Development of an electronic patient-reported outcome measurement system for routine symptom monitoring and management in patients with advanced chronic kidney disease: The RePROM Study.

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Introduction

Chronic Kidney Disease (CKD), and in particular End Stage Renal Disease, is a costly condition, which results in significant physical and psychological burden, reduced quality of life and increased risk of morbidity and mortality. With recent advances in technology, there has been considerable interest in the use of electronic patient-reported outcome measures (ePROMs) for the routine monitoring of patients with CKD. ePROM use in other conditions is associated with improved quality of life, reduced accident and emergency visits, reduced hospitalisations and superior quality-adjusted survival. Research is required to determine if similar benefits could be realised in patients with advanced CKD.

Methods

A design team comprising patients, health care professionals, PROM specialists and IT and informatics experts undertook development of a renal ePROM symptom monitoring system at University Hospitals Birmingham NHS Foundation Trust. Input from oncology ePROM experts at Leeds Teaching Hospitals NHS Trust was also sought. Usability of the prototype platform was tested in 8 adult patients with stage 4-5 CKD (pre-dialysis). The average usability and satisfaction score was 4.6 (5-point scale). The final system was incorporated into an existing secure hospital patient portal, myHealth@QEHB, and linked to the electronic healthcare record (EHR).

Feasibility of the system is currently being tested in a single-centre pilot trial of 66 participants ≥18 years with advanced CKD. Participants will be randomised to receive either usual care or usual care supplemented with monthly ePROM reports. Recruitment will take place over 12-months with 12-months follow-up. The primary aims of the study are to assess the feasibility of undertaking a full-scale multi-centre RCT and to determine the optimal design elements.

Results

The RePROM system allows patients to undertake secure structured symptom reporting using a web-enabled electronic device of their choice. Patients reporting mild or moderate symptoms receive tailored self-management advice on-screen. Severe symptom reports trigger a real-time notification to both the patient (pop-up) and clinical team (automated email), prompting urgent follow-up. Longitudinal ePROM symptom data is available in clinic via the EHR – in both graphical and tabular formats – aimed at informing
patient-clinician discussions and promoting shared-decision making. Recruitment to the pilot trial is underway, with 28% (n=19) of the study sample size randomised at 3 months, ahead of target.

Discussion
Accurate and responsive healthcare for patients as they progress from advanced CKD to End Stage Renal Disease is a key healthcare priority. Provision of routine ePROM data by patients with advanced CKD may aid self-management, whilst also helping to improve the flow of information between patients and their clinicians. This could potentially improve patient safety, enhance clinical interactions, optimise patient outcomes and deliver cost savings to the NHS.