The UK Renal Registry

Overview of site and work

The UK Renal Registry (UKRR) is part of the Renal Association, a not-for-profit organisation registered with the Charity Commission. It collects, analyses and reports on data from 71 adult and 13 paediatric renal centres in the UK, as mandated by the NHS National Service Specification, and provides access to a clinical database that can be used in research. UKRR holds extensive data on renal patients: this is mainly clinical information but they are interested in extending this to include patient-reported outcomes. Within the renal community, there is growing interest in shared decision making and patient-reported outcomes.

The PAM is being used with patients with chronic kidney disease (CKD) (stage 3b and above) as an outcome measure as part of the 'Valuing Individuals: Transforming Participation in Chronic Kidney Disease' work programme. This work commenced in March 2015 and will run until March 2017. The aim of using the PAM is to measure activation levels as part of wider work on person-centred care, building towards a better understanding of care pathways for long-term conditions.

The Valuing Individuals programme has a programme board, co-chaired by clinicians and patients. Three work streams within the programme are linked to PROMs and PAM: measurement; intervention (guiding decisions about what interventions to put into different environments); and commissioning (what services get commissioned, what should be written into service specifications).

Within the programme, as well as the PAM, the UKRR are collecting outcome data including PROMs (patient-reported outcome measures), PREMs (patient-reported experience measures), the CS-PAM (Clinician Support for PAM) and information on shared decision making along the pathway of care.

Building on this work, as PROMs, the measurement work stream have chosen the EQ-5D-5L (which records health-related quality of life states across five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression at five levels of severity) and the POS-S Renal.

Work on measurement is grounded in testing hypotheses agreed with the programme board. Their objectives are to gather evidence about whether it is feasible and useful to collect PAM data routinely for the renal population.

- Can PAM data, along with other PROM and PREM data, be collected on a national basis – what is the feasibility, cost-effectiveness, and robustness of the data gathered?
- Are PAM levels associated with other patient-reported outcome measures (PROMs, PREMs, symptom burden)?

- Are PAM levels associated with clinical outcomes?

The UKRR is able to link its data to Hospital Episode Statistics (HES) data and so, within the work on measurement, it could also examine levels of service use, and include indicators such as blood pressure management, blood sugar control, lower medication costs, likelihood of acute kidney injury (AKI) and survival. UKRR is also interested in whether the PAM is an indicator of other clinical and non-clinical outcomes, what interventions are effective in increasing activation, how long these interventions might be effective for, and whether this leads to improvements in other outcomes. As the programme progresses, its board will establish how the PAM score or activation level will feed into the wider body of work on commissioning.

Because the focus of the programme is to test feasibility and consider sustainability in the longer term, questions about practicability are being prioritised going forward. This has led to extensive and detailed project planning, particularly considering the scale of the project. Initial plans outlined the involvement of 10 renal units, with two more receiving detailed support as part of the programme, but interest in the programme has grown and at least 23 units overall are expected to participate in the project. It had been proposed that some CCGs could participate in the programme so the possibility of identifying CKD patients at an earlier stage in their disease progression pathway could be explored, but CCG partners have yet to be identified. To manage capacity, renal units were split into two cohorts, with cohort 1 (10 units) commencing work in winter 2015.

Patients who are at stages 3b-5 on the CKD scale (with moderate or severe decrease in glomerular filtration rate (GFR) or established renal failure) are most likely to be under the care of renal units, and these patients will be asked to complete the PAM. The project aims to achieve a response rate of 60–70% for each participating unit. As UKRR has access to patient identifiable data, it will also be investigating what types of patient do or do not complete the PAM.

As each renal unit will administer the PAM independently, UKRR is interested in looking at the implications of each approach to completing the questionnaire. The longer term aspiration is to upgrade the Renal Patient View electronic system (where patients can see their own health records) to enable patients to complete and upload measures online; this will include PROMs, PREMs and the PAM. A paper-based system is used to complete the questionnaires, and data is returned to the UKRR for analysis. Depending on the renal unit, peer-assisted or healthcare professional-assisted methods are being used to administer the PAM.

The UKRR have worked hard to optimise collection of the PAM and other measures to balance the need for high quality data with the potential burden of data collection on renal units. PAM and the selected PROMs will be measured quarterly. A suitable, validated PREM could not be found and so the measurement work stream, in collaboration with the BKPA and NKF, have developed a renal specific PREM.

The intervention work stream team was keen to design and test a series of evidence-based interventions to see if these can increase activation scores, and consequently improve outcomes. In May 2016, a toolkit of interventions was being drafted.

The UKRR is also interested in exploring whether feedback of PAM scores to clinicians at individual level has an impact on outcomes, testing the hypothesis that feedback of data alone may drive improvement. Again, this may be tested using randomisation of sites to feedback or no feedback conditions. The UKRR has been using CS-PAM and has a good response rate from renal clinicians. The intervention work stream have been reviewing the data from the CS PAM and designing interventions to improve and support clinician activation.

As part of the broader work, a Person-Centred Care Facilitator was appointed (in June 2015), who supports the individual renal units and provides a link to the central programme board.

As of early 2016, each participating renal unit now has a project team. Ideally, each team was to have been made up of equal numbers of clinicians and patients although this has not been possible in all cases. Each team has been matched with a 'buddy' team from another unit so that learning and resources can be shared.

It was hoped that each unit would have had their team in place before the launch event for cohort 1 in November 2015 but, in practice, a number of teams met there, as a team, for the first time. It was noted that, although guidance has been developed for the data collection element of the project, a need existed for a broader 'getting started' guide for the next cohort which should include advice on configuring a team, and how to use 'learning means' analyses to audit team's skills.

The teams were tasked with writing a 30, 60, 90 day plan for their project, and, by January 2016, seven out of ten plans had been returned. It was intended that the plans would help to indicate if a team lacked any significant skills that might inhibit their ability to complete their work; if skills gaps were identified, then the Person-Centred Care Facilitator would provide teams with, or signpost them to, training and/or expertise.

The guidance and materials for collecting the PAM and the PROM were finalised and sent to the units and data collection began in early 2016. It was expected that completed PAMs and PROMs would start to come in from mid-February and the co-ordinating team had plans in place to road-test their systems to ensure an efficient process of data entry and export to CBS file. Also under review was how best to get data back to the teams and patients. The communications sub-group were especially concerned with getting data into the right format on 'patient view' (originally, a portal where patients could go onto to see their latest blood results, but now used beyond renal medicine) so that it would be most meaningful to patients. It was realised that many would want to access information about what their scores meant, and so work is underway to resolve that. The communications sub-group also recognised that it was important that patients should receive feedback about what work, or benefit,

their scores were contributing to; as one team member commented, ‘And how can we be an advocate to get other patients to do them if this data is going into a black hole?’. Work was also ongoing with an interface for clinical staff; again, a web-based portal (Sonar) showing PAM and PROM data.

It was envisaged that the first six months of 2016 would be a period in which data collection and processing systems would be refined, and possible improvement interventions would be explored; it was not intended that any patient interventions should be started.

A second Learning and Sharing Peer Review Event took place in May 2016.This event provided opportunities for the unit teams in cohort 1 to meet to share their successes and challenges and, further, to capture and translate their experiences into learning for cohort 2. It was reported, at this event, that 467 PAMs, and 324 CS-PAMs had been returned.