

Optimising engagement in routine collection of electronic patient-reported outcome data (OPT-ePRO)

Background

Electronic patient-reported outcome (ePROs) are digitally collected outcomes that reflect the impact of illness and treatment as assessed directly by patients, such as symptoms or side effects. Routinely collecting and using ePROs as part of clinical care may improve patients' care, experiences and outcomes, but it is still largely unknown how to best to implement ePROs in clinical practice more widely in order to harness these potential benefits. The OPTimising engagement in routine collection of Electronic Patient-Reported Outcomes (OPT-ePRO) study aims to address this knowledge gap, using renal centres in the UK as the exemplar context.

Aim of the research

To develop, implement and refine a strategy to engage patients, clinicians and other stakeholders in routine collection and use of ePROs as part of renal services in the UK.

Specific objectives are to:

1. Develop an strategy to optimise engagement in ePROs as part of usual care pathways in renal services;
2. Implement, evaluate and further refine the strategy in routine practice settings;
3. Explore views of stakeholders on drivers and requirements for introducing ePROs more to provide, assess services for people with long-term conditions.

Research plan

For objective 1, we will conduct observations of workflows and clinic consultations in renal centres, and organise participatory co-design workshops with patients and healthcare professionals. Findings will increase our understanding of how to embed ePROs in routine renal care, and inform the development of the OPT-ePRO strategy.

For objective 2, we will implement the OPT-ePRO strategy across three renal centres that will each select one in-centre haemodialysis unit and one outpatient clinic as the settings for implementing ePROs. Once centres start using the strategy, we will iteratively refine it to ensure engagement of a broad range of patients in ePROs collection. We will monitor ePRO response rates and conduct embedded qualitative research to identify issues and address them as they arise. Lastly, we will interview specific patient groups who struggle to engage with ePRO collection to gain a more in-depth understanding of their needs. We will undertake a review to explore what materials and resources are available to offer these groups additional support.

For objective 3, we will interview a range of stakeholders on what they consider drivers and needs to support ePRO collection and use at a national level in the UK. Interviewees will include NHS commissioners, representatives of patient organisations, clinical directors of renal centres, and renal implementation and quality improvement experts.

Timelines

Originally from April 2018 for three years. Now extended by 20 months to November 2022.

Outputs

We expect the findings from the project to inform how routine ePRO collection can be integrated into renal services. To facilitate this, the project will produce a roadmap to inform a strategy for rolling out routine renal ePRO collection at a national level. The roadmap will present recommendations for national stakeholder groups and renal service providers on how to scale up renal ePRO collection across centres in the UK.

In addition, we will deliver a report that outlines factors that influence digital access and ePRO engagement for older CKD patients and those from deprived areas. This report will include signposting to existing support resources or initiatives which could serve as models of engagement for ePRO programmes. The report will also identify novel challenges requiring further research.

Journal publications

Knowles SE, Ercia, A, Caskey FJ, Rees M, Farrington K, Van der Veer SN. Participatory co-design and normalisation process theory with staff and patients to implement digital ways of working into routine care: the example of electronic patient-reported outcomes in UK renal services. *BMC Health Services Research* 2021;21(1):706. doi: 10.1186/s12913-021-06702-y

Van der Veer SN, Ercia, A, Caskey FJ, Farrington K, Jury F, Rees M, Whitlock T, Knowles S. Developing an intervention to implement electronic patient-reported outcomes in renal services in the UK. *Stud Health Technol Inform* 2020; 270: 936-940 doi: 10.3233/SHTI200299

Updates

November 2021	Research restarted for objective 2
May 2021	The funder approved an extension until 30-Nov-2022. The focus for the project's last year will be on gaining an in-depth understanding of the needs of CKD patients who are older or from deprived areas to collect ePROs as part of their care. Preliminary findings from our research so far suggested that these groups as being less likely to engage with ePROs.
Mar 2021	All stakeholderholder interviews for objective 3 completed and data has been analysed; manuscript to report findings to be submitted Apr-22
April 2020	Due to COVID-related restrictions on all research activities, the OPT-ePRO study has been paused until further notice
March 2020	King's College starts ePRO data collection for objective 2
October 2019	East & North Hertfordshire starts ePRO data collection for objective 2
September 2019	Salford Royal starts ePRO data collection for objective 2
May 2019	The research for objective 1 has been completed, resulting in the OPT-ePRO strategy

The team

Lead Investigator:

Sabine van der Veer sabine.vanderveer@manchester.ac.uk

Researcher:

Helen Chadwick

Co-Investigators:

Fergus Caskey

Ken Farrington

Sarah Knowles

Michael Rees

Local clinical leads

Rob Elias (King's College hospital London)

Janet Hegarty (Salford Royal NHS Foundation Trust)

Suresh Mathavakkannan (East & North Hertfordshire Trust)

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