Article:

Allsop, MJ orcid.org/0000-0002-7399-0194, Chumbley, K, Birtwistle, J orcid.org/0000-0002-6083-589X et al. (2 more authors) (2021) Building on sand: digital technologies for care coordination and advance care planning. BMJ Supportive and Palliative Care. ISSN 2045-435X

https://doi.org/10.1136/bmjspcare-2021-003304

Title: Building on sand: digital technologies for care coordination and advance care planning

Authors: Matthew J Allsop[1], Karen Chumbley[2], Jacqueline Birtwistle[1], Michael I Bennett[1], Lucy Pocock[3]

Affiliations:

1 = Leeds Institute of Health Sciences, University of Leeds, Leeds, UK
2 = North East Essex Health and Wellbeing Alliance, NHS North East Essex Clinical Commissioning Group, Colchester, UK
3 = Bristol Medical School, University of Bristol, Bristol, UK

Corresponding author:

Matthew J Allsop
Address: Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds, Leeds, LS2 9LU
Email: m.j.allsop@leeds.ac.uk
Telephone: +44(0) 113 343 4185

Keywords: Advance Care Planning, Digital Technology, Palliative Care, Continuity of Patient Care

Word count: 1,812

Abstract

Approaches using digital technologies to support advance care planning (ACP) and care coordination are being used in palliative and end of life care. Whilst providing opportunities to facilitate increases in the completeness, sharing and availability of care plans, the evidence base underpinning their use remains limited. We outline an approach that continues to be developed in England; Electronic Palliative Care Coordination Systems (EPaCCS). Stages governing their optimal use are outlined alongside unanswered questions with relevance across technology-mediated approaches to ACP. Research has a critical role in determining if technology-mediated approaches to ACP, such as EPaCCS, could be useful tools to support the delivery of care for patients with chronic and progressive illnesses.

Advance care planning (ACP) aims to ensure that people approaching the end of life receive care that is consistent with their values, goals and preferences[1]. ACP has been associated with better quality care for people approaching the end of life[2], can enable individuals to remain in their usual place of residence[3], and may lead to better continuity of care[4,5]. ACP is also associated with fewer hospital admissions and a decreased likelihood of hospital death[6]. However, the overall efficacy of ACP in palliative and end of life care is contested and remains controversial. Multiple, high-quality studies indicate ACP has no effect on patient outcomes[7,8] and its documentation does not serve as a reliable and valid quality indicator of an end-of-life discussion[9].

Despite the limited evidence of its effect, the intrinsic logic of ACP continues to drive research exploring its use in palliative and end of life care and the development of ACP interventions. This includes, for more than a decade, the development of ACP approaches using digital technologies to facilitate the collection, recording and sharing of information, largely in the United States, Australia and UK[10,11]. The rationale of leveraging digital technologies to facilitate increases in the completeness, sharing and availability of advance care plans appears plausible, but there is very little evidence to inform whether and how this is being realised in practice. Many questions remain unanswered that could provide important evidence to inform the development and implementation of technology-mediated approaches to ACP.

Here we highlight an approach proposed by the UK Department of Health in 2009; Electronic Palliative Care Coordination Systems (EPaCCS). The End of Life Care Strategy in 2008[12] identified EPaCCS (then referred to as Locality Registers) as a mechanism for enabling coordination of care. Since proposing their use, no standardised approach to EPaCCS has been mandated, with multiple and varied versions being implemented across the UK. We draw on findings from the currently limited evidence base underpinning EPaCCS and consider future steps to enhance their implementation for palliative and end of life care. The questions raised have broad relevance to technology-mediated sharing of care plans and care coordination, regardless of the technology platform or country.

Context of EPaCCS in England

EPaCCS have been implemented across a third of the 213 commissioning regions for healthcare in England when last surveyed in 2013[13]. An EPaCCS record is created by a health professional and is designed to be shared across all healthcare providers involved in the care of a patient to improve coordination of care. This approach is seen as a key tool to enabling care coordination for palliative and end of life care in health policy for England[14]. Currently, multiple, varied approaches to EPaCCS implementation exist as local regions develop their own approaches to EPaCCS implementation, including standalone web-based platforms. For most regions, EPaCCS comprise a template forming part of a patient's primary care electronic health record, with fields to capture preferences for care (e.g. do not resuscitate decision, and preferred places of care and death) where content is required to align with existing information standards[15].

Four stages to technology-mediated ACP

Following their commissioning, EPaCCS are premised on four, chronological stages to enable their optimal role to inform decision making by health professionals involved in a patient's care. Each stage may have relevance across technology-mediated ACP approaches, from patient identification and initiation of ACP, to documenting, sharing and revisiting recorded information.

1) The initiation of a discussion between a health professional and patient about their preferences for care, typically targeting people in the last year of life

The initiation of an EPaCCS record is reliant on identifying that a person may benefit from ACP. Apprehension, time pressures, and lack of education[16] are among the known barriers to ACP in practice which will not be overcome through EPaCCS implementation alone. Reluctance to engage in ACP discussions may account for reported low uptake of EPaCCS in regions where they have been implemented with, for example, only 18-26% of people having an EPaCCS record at death in two UK cities[17,18].

EPaCCS have been reported as working best for those with cancer and those close to the end of life[19]. Furthermore, its reliance on initiation almost exclusively by community-based health professionals in some regions may lead to those most likely to die at home having an EPaCCS record created (i.e. dying at home triggering the initiation of an EPaCCS record) rather than EPaCCS records being a contributing factor in supporting patients to die at home[20].

At the point of initiation, there is differing practice around whether consent is required from a patient prior to having an ACP discussion which may include ensuring their understanding of the subsequent preferences that will be recorded and shared through an EPaCCS record. This may differ in standalone systems, which may require additional consent and introduce the potential for additional data entry burden across multiple information systems.

EPaCCS development has largely focused on adults to date, with little attention paid to the potential role or necessary augmentation required to facilitate ACP for children and young people. It would be necessary to determine who would host and initiate EPaCCS records for children and young people (e.g. general practice, hospice, multi-disciplinary team members), which might differ to adults.

2) The recording of a patient's stated care preferences as part of a template in an electronic health record, or in a separate web-based solution

With most EPaCCS existing within an electronic health record system, health professionals are restricted to the office base to update and amend records following discussions with patients, although approaches to remote access to electronic health records are being developed for community-based staff. Where preferences are recorded, the fields available for determining which preferences can be recorded are prescriptive, determined by core content outlined in national information standards (e.g. primary end of life diagnosis, preferred place of death). The unintended outcomes from gathering and sharing this obtainable and measurable information are not yet clear (e.g. does the drive to keep people out of hospital and in their preferred place have an unintended outcome of worse symptom control?). Furthermore, a critical gap in the recording of patient preferences is, with the exception of a system in London[21], an inability for patients across most of England to access their own EPaCCS record to directly view or propose changes to their recorded care preferences.

The digital systems underpinning access to an EPaCCS record are important. If an EPaCCS record is hosted in electronic health record systems to facilitate completion by community-based practitioners, accessibility across other settings (e.g. secondary care and ambulance trusts) may be affected. Alternative web-based, standalone systems may have the advantage of enabling regionwide access across settings, alongside facilitating patient access through web-based or mobile phone-based access, but having to access a separate system may disincentivise access by busy health professionals.

3) Access to a patient's clinical record, or recorded preferences, by all health professionals involved in their care to facilitate person-centred decision making

Whilst perceived as a route to accessing timely information to inform management of patients, EPaCCS records currently try to be many things for many people. General Practitioners (GPs) may be donors of information, capturing and recording preferences of care into an EPaCCS record, largely for the benefit of professionals across different settings. This could include out of hours GPs who may, for example, seek a quick summary of prognosis, plans and resources available at home to inform decision making, alongside access by secondary care professionals and ambulance trusts who may seek and prioritise different information within a record. While recording and sharing of information is important, so too is its sharing and presentation in a form that maximises engagement across health professional groups. It is not yet clear what optimal approaches might be to achieving this. A critical barrier to facilitating tailored information sharing is semantic interoperability (the ability of systems to both exchange and use the information that has been transmitted). This has not been realised for EPaCCS in most areas of England. For example, a critical component of palliative care in the community is the ambulance service. EPaCCS are seen as a possible means to enabling timely access to patient information for paramedics, but are often not available[18,22]. This is likely to be hindered by the expanse of geographical areas covered by ambulance trusts across which multiple EPaCCS may exist.

4) Iterative review and updating of recorded preferences with a patient over time and during the progression of an illness

As a disease progresses, a patients' willingness and ability to discuss and relay their preferences may change, as could their stated preferences, which necessitates iterative conversations and their subsequent recording in an EPaCCS record. It is not currently clear whether, or how frequently, EPaCCS records are reviewed and updated once initially created, with implications for the accuracy of preferences recorded. And whilst creating an EPaCCS record may indicate ACP has been initiated, its impact on the behaviour of other health professionals is not known, including whether it may inhibit further ACP discussions.

Unanswered questions and the role of research

The evidence base underpinning EPaCCS, and technology-mediated ACP more generally, remains underdeveloped. In England, this is despite continued policy support for the uptake of EPaCCS. To date, much of the current literature on EPaCCS comprises expert opinion, and there is an absence of experimental studies evaluating the impact of EPaCCS records on end of life outcomes[23]. The most common outcome measured for technology-mediated ACP is the documentation of an advance care planning conversation in an electronic health record[10]. This is a useful way of identifying patients for whom ACP has been initiated but fails to capture the complexity and impact of this approach on health professional practice and patient care.

Research has a critical role to play in understanding how technology-mediated approaches to ACP are currently being used, their impact on health professional behaviour and patient and caregiver outcomes, and approaches that can optimise their implementation to facilitate the delivery of high-quality care. We summarise the intended characteristics of EPaCCS from existing literature and pose questions for future research in Table 1.

Table 1: EPaCCS characteristics and unanswered research questions

EPaCCS characteristics	Unanswered questions
Improve coordination and quality of care received	• What is the role of EPaCCS in moderating any effect on the outcomes of patients receiving ACP interventions? • Are there differences in the coordination and quality of care received by people with an EPaCCS record when compared to those without an EPaCCS record? • What are the intended outcomes of EPaCCS at a local level and how can these be measured? • There is tension between national policy for EPaCCS against widespread local variation and adaptation in the types of approaches being implemented. What are unintended harms, consequences and optimal approaches to EPaCCS implementation? • Variation in implementation exists at many levels, including the type of system used to host EPaCCS (including both standalone and leveraging electronic health record systems), health professional groups with access, the information and preferences captured, education and implementation support, and routine monitoring and evaluation of EPaCCS uptake and use. Do different approaches to EPaCCS implementation influence who receives an EPaCCS and patient outcomes? Are EPaCCS records being initiated and used equitably across palliative care populations?

Capture meaningful data to facilitate advance care planning	• To date, the content of EPaCCS has been restricted with a need to align to national information standards. Standards relating to the core content of EPaCCS are currently being reviewed by NHS England. Which information gathered in EPaCCS records are deemed meaningful versus not useful across different health professional groups? Is there scope for existing or future EPaCCS information standards to reflect what is important to patients and their caregiver(s)? How can EPaCCS contribute to ensure care is delivered in a way that aligns with what is important to a patient? • Does EPaCCS facilitate ACP and access to patient preferences in a timely way? • EPaCCS have been focused on adult care to date. Could an EPaCCS approach have relevance to ACP for children and young people?
Iterative discussions that are facilitated, recorded and shared	• How should the validity of data in an EPaCCS record be determined and how does its role change over the course of a progressive disease (e.g. how current are data held in EPaCCS records when being used to inform decision making and is there a duration of time after which its validity should be questioned)? • Once created, how frequently are EPaCCS records reviewed (i.e. edited or viewed) and by whom?
Accessible to all relevant health and social care professionals (including care homes and social care)	• To what extent do clinical record systems in which EPaCCS are currently being developed influence accessibility and sharing of data? Are existing software programs or platforms effective in facilitating the requisite recording and sharing of data across multiple care settings during EPaCCS implementation? • What factors influence engagement with EPaCCS approaches for health professionals across different settings? • The efficiency with which EPaCCS facilitate the collection, sharing and review of data should be considered as part of accessibility for health and social care professionals. How can EPaCCS implementation balance simple and efficient use with the provision of necessary information to inform clinical decision making? Are EPaCCS cost-effective approaches to facilitating ACP and patient care?
Patient accessibility to their advance care plan and preferences for care	• What are patient preferences for access to their EPaCCS record? • Do EPaCCS records capture information that enables care to be delivered in accordance with what is important to a patient? • What are the benefits and considerations relevant to patient access to their own EPaCCS record? • What will the impact of emerging digital approaches (e.g. the UK National Health Service mobile phone application) have on access to EPaCCS for patients and their caregivers?
Enabling access to data to facilitate the routine evaluation of	• How can the granularity and quality of routine data be improved to enable the evaluation of EPaCCS locally and nationally?

technology-mediated ACP	• Where can qualitative research approaches be used to provide insights into the experiences and preferences of different health professional groups in access to and use of EPaCCS?

Conclusion

EPaCCS are large, complex interventions where local development of solutions has been encouraged, creating challenges for comparative or national evaluation. They have been developed and advocated for based on the notion that ACP increases the likelihood of receiving the care you want, but the evidence base forming this foundation is disputed. Critical to the development of EPaCCS, and other technology-mediated approaches to ACP, will be the creation of a clear theoretical underpinning to their role. This is necessary to determine whether EPaCCS, for example, are themselves interventions with important components or a mechanism of action within a wider framework of ACP, and to ascertain and measure their respective intended impact. Maturing the evidence base beyond associations and addressing unanswered questions is critical to guide the implementation of EPaCCS and other technology-mediated approaches to ACP. It is time to determine whether they are integral and valuable tools in the delivery of care for patients with chronic and progressive illnesses.

Funding

MJA, JB and MIB were funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research (HS&DR) Programme (NIHR129171). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. KC and LP have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests

No competing interests for any author.

Patient consent for publication

Not required.

Contributor statement

MJA drafted the initial manuscript. KC, JB, MIB and LP were involved in the subsequent development and writing of the manuscript. All authors approved the final manuscript. MJA is responsible for overall content as guarantor.

References

1. Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage. 2017;53(5):821-32.e1.
2. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. Palliative medicine. 2014;28(8):1000-25.
3. Klingler C, in der Schmitten J, Marckmann G. Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. Palliative medicine. 2016;30(5):423-33.
4. Browne AJ, Varcoe CM, Wong ST, et al. Closing the health equity gap: evidence-based strategies for primary health care organizations. International journal for equity in health. 2012;11:59.
5. Nutting PA, Goodwin MA, Flocke SA, Zyzanski SJ, Stange KC. Continuity of primary care: to whom does it matter and when? Annals of family medicine. 2003;1(3):149-55.
6. Abel J, Pring A, Rich A, Malik T, Verne J. The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Supportive &amp; Palliative Care. 2013;3(2):168.
7. Rietjens J, Korfage I, van der Heide A. Advance care planning: Not a panacea. Palliative Medicine. 2016;30(5):421-2.
8. Korfage IJ, Carreras G, Arnfeldt Christensen CM, et al. Advance care planning in patients with advanced cancer: A 6-country, cluster-randomised clinical trial. PLoS Med. 2020;17(11):e1003422.
9. Morrison RS, Meier DE, Arnold RM. What's Wrong With Advance Care Planning? JAMA. 2021. doi:10.1001/jama.2021.16430
10. Huber MT, Highland JD, Krishnamoorthi VR, Tang JW-Y. Utilizing the Electronic Health Record to Improve Advance Care Planning: A Systematic Review. American Journal of Hospice and Palliative Medicine®. 2017;35(3):532-41.
11. 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(1):136-49.
12. Department of Health. End of Life Care Strategy: Promoting high quality care for all adults at the end of life. London: Department of Health; 2008.

13. Public Health England. Electronic Palliative Care Co-ordination Systems (EPaCCS) in England: Survey of clinical commissioning groups (2013) by the National End of Life Care Intelligence Network. London: Public Health England; 2013.
14. National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. London: National Palliative and End of Life Care Partnership; 2016.
15. Public Health England. Palliative care co-ordination: core content. Requirements specification. National Information Standard (SCCI1580). London: Public Health England; 2015.
16. Mullick A, Martin J. An introduction to advance care planning: practice at the frontline. In: Thomas K, Lobo B, Detering K, editors. Advance Care Planning in End of Life Care. Oxford: Oxford University Press; 2017.
17. Pocock L, Morris R, French L, Purdy S. Underutilisation of EPaCCS (Electronic Palliative Care Coordination Systems) in end-of life-care: a cross-sectional study. BMJ Support Palliat Care. 2021.
18. Allsop MJ, Kite S, McDermott S, et al. Electronic palliative care coordination systems: Devising and testing a methodology for evaluating documentation. Palliat Med. 2017;31(5):475-82.
19. Wye L, Lasseter G, Percival J, et al. What works in 'real life' to facilitate home deaths and fewer hospital admissions for those at end of life?: results from a realist evaluation of new palliative care services in two English counties. BMC palliative care. 2014;13:37-.
20. Wye L, Lasseter G, Simmonds B, et al. Electronic palliative care coordinating systems (EPaCCS) may not facilitate home deaths: A mixed methods evaluation of end of life care in two English counties. Journal of Research in Nursing. 2016;21(2):96-107.
21. Riley J, Droney J. Transforming End-of-Life Care Through Advance Care Planning and Sharing of Information Digitally. In: Silbermann M, editor. Palliative Care for Chronic Cancer Patients in the Community: Global Approaches and Future Applications. Cham: Springer International Publishing; 2021. p. 171-8.
22. Patterson R, Standing H, Lee M, et al. Paramedic information needs in end-of-life care: a qualitative interview study exploring access to a shared electronic record as a potential solution. BMC Palliat Care. 2019;18(1):108.
23. Leniz J, Weil A, Higginson IJ, Sleeman KE. Electronic palliative care coordination systems (EPaCCS): a systematic review. BMJ Support Palliat Care. 2020;10(1):68-78.