

# Collaboration for Leadership in Applied Health Research and Care East of England

## CLAHRC BITE

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A bite-sized summary of CLAHRC research



**“Prepared to Share?”: patient data sharing  
in complex conditions and at the end of life**

### What?

An evaluation of the Cambridgeshire & Peterborough EPaCCS (Electronic Palliative Care Coordination System), nested in broader research into England’s EPaCCS and professionals’, patients’ and carers’ perceptions of data sharing.

### Who?

Patients approaching the end of their lives may: experience rapid changes in their condition and symptoms which are distressing for them and their carers; have clear preferences about their care priorities, with few opportunities to meet them other than ‘now’; and are often cared for by a large number of health and social care professionals.

### Why?

It is crucial to have systems for the effective sharing of up-to-date information for patients at the end of their lives. There is a drive to increase the relevant evidence base to enable the development of EPaCCS nationally.

## Background

EPaCCS take the idea of Locality Registers, proposed by the 2008 End of Life Care Strategy, into the age of digital communication. They take various forms, such as web-based electronic registers, systems based on sharing care summaries and plans alongside patients' electronic records, or patient portals. They aim to provide up-to-date information about patients believed to be in the last year of their life in a growing number of health and social care settings. EPaCCS aim to improve communication and coordination and ensure that all those involved in a patient's care are aware of their wishes, preferences, and advance care plan.

## The research stage

Fieldwork for the study, with Dr Stephen Barclay, Principal Investigator, and Dr Mila Petrova, Research Associate (Palliative and End of Life Care Group at the Primary Care Unit, University of Cambridge) is now complete. Data sources include 40 interviews, 405 questionnaires (64% response rate), over 500 documents and fieldwork items, and a comparison between the Cambridgeshire and Peterborough project, London's "Coordinate My Care" and the South-West EPaCCS.

## Key findings

- Main challenges faced by EPaCCS: scope of projects; unrealistic expectations set by existing guidance; discrepancy between IT realities in healthcare and our broader lives; information governance; and "death register" associations.
- Main drivers supporting EPaCCS: robust concept; striking outcomes; national support and strong clinical leadership; clinician commitment; education; and funding.
- The equity and autonomy in patient decision making about data sharing may not be consistently upheld. There were strong associations (survey findings) between characteristics of General Practitioners and Practice Managers and their organisations and the reported frequency of discussions with patients and their responses.

The study team ran the First National EPaCCS conference, held in Cambridge in July 2015. The initiative was taken up by Public Health England and the North West EPaCCS who organised the Second National EPaCCS conference in Manchester in March 2016.

## References

Petrova M., Riley J., Abel J. and Barclay S. (under review) A Crash Course in EPaCCS: Eight years of successes and failures in patient data sharing to learn from.

Petrova M., Barclay M., Barclay SS. and Barclay S. (pre-submission) Between 'the best way to deliver patient care' and 'chaos and low clinical value': General Practitioners' and Practice Managers' views on data sharing.

## What is NIHR CLAHRC East of England?

The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England is a five year programme of applied health and social care research which focuses on the needs of people with complex problems, often vulnerable, when multiple agencies are involved in their care: young people, frail older people, those with dementia, learning disabilities, acquired brain injuries or mental ill health.

The CLAHRC East of England collaboration encompasses some thirty-six organisations, with research hubs in the Universities of Cambridge, Hertfordshire and East Anglia working closely with individuals and organisations involved in the whole care pathway.

Service users and carers are at the heart of what we do, in parallel with an ambitious public health research programme.

Co-production and collaboration at all stages of the research process are fundamental to making a positive impact through applied health research.

### For more information:

Website: <http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/other-projects/preparedtoshare/>

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