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Allsop, MJ orcid.org/0000-0002-7399-0194, Kite, S, McDermott, S et al. (3 more authors) (2017) Electronic palliative care coordination systems: Devising and testing a methodology for evaluating documentation. Palliative Medicine, 31 (5). pp. 475-482. ISSN 0269-2163

https://doi.org/10.1177/0269216316663881

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Palliative Medicine; March 2016

Title: Electronic Palliative Care Co-Ordination Systems (EPaCCS): devising and testing a methodology for evaluating documentation

Short title: Evaluation of Electronic Palliative Care Co-Ordination Systems

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Abstract

Background: The need to improve co-ordination of care at end of life has driven Electronic Palliative Care Coordination Systems (EPaCCS) implementation across the UK and internationally. No approaches for evaluating EPaCCS use in practice have been developed.

Aim: This study outlines and applies an evaluation framework for examining how and when electronic documentation of ACP is occurring in end of life care services.

Design: A pragmatic, formative process evaluation approach was adopted. The evaluation drew on the Project Review and Objective Evaluation (PROBE) methodology to guide the evaluation framework design, focusing on clinical processes.

Setting/participants: Data were extracted from EPaCCS for 82 of 108 general practices across a large UK city. All deaths (n = 1,229) recorded on EPaCCS between April 2014 – March 2015 were included to determine the proportion of all deaths recorded, median number of days prior to death that key information was recorded and observations about routine data use.

Results: The evaluation identified 26.8% of all deaths recorded on EPaCCS. The median number of days to death was calculated for initiation of an EPaCCS record (31 days), recording a patient's preferred place of death (8 days), and entry of DNACPR decisions (34 days). Where preferred and actual place of death was documented, these were matching for 75% of patients. Anomalies were identified in coding used during data entry on EPaCCS.

Conclusions: This study reports the first methodology for evaluating how and when EPaCCS documentation is occurring. It raises questions about what can be drawn from routine data collected through EPaCCS and outlines considerations for future evaluation. Future evaluations should consider work processes of health professionals using EPaCCS.

What is already known about the topic?

- Government policy is promoting the use of electronic documentation of advance care planning (ACP) discussions
- Electronic Palliative Care Coordination Systems (EPaCCS) are being implemented internationally to facilitate electronic ACP but no approaches to evaluating their use have been developed

What this paper adds?

- This paper presents an evaluation framework for EPaCCS which details methods for assessing how and when electronic documentation of end of life care preferences are taking place
- Application of the presented EPaCCS evaluation framework can be used to explore system use and inform service improvement strategies

Implications for practice, theory or policy?

- Government policy in the UK and internationally outlines the need to enhance documentation of end of life care preferences, with electronic systems facilitating storage and sharing of these data
- The presented framework can support appropriate evaluation of emerging electronic systems for advance care planning documentation, supporting both implementation and subsequent development

Keywords

Palliative care, electronic palliative care coordination systems, advance care planning, end of life care, technology

Introduction

Advance care planning (ACP) is the process of discussion with a person and their families or carers about the wishes and preferences for the future of the person and the care to be received. Such discussions may inform care at a time when the person is unable to make decisions for themselves. Integrating ACP into end of life care communication and decision making has been associated with higher quality of life for patients and their families, lower health care costs, less aggressive medical care near death and earlier hospice referrals (1, 2). The United Kingdom (UK) is currently a leading proponent for developing electronic systems that facilitate documentation and sharing of patient preferences for end of life care (3). Arising from UK government policy outlining the need to improve co-ordination of care at end of life (4), summaries of preferences are stored in patient electronic medical records. They detail patient preferences from ACP discussions with the aim of being accessible to all health professionals involved in a patient’s care (5). These summaries are referred to as Electronic Palliative Care Coordination Systems (EPaCCS)(6, 7) in England and Wales, and Electronic Palliative Care Summary (ePCS) (3) in Scotland and Northern Ireland. The approach is not limited to the UK, with similar approaches documented in the US (8, 9) and Australia (10).

Adopting an approach to end of life care that includes an EPaCCS is designed to ensure people receive appropriate treatment and care from any health and social care professional they encounter. For health professionals, EPaCCS seeks to ensure effective handover of information between professionals (without duplication), improve continuity of care, and prevent deaths in hospital where this was not the person’s preferred place of death (11). Current UK policy continues to encourage the use of electronic systems to improve coordination of care at end of life (12) and acknowledges the potential value of an EPaCCS approach (13, 14). Reported benefits to health services from EPaCCS use include more people being supported to die in their preferred place of death, decreases in deaths in the hospital setting and increases in home, care home and hospice deaths, alongside potential savings and increased efficiencies (15, 16). However, evidence of benefits stem from indirect evaluation of EPaCCS through surveying of regional health authorities and commissioners (15) or extracting basic locality data to inform cost estimates and performance (16).

With recent UK policy outlining an expectation that all electronic systems for sharing health related preferences should encompass end of life care preferences(18), an approach to evaluating an

EPaCCS approach is required. Evaluation can directly inform UK-wide approaches to electronic documentation of ACP and has relevance for similar models emerging internationally. This study outlines the first evaluation framework for examining how and when electronic documentation of ACP is occurring in end of life care services.

Method

Context

The EPaCCS project in Leeds was initiated as part of a UK Department of Health funded pilot in 2009 – 2011. A dedicated local team subsequently continued with the roll-out of EPaCCS across Leeds City with the additional support of project management from the Yorkshire and Humber Commissioning Support (YHCS) from August 2013. EPaCCS development completed on 31st March 2015 and has been included on both electronic patient record systems used in Leeds; SystmOne and EMIS Web. In Leeds, EPaCCS is designed to enable community-based palliative care providers to enter and review end of life care preferences in a patient's medical record. An EPaCCS record is accessed through an 8-page template that can be found in a patient's medical record. A template is a structured form that dictates categories of information to include and, where information is not entered in free text, will link responses to existing clinical codes. The template includes core content recommended nationally for use in EPaCCS by the Information Standard Board for End of Life Care Co-ordination (ISB 1580) (19). Data items included in the template are outlined in Figure 1. An EPaCCS template can be initiated in a patient's record by either the GP of a patient, a community nurse, or a member of a community palliative care team. The record is then designed to be continually updated following any ACP discussions with patients to ensure that wishes expressed on the system are relevant and up-to-date for a patient. Components of the template are currently used to inform clinical practice in Leeds. For example, prognostic estimates can be recorded via patient templates to guide the management of patients at a practice level, focusing often on patients with a short prognosis of <30 days to ensure that essential care and support is in place for a patient and their family.

Figure 1: Process diagram for EPaCCS system use in Leeds

Approach

This evaluation falls within a period shortly after all practices in Leeds had been inducted with EPaCCS through training, and after a year of all primary care practices in Leeds using EPaCCS. Flexible evaluation designs and methodologies that can accommodate real world complexities are essential for supporting policymakers and practitioners (20). They can be used to understand and capture the realities of what is occurring in practice and enable response through effective intervention. A pragmatic, formative process evaluation approach was adopted to explore EPaCCS use in this study; shortly after system roll out into clinical practice. The evaluation used the PROBE (Project Review and Objective Evaluation) methodology(21) to guide the design of a framework for evaluating the EPaCCS system. PROBE was developed for use in IT projects and in particular those involving electronic patient records and electronic health records projects. It has been used widely across the UK, including as part of UK Department of Health electronic record development programmes(22). It encourages adoption of an approach where evaluation is undertaken formatively in parallel with system implementation, rather than in response to system issues. The PROBE evaluation hierarchy comprises four levels, each level dependent upon the success of its predecessor. An evaluation should seek to ensure that the realisation of each level is adequately met. The EPaCCS team in Leeds reported that technical testing and usability work had occurred prior to the evaluation; clinical processes were the focus of this study. The most elusive and complex challenge, the evaluation of clinical outcomes, such as improved clinical decisions, will be a subsequent piece of work.

Figure 2: The Leeds EPaCCS Programme Evaluation Hierarchy

Methodology

The project was approached as a formative evaluation, helping to detect problems and inform the re-design of the EPaCCS programme in Leeds. Data that had been routinely collected in SystmOne and EMIS via the EPaCCS template were exported by YHCS. For each patient, where recorded, the following fields were extracted with a date that information was added to a record: age, sex, ethnicity, preferred place of death, actual place of death, and prognosis grouping. For the following items, only data on the date of entry into a record was exported, indicating inclusion of information into the field as part of an EPaCCS record: out-of-hours handover form, assignment of a key worker, anticipatory medication record, Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision, and a summary record of carer data. Data were extracted for all patient records where the patient had died from 1st April 2014 – 31st March 2015. Data were provided in four quarters across this time period, aligned with quarterly reporting processes in Leeds that had been evolving during 2014 - 2015. Summary data were also provided on the number of all deaths in Leeds during the same period. Obtained data were anonymised, with a unique patient ID provided for use during analysis. Ethics approval was granted from NHS ethics (15/SC/0325) through an application via the Integrated Research Application System.

Analysis

The analysis adopted an approach that can be replicated by local EPaCCS teams, utilising data captured by the system. We calculated the proportion of patients who had died with an EPaCCS record from all patients who died during the study period, and the proportions of patients with completed items within their EPaCCS record (preferred place of death, DNACPR, carer assessment completion). This method was chosen to indicate the extent of EPaCCS use by health professionals encountering patients with chronic conditions at end of life alongside how the EPaCCS template was being used. We then calculated median time, from time of entry on EPaCCS of ACP activity to the patient's death for items contained on the EPaCCS record. This can be used to provide an indication of when data were being entered on EPaCCS in relation to a patient's death. Only Leeds practices using SystmOne data (n = 82/108 practices) were included in the analysis. Analysis of training data identified EMIS practices as being engaged with training at a late stage in the schedule (see Figure 3) linked to delays with integrating an EPaCCS template into EMIS systems. At the time of the study, data extraction for EMIS practices was being developed, so limited only to number of deaths at EMIS practices and the number of patients with an EPaCCS record at death during the study year. All analysis was carried out using SPSS 22 software.

Figure 3: Outline of training schedule across all Leeds practices, including pilot work in January 2011. The shaded area outlines the period from which EPaCCS data was drawn for analysis.

Results

Patients who died in Leeds from April 2014 – March 2015 with an EPaCCS record in a SystmOne practice were included in the analysis (n = 1,229). The median age at death for EPaCCS patients was 80 years old, with a range of 15 – 104 years. 639 (52%) records were female patients and 590 (48%) male. Age-adjusted profiles of ethnicity identified 82.9% of patients aged between 15 – 64 years old were registered on EPaCCS as "White British" or "British or mixed British", with missing ethnicity data for 4.7% of patients, and the remainder distributed across eight ethnic categories. For patients aged 65 years and older, 88.5% were coded as "White British", there was missing ethnicity data for 6.0% of patients, and the remainder were distributed across ten ethnic categories. Overall, the black, minority and ethnic communities in Leeds account for 18.9% of the resident population (23).

Proportion of deaths recorded on EPaCCS

Across Leeds, 5,793 patients died during the study period. Of these, 21% (n = 1,229) had an EPaCCS record in place at death. Data on all deaths in Leeds included all emergency and acute cases, alongside deaths from chronic conditions. EPaCCS is designed for use in the management of chronic advanced diseases; all deaths data are not an accurate benchmark to compare EPaCCS performance against. We judged that Public Health England (PHE) data on average number of deaths with underlying cause of cancer, circulatory, respiratory is a more appropriate metric for understanding the proportion of patients who might be suitable for registration on EPaCCS. Across Leeds, using PHE data, 26.8% of all patient deaths had an EPaCCS in place in Leeds.

Table 1: Proportion of patients with an EPaCCS template in place at death in Leeds

All deaths recorded in Leeds between 2014 – 2015	n = 5793
Number of deaths on EPaCCS in Leeds between 2014 – 2015	n = 1229
Proportion of patients dying with EPaCCS record vs all deaths in CCG	(1229/5793) = 21%
Average annual number of deaths from chronic advanced diseases recorded by PHE between 2011 – 2013 in each CCG (% estimate of all deaths)	n = 4579
Proportion (%) of deaths included on EPaCCS between 2014 – 2015 of patients dying with chronic advanced diseases	(1229/4579) = 26.8%

Figure 4 depicts the documentation of discussions occurring by median times across Leeds. Both OOH forms and DNACPR records are reported prior to an EPaCCS record being created, and preferred place of death is initially recorded on a patient's record a median time of 8 days prior to death. For all data there were instances of information being entered after a patient's death.

Figure 4: Overview of median time to death of items added to an EPaCCS record in Leeds

Of the records where preferred place of death was recorded (n = 1,202), the largest proportion of patients (n = 666, 55%) stated an initial preference to die at home. Other recorded preferences included hospice (n = 305, 25%), care home (n = 225, 19%), and hospital (n = 6). For records where preferred and actual place of death was recorded (n = 1,200), 896 (75%) patient records had matching preferred and actual places of death, with 304 (25%) patients having a different preferred and actual place of death recorded. The proportion of patients achieving their preferred place of death varied where preference was for home (431/664 patients, 65%), hospice (253/305 patients, 83%), care and residential homes (207/225 patients, 92%) and hospital (5/6 patients, 83%).

Additional data from EPaCCS records, where recorded, included carer assessments which were completed a median of 47 days prior to death (n = 61; range -5 to 348 days) and the assignment of a key worker recorded a median of 25 days prior to death (n = 47; range -1 to 754 days).

The analysis utilised routinely collected data entered into electronic medical records using UK READ Codes Clinical Terms Version 3 (a coded thesaurus of clinical terms used for data entry in electronic systems). Issues encountered with the data included crossover and ambiguity in categories for ethnicity, registration of patients to a CCG being linked to where an EPaCCS was initiated and not specifying where end of life care was received specific to a Leeds CCG, and duplication in the coding available for small number of fields. Duplication occurred for recording preferred place of death (both '(XaJ3h) Preferred place of death: home' and '(Y105f) Preferred place of death: home (first choice)') and actual place of death ('9495 Patient died in hospital' and '8HG.. Died in hospital'). Anomalies were also present for coding of actual place of death, where a range of unspecified codes were present in the data ('(Xaafy) Patient died in usual place of residence', '(XaEKH) Place of death', '(XaJ2g) Patient died in community hospital' and '(XE2xp) Patient died - to record place'). The use of exported structured data limited narrative around processes of care, relating to items such as recording of anticipatory medication prescribing and the extent of data recorded about carers.

Discussion

An evaluation framework was applied to data captured through an EPaCCS to explore how and when electronic documentation of ACP occurs in a large UK city. The evaluation identified that just over one quarter of patients dying of cancer, circulatory and respiratory diseases had an EPaCCS record in place prior to death. This was often initiated within a month prior to death, with around three quarters of all patients achieving a stated preference for place of death. There was wide variation in both the number of data items completed as part of patient EPaCCS records and the number of days prior to death that fields were completed. During pilot testing of EPaCCS, sites identified 12 months as an appropriate length of time for patients to have a template established. This was not achieved for most patients, highlighting a need to reconsider the expectations of EPaCCS and how these can be aligned with clinical practice. Additionally, key information (DNACPR status and out-of-hours forms) was being recorded on patient records prior to an EPaCCS template being initiated. There is a need for further enquiry into the way in which health professionals are interacting with EPaCCS.

This is the first reported application of an evaluation framework on routinely captured EPaCCS data. It demonstrates that a picture of EPaCCS use can be generated, which has value in directing development of end of life services where electronic ACP is occurring. The evaluation outlines a process for identifying the extent of EPaCCS data entry and how broader datasets, such as those from Public Health England, can be used to gauge the likely extent of patients requiring an EPaCCS record. The approach also demonstrates how EPaCCS data can inform at what stage an EPaCCS is being initiated for end of life care patients and how records reflect attainment of patient preferences for care. Limitations to the study included the variation in completeness of data that were extracted from electronic medical records, with exclusion of data from a small proportion of general practices using EMIS in Leeds. Interpretation of findings should be mindful of concurrent initiatives that were taking place alongside EPaCCS implementation that may have influenced data entered by community practitioners. For example, two initiatives in 2010-12 involved training senior community nurses in Leeds to complete DNACPR forms and the implementation of a single regional form for recording a patient's DNACPR wishes.

In England, there is an expectation at policy level for end of life care to involve communication and information for patients and their families and carers to tailor support appropriate to their preferences (14). Considered implementation of electronic systems to facilitate sharing of ACP outcomes can form part of a system-wide commitment to patient-centred care and may be more likely to lead to improvements than a reliance solely on specialist palliative care consultations (24). EPaCCS research literature to date consists mostly of descriptions of the systems themselves, how they have been used, and the experience of those implementing them (3, 25-27). However, despite the importance of evaluation in implementation, no clear processes or guidance has been generated for use with EPaCCS.

The framework adopted in this study has relevance both pre- and post-implementation, with a focus on clinical processes leading to the identification of practical considerations for future evaluation and interpretation of data captured via an EPaCCS. An EPaCCS record can only be assumed to hold the most recently documented preference of a patient, but these may change in advanced disease and may not always be updated on a patient's record. While many patients were identified as achieving their documented preferred place of death, the proportion who achieved their actual preference is impossible to ascertain from data currently collected. In this study, while many patients likely had discussions prior to death, there were instances of EPaCCS records being updated posthumously for each item evaluated. The composition of health professionals using EPaCCS should also be considered in the interpretation of an EPaCCS evaluation. Just under half of all patients had a preferred place of death recorded as hospice or care home. This may reflect greater use of EPaCCS by hospice-based clinical nurse specialists or a disproportionate representation of general practitioners and district nurses that visit care homes using EPaCCS. The inclusion of health professional engagement in future evaluations is suggested to enhance understanding and interpretation of findings.

Table 2: Key considerations for evaluating EPaCCS data

- There are currently no reported approaches to EPaCCS evaluation available in the research literature
- An evaluation framework can guide enquiry into the use and timing of EPaCCS records as part of end of life care discussions
- The focus of an evaluation can be targeted at four dependent key domains: technical aspects, usability issues, clinical processes and clinical outcomes
- Considering which data are required to inform an EPaCCS evaluation is important to understand pre-implementation and may improve data quality
- EPaCCS data can be evaluated to understand the extent of documentation occurring and offer insight into types of data being collected
- EPaCCS data can only provide a proxy measure of the occurrence of ACP discussions to inform broader service improvement initiatives
- An EPaCCS record only holds the most recently documented preference of a patient, but these may change in advanced disease and may not always be updated on a patient’s record
- Regional data on deaths from chronic advanced diseases can be used as an indication of the number of deaths that may be appropriate for EPaCCS. In England, Public Health England data is available for this purpose
- Integrating an EPaCCS record into existing clinical IT systems may require revision and alignment of clinical coding, such as those for recording a patient’s preferred place of care and preferred place of death
- Engaging directly with health professionals about their use of EPaCCS may offer greater

insight into the role of electronic systems as part of ACP and documentation

- EPaCCS is an emerging approach to documenting end of life care preferences; understanding the patient and caregiver perspectives on consent and information sharing is essential to ensure effective ACP supported by electronic systems

The development of electronic systems to support sharing of end of life care preferences continues to be highlighted in national policy documentation. This study sets an important benchmark for what is occurring at the level of a large UK city – such granular data has not been reported in detail to date. It also raises a discussion about what can be drawn from routine data collected as part of an electronic system to facilitate ACP. While there are caveats to consider when interpreting routinely collected clinical data, the evaluation approach outlined in this study can be used to explore usage of EPaCCS locally, supporting the construction of a national picture of practice around EPaCCS use. Future EPaCCS development may benefit from considering the work processes surrounding EPaCCS use by health professionals, and how such systems can be incorporated into complex and time pressured clinical workflows (28). For example, recent qualitative work has highlighted insufficient time, cumbersome technology, and a reluctance to label patients as 'end of life' as some of the barriers influencing EPaCCS use by health professionals (29). Similarly, understanding how patients and families can be supported to fully understand and participate in ACP could inform how their broader priorities (aside from those relating to place of care and death) could, where appropriate, be reflected in an EPaCCS record. These developments should occur while continuing to explore the most cost-effective models for implementation.

Funding

This research was funded by NHS South and East Leeds Clinical Commissioning Group.

Acknowledgements

The authors acknowledge support of Yorkshire and Humber Commissioning Support (YHCS) who provided data searches and extraction for the evaluation.

Conflict of interest

The authors declare no conflict of interest.

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