A NATIONAL SURVEY OF

PATIENT AND PUBLIC VIEWS ON DIGITAL APPROACHES TO THE DOCUMENTATION AND SHARING OF ADVANCE CARE PLANS

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Introduction

- Advance care planning is a discussion between patients and their care providers about preferences and priorities for their future care (1).
- Patients receiving palliative care require input from many health professionals in a range of different community, hospital and emergency services as well as residential care.
- Electronic Palliative Care Coordination Systems (EPaCCS) are a template typically forming part of a patient's electronic health record. They aim to facilitate the documentation of advance care plans (ACPs) for people with health conditions that require multi-professional and multi-setting involvement.
- It is not clear how EPaCCS are meeting patient need (2).
- We sought to address a critical gap in the evidence base to elicit patient and carer views and experiences of documentation and sharing of electronic health and advance care planning information.

Method

- A brief online questionnaire was developed using Survey Monkey by Compassion in Dying (CiD) and the Professional Record Standards Body (PRSB).
- It was circulated via CiD service users and PRSB networks to UK residents in February 2021.
- Questions sought views on electronic documentation and sharing health records.
- Participants were asked to think about "if they or the person they care for became more ill and needed to be cared for somewhere else or by a different team of people to the people they already know" in order to provide a rating on a scale of 1 to 5 on the following:
  - Their level of confidence (*where 1 is not confident at all and 5 is very confident*). that systems for electronic documentation and sharing would enable health professionals to access information about their health and their preferences
  - The importance of different features of systems for electronic documentation and sharing care (*where 1 is this does not matter to me and 5 is this is very important to me*)that would increase their confidence they would get the right care
- Free-text items captured information about their experiences of sharing electronic health and planning information and what they consider to be important for future record sharing.
- This is a secondary analysis of the dataset. Descriptive statistics were used to analyse ratings and content analysis was used to analyse text.

Results

Participants
A total of 1728 responses from eligible participants in February 2021:
- 33 with a terminal condition (TC)
- 442 with a long-term condition (LTC)
- 229 carers of people with a terminal or long-term condition (C)
- 1024 healthy people interested in planning for the future (H)

All geographical regions of the UK represented.

Respondents gave low to moderate confidence ratings that the healthcare team would have access to:
- "Information about my health that they need when caring for me at the end of life"
- "My end-of-life wishes and preferences"
- "Information on who I want to be involved in decisions about my health and care at the end of life"

Carers of people with a terminal or long-term condition were more likely to give lower ratings than other participant groups.

Respondents gave consistently high ratings that the following features of electronic records would give them confidence they would get the care that is right for them at the end of life:
- "The healthcare team supporting or treating me can see details of the people I want to be involved in decisions about my care"
- "The healthcare team supporting or treating me can see my preferences such as where I want to be cared for"
- "The healthcare team supporting or treating me can see which treatments I do and do not want"
- "I can view my end-of-life care record via a website or app"
- "I can record and make changes to my end-of-life care preferences via a website or app"
- "I can share my end-of-life care record with my family and loved ones"

Key point 1: Low to moderate level of confidence that health professionals can access their ACPs.

""Our local community health care provider has a shared electronic record (full health records, not just end of life) so everyone that attended was well informed about the local care. Our biggest issue was that [mum's] previous oncology care was provided in a neighbouring CCG area, so none of their records were available to anyone." (Carer)

Key point 2: The ability to view their own ACPs, record and update care preferences, and share ACPs with family and loved ones were deemed likely to increase confidence.

"I had a major surgery so filled in an electronic record and printed it off. Gave a copy to my a copy to the hospital and my daughter also knows about it. We have done the same for my elderly mother…. I think these are very important especially when people won't talk about such matters. We haven't had to use them yet but the fact we have them makes me confident that things will go both how my mother wishes and my wishes will be carried out." (Person with LTC)

"I want the option to change my mind on treatments etc. as I go along and to have this updated information available to those who should be aware of it. I like the idea of an online system where I can make updates easily." (Carer)

Key point 3: Experiences of patient care that did not align with their wishes, motivated respondents to consider the benefit of electronic advance care plans

"My mother has a clear advanced directive. I had a fight with an ambulance driver who said there was no such thing … He refused to take my mother's advanced directive with him. Every time I go to hospital with my elderly mother they lose her advanced directive or fail to pass it from one ward to another. A recognised electronic form would be fantastic and very reassuring." (Carer)

My father suffering from bladder cancer and kidney problems had 3 different forms (Compassion in dying, hospital and GP) held in files by his bedside at home. There were no problems or questions at all about his wishes." (Carer)

"Staff need to check not only EMR but also medic alert pendants and bracelets and cards. If someone has a tattoo across their chest saying DNR, then that is a formal statement and should be adhered to as well." (Person with LTC)

Key point 4: "backup" methods of sharing or alerting professionals to preferences were considered necessary.

Key point 5: Previous quality discussions and documentation of ACPs engendered confidence

"I've just had a very good experience with medics dealing with my mum's end of life wishes following a covid diagnosis … and I found the careful conversation with me (as next of kin) very reassuring in the context of my own incurable condition. I have my own-on paper-completed when I got diagnosed with cancer-that is the one my people will have access to."
(Person with TC)

Conclusion

- People value the process of creating advance care plans, striving to ensure their wishes and preferences are shared.
- Experiences of receiving care that doesn't align with own preferences or others' preferences, can increase motivation to document an electronic advance care plan.
- Electronically documented and shared advance care plans are more likely than paper records to increase confidence that preferences will be shared.
- Previous experience of poorly shared or accessed electronic health records leads to apprehension that electronic advance care plans will be used at the times of patient need.

References [1] NHS England, Universal Principles for Advance Care Planning (ACP). 2022: UK. [2] Allsop MJ, Chumbley K, Birtwistle J, Bennett MI, and Pocock L. Building on sand: digital technologies for care coordination and advance care planning. BMJ Support Palliat Care 2021. https://doi.org/10.1136/bmjspcare-2021-003304 PMID: 34876456

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