Addressing the gap in evidence of

Patient and caregiver perspectives on electronic systems for recording and sharing advance care plans

Authors: Ms Jacqueline Birtwistle, Associate Professor Matthew Allsop
Affiliation: University of Leeds, Academic Unit of Palliative Care, Leeds, UK
CONTACT: J.Birtwistle@leeds.ac.uk

Background

- Advance care planning is a discussion between patients and their care providers about their preferences for their future care(1).
- Care records for people living with a long term condition should encompass their needs and their preferences as they approach the end of life.
- Electronic Palliative Care Coordination Systems (EPaCCS) are designed to document and share advance care planning information to ensure that any health professional involved in the patient's care has access to the most up-to-date information(2).
- Intended benefits of EPaCCS have been framed around organisational changes, rather than patient outcomes(3).

Research questions

- **What are patient and carer experiences of EPaCCS use?**
- **What are development priorities of EPaCCS for patients and carers?**

Methods

- Semi-structured focus groups and interviews in two regions of England.
- Patients with an advanced life-limiting condition.
- Carers of patients with a life-limiting condition.
- Recruited via hospices, care homes, support groups and advocacy groups.

Conclusion

- Electronic systems for recording and sharing advance care plans seek to facilitate the delivery of personalised care but are not understood or trusted by those they seek to support.
- Patient access to view their record could provide a route to acknowledging and validating records ensuring they continue to reflect their wishes.

Results

Patients
8 receiving specialist palliative care
23 not receiving specialist palliative care
Carers of patients
7 receiving specialist palliative care
6 not receiving specialist palliative care

"even if you make a care plan with the hospital, one consultant with one condition, another consultant with a different discipline may not necessarily have that access and your GP may not have that access"
Patient (not receiving specialist palliative care)

Key point 1: Patients experience uncertainty about EPaCCS records and how they share within and across service providers.

"There's meant to be this kind of joined up system there needs to be some kind of failsafe like a band, or something like that or the medi-alert bracelet where its recognisable that yeah you've done your stuff online but you've also got this instant visual prompt so that if people are called if you pass out they can see that instantly what your wishes are"
Carer of patient (receiving specialist palliative care)

Key point 2: Participants recognised quality discussions with health professionals are necessary to make and document informed decisions about preferences for care.

Key point 3: Participants expressed concern that health professionals would not have time to support discussion and documentation of their plans.

"in an ideal world, a specially trained person who was not burdened with other tasks, who was psychologically trained to know how to initiate those conversations but also was clinically trained to know all the different scenarios that you might be faced with… not just OK, I've got a form quick tell me do you want to die in hospital or at home"
Carer of patient (not receiving specialist palliative care)

"I don't want to bother my doctor with it because it says the next stage, take this to your doctor and have it registered. I have a long and very happy relationship with my doctor and I'm sure he would do that but he's incredibly busy as most GPs are"
Patient (not receiving specialist palliative care)

Key point 4: Participants expressed concern that some services would not automatically know if the person has an EPaCCS record.

"my wife is my caregiver and she knows everything I know and her having access I don't have any problem with that … that it can be layered you know … certain people are going to need to know x amount but you know say it's my consultant might need to know x and y and z."
Patient (receiving specialist palliative care)

Key point 5: Participants expressed a desire to view their own EPaCCS records, whist keeping control of carer access.

"I don't want to edit it but I'm just interested in seeing everything that's there. If I had an issue with anything there, I'd hopefully be able to speak to the person who had written that or included that information"
Patient (receiving specialist palliative care)

Implications for practice, policy or research?

There is a need for health professional education and training to support patients and their carers with:

- making informed advance care planning choices to document on an electronic system
- clarification about which services can view their preferences
- instilling confidence that their preferences will be acted upon
- clarification of the limits of what preferences can be acted upon

Further research is needed to explore how patient and carer access and editing of electronic advance care plans can be developed in line with their preferences.

Image: Vecteezy©2023 Eezy Inc. vecteezy.com

References

1. NHS England, Universal Principles for Advance Care Planning (ACP). 2022: UK.

2. National Palliative and End of Life Care Partnership, Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. 2nd Ed. Accessed 15th May 2023: Available at https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf

3. 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

We acknowledge our co-investigator and patient representation, **Dr Barbara Hibbert.** Barbara died from cancer in January 2022.

We are indebted to Barbara for help and support with developing project plans and her inclusive involvement of the patient voice through her work with patient groups across England.