

## How to routinely collect electronic patient-reported outcomes in renal units in the UK?

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### BACKGROUND

The Transforming Participation in CKD (TP-CKD) initiative showed there was an appetite to collect patient-reported outcome (PRO) data as part of renal services; studies in other disease areas suggested that this may improve patients' experiences and outcomes [1]. However, how best to embed collection and use of PROs into usual care pathways is still largely unknown [2]. The Optimising routine collection of electronic patient-reported outcomes (OPT-ePRO) study therefore aimed to develop a strategy for implementing electronic PROs (ePROs) in UK renal units.

### METHODS

Normalisation Process Theory (NPT) guided the development of the OPT-ePRO strategy [3]. We had three dialysis units and three outpatient clinics (transplantation, low clearance and peritoneal dialysis) across three trusts.

We reviewed the literature and conducted: non-participant workflow observations (39 hours); audio-recordings of clinic consultations (177 minutes); and three participatory co-design workshops with patients (total n=25) and two with staff (n=13). We thematically analysed all data using the constant comparative method [4]. For the IT elements of the strategy, we worked with the UK Renal Data Collaboration (UKRDC), trusts' IT departments and the PatientView supplier. We described all intervention elements in line with relevant reporting guidance [5], while mapping them to NPT constructs.

The study was approved by the North West - Greater Manchester West REC (ID 245870).

### RESULTS

As part of the OPT-ePRO implementation strategy, we extended the UKRDC IT infrastructure to facilitate collection, transfer and feedback of ePRO data (see Figure). It enabled patients to enter ePRO data via PatientView, which they could access on any PC or mobile device. Before each clinic consultation, staff would invite a patient to enter their ePRO data. Results were sent to the UKRDC, and pushed into the renal unit's EPR system for the renal team to review and discuss with the patient. An overview screen in the EPR displayed current and previous ePRO results in tabular format, with colour-coding linked to severity. Clinicians could generate pop-up screens to graphically display scores for individual ePRO items. Patients could access their own ePRO results in PatientView.

The table presents all strategy elements. Materials and procedures left room to organise ePRO implementation in a way that fitted units' local context. All staff materials were combined into a handbook that contained information on how different aspects of the ePRO implementation would work. Patient materials were mostly delivered as flyers with concise messages, handed out in clinic, or included in patient

letters. Local champions were involved in delivering several parts of the strategy, and were usually a nurse manager and consultant nephrologist.

#### DISCUSSION

Study sites have started using the strategy in practice. We are currently monitoring ePRO response rates and conducting qualitative research to identify implementation barriers and explore ways to address them in order to iteratively refine the strategy. Once all major barriers have been addressed, we expect the strategy to be suitable for deployment by other renal units, thereby enabling national implementation of ePROs in UK renal services and contributing to harnessing their potential benefits for patients and healthcare services.