

Addressing the gap in evidence of

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

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.

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Results

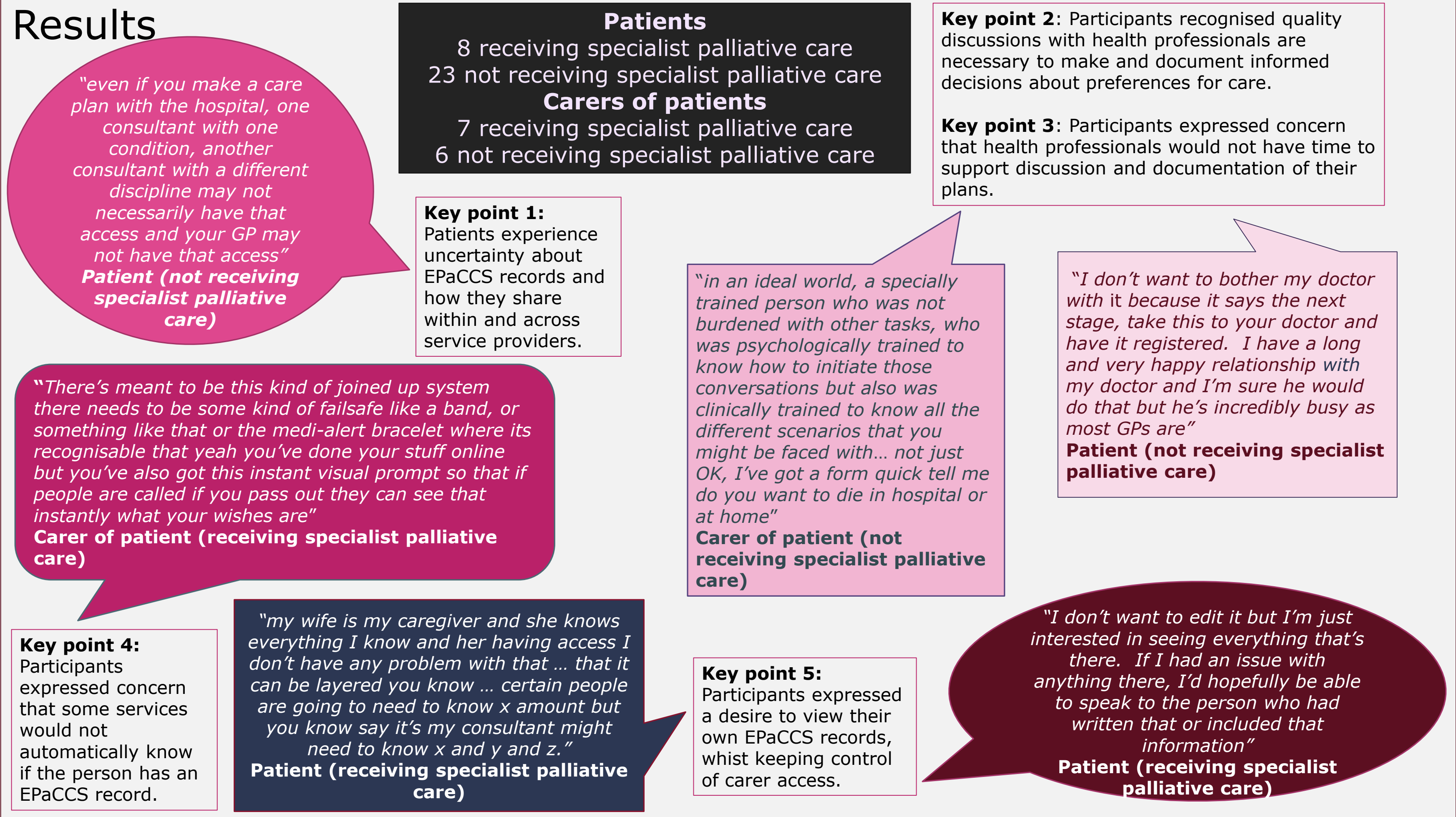


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Implications for practice, policy or research?

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.