

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?

“Prepared to Share?” – evaluation of the Cambridgeshire & Peterborough Electronic Palliative Care Coordination System (EPaCCS) nested in broader research on data sharing – is one of the most rigorous studies on patient data sharing.

Who?

End-of-life patients 1) may experience rapid changes in their condition and symptoms which are distressing for them and their carers; 2) may have care preferences they have not had the chance to discuss; 3) are often cared for by a large number of health and social care professionals.

Why?

It is crucial to have systems that effectively share up-to-date information at the end of life, including about how and where patients want to be cared for.

Background

The 2008 National End of Life Care Strategy recommended Locality Registers as a way to enable effective communication and coordination in End of Life Care. Electronic Palliative Care Co-ordination Systems (EPaCCS) were being developed since then and are now mandated for all areas of England by 2020. EPaCCS contain key information about an individual approaching the end of life and are envisaged as a shared locality record for health and social care professionals. They have been extraordinarily difficult to develop and implement.

The research

The “Prepared to Share?” study is the most in-depth and multi-modal evaluation of an EPaCCS and one of the most rigorous studies on patient data sharing in general. Methods included: interviews (44 participants, close to 300,000 words) with findings mapped against those of 4 literature reviews of other teams (135 studies); survey of local GPs and Practice Managers (N=405, 64% response rate); case study comparison with “Coordinate My Care” and the South-West EPaCCS; ethnographic observations; document analysis.

The team

Dr Mila Petrova and Dr Stephen Barclay (PI) – Cambridge Palliative and End of Life Care Group, Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge.

Key findings

A framework of > 500 challenges and >300 drivers to data sharing. 110 drivers and 90 challenges were associated primarily with the IT solution. The remaining concerned contextual, user-related and project team-related parameters. This suggests that teams working on data sharing projects may need to focus less on refining their IT tools and more on shaping relevant social interactions and contexts.

References

- Petrova M, Riley J, Abel J and Barclay S. Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 Years of successes and failures in patient data sharing to learn from. *BMJ Support Palliative Care* 2018;8:447–455, <https://spcare.bmj.com/content/8/4/447>
- Petrova M, Barclay M, Barclay SS and Barclay S. Between “the best way to deliver patient care” and “chaos and low clinical value”: General Practitioners’ and Practice Managers’ views on data sharing. *International Journal of Medical Informatics* 2017; 104:74–83, <https://doi.org/10.1016/j.ijmedinf.2017.05.009>
- Petrova M and Barclay S. “Wading through treacle”, with more to come: A study of drivers and challenges to data sharing based on four pre-existing reviews and the evaluation of an EPaCCS (Electronic Palliative Care Coordination System) (under review).

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: <https://www.phpc.cam.ac.uk/pcu/research/research-projects-list/prepared-to-share/>

Contact: Dr Mila Petrova mp686@medschl.cam.ac.uk (about the research) or Dr Stephen Barclay sigb2@medschl.cam.ac.uk (about the CP Project for Data Sharing in EOLC)

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