

Delivering the First PREM –

The Newcastle Approach

October 2016

The UK Renal Registry (UKRR) and British Kidney Patient Association (BKPA) developed a national strategy for an annual Patient Reported Experience Measure (PREM) Survey in the late spring of 2016. The PREM pilot ran over a few weeks in early summer with a fairly short time to implement and return completed surveys.

The survey comprises 43 questions and was developed by members of the Measurement Workstream of the Think Kidneys Programme – Transforming Participation in Chronic Kidney Disease. The survey also had input from kidney patient charities such as the National Kidney Federation, BKPA and the UKRR Patients’ Council. The pilot PREM was sent to the 52 Renal Units in England. The aim of the pilot was to collect data to start to facilitate benchmarking kidney patient experience and to inform service improvement for individual renal teams. We also needed to learn from the experience of running the survey in Renal Units so that we could improve the process for next and subsequent years’ survey.

*The **Newcastle upon Tyne Hospitals NHS Foundation Trust** was one of the Renal Units that took part in the PREM Survey and they did so with much commitment. Here they share their experiences, learning and outcomes.*



**Dr Katy Jones and colleague,
Pharmacist Rachel Fraser**

By Dr Katy Jones, Consultant Nephrologist

“Newcastle started the PREM by bringing together a group of staff members from different areas of the department as well as a lead patient. The PREM survey had to be delivered within a tight time frame, so the team at Newcastle agreed a provisional plan and allocated a lead person in each area during our initial (only!) planning meeting to get momentum and enthusiasm going. We agreed that we were keen to hear from as many of our patients as possible to provide us with an accurate picture of our strengths and weaknesses and, thanks to commitment from colleagues and volunteers, we were able to survey very widely. We were able to survey all in- and out-patients in the department during our selected week. We also approached the TP-CKD team who were happy to provide us with enough extra surveys

and envelopes to cover not only those patients, but also all our peritoneal dialysis, transplant, young adults (over 18 years only), best supportive care and home haemodialysis (HD) patients too.

A cover letter was sent out with the survey which had a contact number for the patient lead, Keith Vickers, who could respond to any questions patients had. We had help from four volunteers, two from the Tyneside Kidney Patients Association and two from the Trust Volunteer Bureau; volunteers committed a few hours or, in two cases, were with us all week! We were fortunate that our volunteers could attend every out-patient clinic to assist in the distribution and completion of surveys. Our HD lead recruited two senior student nurses to provide help with this on the HD unit to ensure that staff members weren't helping to complete feedback on their own performance. On our inpatient ward the lead for the project was a HCA and the ward housekeeper collected the completed surveys. We have an advantage in geography as all our in- and out-patient areas are in the same part of the hospital, we don't have many inpatients on other wards and our satellite units are small, so all our patients are really close by to us.

We agreed that it's really important to share the results and give feedback to everyone who took part, patients, volunteers and colleagues alike. Once we've received the report the team will meet to review the results and feedback, then to encourage engagement in the next PREM survey (next year) we will share our findings and the actions we are going to take as a result, probably in a 'You said; we did' format.

A number of our patients commented that they were being asked to complete 'yet another survey' so we're keen to demonstrate the value of the findings to our patients.

The learning from the pilot of the PREM will be a valuable resource to the UK Renal Registry and the BKPA and will contribute toward the next phase of the PREM. Sharing the learning between Newcastle staff members and being involved in sharing learning with and from other participating units is also vital for the PREM's development for the future.

Here are some of the actions we took that we think were key to us achieving a high response rate:

- Arrange an inclusive meeting to plan your approach to PREM with as much lead time as possible – this meeting can be used to identify a lead in each area of the unit to organise the distribution of surveys and decide which patient groups to include
- Wide involvement at this early stage is likely to help to 'spread the word' so that colleagues know the PREM survey is happening and can support it and build enthusiasm and increase involvement further
- We found the help we got from the Trust volunteer team and the Tyneside Kidney Patients Association to be invaluable and strongly recommend using volunteer groups to help deliver the PREM survey to patients
- Patient volunteers were essential and provided independent support to patients to complete the survey



Tanya Ramshaw, one of our very helpful patient volunteers

- Manually completing the 'Renal Unit Name' and 'UKRR Code' on each survey, and completing the return address on the SAE was time-consuming. We hope that pre-populated documents will be available next time
- The survey itself raised questions from both patients and professionals –patients had difficulty in understanding the difference between medical and practical problems and what to do if the question was not applicable to them. The UKRR will undertake further work on the survey questions before the next PREM in response to this. Patient volunteers also commented that the front page of the survey is too long and crowded and thought that this put some patients off tackling the survey
- For future analysis the Newcastle team thought it would be beneficial to have more options for the different patient groups such as
 - General nephrology
 - Vasculitis
 - Hypertension
 - Young Adults
 - Best Supportive Care
 - Inpatients

The Newcastle Team has really valued the excellent teamwork with the TP-CKD team, who were really responsive to our ideas and questions about how to deliver the PREM this year and getting the survey to so many patients. We are really excited to hear of our return rate. We hope that this will provide us with a lot of information about our service.



Connie Driver, volunteer and Keith Vickers, secretary of the Tyneside Kidney Patient Association who were instrumental in getting the survey to patients and making it all work



Helen Ritson (Young Adult Coordinator) and Julia Ibbotson (Matron)

For more details on the implementation of the pilot PREM Survey at Newcastle please contact Katrin Jones on Katrin.Jones@nuth.nhs.uk and for further information on the whole programme you can contact Sarah Evans on sarah.evans@renalregistry.nhs.uk.
