advance care planning and end-of-life care resources. *BMC Palliative Care* 2022;**21**:211.

43. *NoMAD Study [Internet]*. 2023. URL: https://normalization-process-theory.northumbria.ac.uk/nomad-study/how-to-use-nomad/ (accessed 3 January 2025).

44. Murray E, Treweek S, Pope C, MacFarlane A, Ballini L, Dowrick C, *et al*. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC Med* 2010;**8**:63.

45. Bradshaw A, Birtwistle J, Evans C, Sleeman KE, Richards S, Foy R, *et al*. Factors influencing the implementation of digital advance care planning: qualitative interview study. *J Med Internet Res* 2024;**26**:e50217.

Appendix 1 Coefficients derived from latent class analysis for familiarity (Section A) and the NPT constructs (coherence, cognitive participation, collective action, reflexive monitoring) (Section B)

Section A:

==

Familiarity: Three classes

==

Class A (EPaCCS are very familiar)

Class B (EPaCCS are familiar)

Class C (EPaCCS are somewhat familiar)

==

Class B compared to Class A

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) −0.19006 0.34171 −0.556 0.578

West Yorkshire region −0.59292 0.28505 −2.080 0.038

Care Home Team 0.95603 0.62737 1.524 0.128

Community nurse 0.52865 0.51989 1.017 0.310

GP Practice team 0.57208 0.41084 1.392 0.165

Hospice team −1.14885 0.47668 −2.410 0.016

Hospital team 0.05225 0.50097 0.104 0.917

==

Class C compared to Class A

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) −1.42345 0.55442 −2.567 0.011

West Yorkshire region −1.28985 0.36119 −3.571 0.000

Care home team 1.03681 0.95533 1.085 0.279

Community nurse 0.02492 1.09053 0.023 0.982

GP practice team 2.27563 0.58533 3.888 0.000

Hospice team −1.01052 0.76610 −1.319 0.188

Hospital team 0.56970 0.76650 0.743 0.458

==

Number of observations: 465

Number of estimated parameters: 104

Residual degrees of freedom: 361

Maximum log-likelihood: −2136.502

AIC(3): 4481.005

Bayesian information criterion (BIC)(3): 4911.777

X^2(3): 1467.871 (Chi-square goodness of fit)

===

Section B: NPT constructs

===

Coherence: two classes

===

Class A (moderate distinctiveness and purpose of EPaCCS)

Class B (EPaCCS as having a distinct and agreed upon purpose)

===

Class B compared to Class A

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) −0.30032 0.35381 −0.849 0.396

West Yorkshire region −0.11599 0.27947 −0.415 0.678

Care home team 0.70904 0.61219 1.158 0.247

Community nurse 1.32735 0.55402 2.396 0.017

GP practice team 1.66849 0.41181 4.052 0.000

Hospice team 0.21802 0.44822 0.486 0.627

Hospital team 1.39403 0.55294 2.521 0.012

===

Number of observations: 464

Number of estimated parameters: 47

Residual degrees of freedom: 417

Maximum log-likelihood: −1913.215

AIC(2): 3920.43

BIC(2): 4115.004

χ^2(2): 42,156.02 (Chi-square goodness of fit)

===

Cognitive participation: three classes

===

Class A (collaborative working and support around EPaCCS as a legitimate part of the role)

Class B (moderate support for EPaCCS within the role)

Class C (neutral stance on collaboration around and support for EPaCCS for ACP)

===

Class B compared to Class A

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) 0.36225 0.33946 1.067 0.287

West Yorkshire region 0.44501 0.24386 1.825 0.069

Care home team −1.31736 0.60777 −2.168 0.031

Community nurse −0.62314 0.50098 −1.244 0.214

GP practice team −1.09663 0.39061 −2.807 0.005

Hospice team −0.19939 0.42141 −0.473 0.636

Hospital team −0.22934 0.47691 −0.481 0.631

===

This article should be referenced as follows:
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. https://doi.org/10.3310/XCGE3294

Class C compared to Class A

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) −16.97785 0.42039 −40.386 0.000

West Yorkshire region −1.49047 1.32788 −1.122 0.262

Care home team 15.21600 0.77354 19.671 0.000

Community nurse 15.43097 0.79367 19.443 0.000

GP practice team 15.49598 0.45000 34.435 0.000

Hospice team 0.36050 0.00011 3255.157 0.000

Hospital team 14.24247 0.90486 15.740 0.000

==

Number of observations: 463

Number of estimated parameters: 74

Residual degrees of freedom: 389

Maximum log-likelihood: −1557.29

AIC(3): 3262.58

BIC(3): 3568.771

χ^2(3): 3849.342 (Chi-square goodness of fit)

==

Collective action (three classes)

==

Class A (high confidence, training and resources to support EPaCCS for ACP)

Class B (lower agreement that EPaCCS are integrated into existing work with skills and support in its use across colleagues)

Class C (ambivalence around confidence and skills of colleagues in EPaCCS use for ACP)

==

Class B compared to Class A

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) 0.54804 0.63271 0.866 0.387

West Yorkshire region −0.27796 0.43991 −0.632 0.528

Care home team −1.15639 1.03690 −1.115 0.266

Community nurse −2.05958 1.04840 −1.965 0.050

GP practice team −2.09047 0.77145 −2.710 0.007

Hospice team −1.29098 0.78400 −1.647 0.101

Hospital team −1.86579 1.04935 −1.778 0.076

==

Class C compared to Class A

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) 0.92143 0.52549 1.753 0.080

West Yorkshire region −0.18649 0.33421 −0.558 0.577

Care home team −1.70504 0.94024 −1.813 0.071

Community nurse −0.76734 0.68871 −1.114 0.266

GP practice team −1.07196 0.56861 −1.885 0.060

Hospice team −2.87698 0.74787 −3.847 0.000

Hospital team −0.20192 0.65470 −0.308 0.758

==

Number of observations: 461

Number of estimated parameters: 119

Residual degrees of freedom: 342

Maximum log-likelihood: −3963.087

AIC(3): 8164.174

BIC(3): 8656.048

χ^2(3): 1228777 (Chi-square goodness of fit)

===

Reflexive monitoring (three classes)

===

Class A (low–to-moderate agreement of EPaCCS being worthwhile and of value)

Class B (strong agreement of EPaCCS being worthwhile and of value)

Class C (moderate view of EPaCCS being worthwhile and of value)

===

Class A compared to Class C

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) −20.97062 0.56891 −3.686100e+01 0.000

West Yorkshire region 20.30555 0.74932 2.709900e+01 0.000

Care home team 17.63208 0.00000 2.704816e+07 0.000

Community nurse −17.82161 0.00000 −1.566049e+08 0.000

GP practice team −0.68518 1.31877 −5.200000e-01 0.604

Hospice team 36.87611 0.22369 1.648510e+02 0.000

Hospital team −2.13946 2.02432 −1.057000e+00 0.291

===

Class A compared to Class B

Coefficient Standard error *t*-value *p*(>|*t*|)

(Intercept) −17.72536 0.22369 −7.923900e+01 0.000

West Yorkshire region −17.14640 0.00000 −5.882305e+07 0.000

Care home team 34.48084 0.00000 8.659711e+07 0.000

Community nurse −0.07854 0.00000 −5.607519e+06 0.000

GP practice team −11.62660 0.00000 −4.694305e+11 0.000

Hospice team 33.15811 0.22369 1.482300e+02 0.000

Hospital team 0.42907 0.00000 1.153326e+07 0.000

===

Number of observations: 464

Number of estimated parameters: 89

Residual degrees of freedom: 375

Maximum log-likelihood: −2749.469

AIC(3): 5676.939

BIC(3): 6045.388

χ^2(3): 1231632 (Chi-square goodness of fit)

Appendix 2 Summary of distribution of respondents by survey sections for items relating to familiarity (Section A) and the NPT constructs (coherence, cognitive participation, collective action, reflexive monitoring) (Section B)

		Ambulance team	Care Home team	Community nurse	GP team	Hospice team	Hospital team
Section A	***Familiarity***						
	Class A	22	8	21	56	66	23
	Class B	20	14	20	67	15	17
	Class C	5	4	2	94	4	7
Section B	***Coherence***						
	Class A	22	16	32	171	44	13
	Class B	25	10	11	45	41	13
	Cognitive participation						
	Class A	27	7	21	67	47	26
	Class B	19	17	20	126	38	20
	Class C	0	2	2	23	0	1
	Collective action						
	Class A	17	5	3	20	23	3
	Class B	23	5	20	85	6	30
	Class C	7	13	20	111	56	14
	Reflexive monitoring						
	Class A	47	0	43	207	0	47
	Class B	0	10	0	9	60	0
	Class C	0	16	0	0	25	0