

## Team update for everyone involved in the TP-CKD Programme



December 2016, no.6

Rachel Gair, Person Centred Care Facilitator and Sarah Evans, Programme Support Officer have produced this month's update

### Welcome

This is a really exciting time for the TP-CKD programme as we come to the end of phase 1 which has been about testing whether it is possible to routinely gather a patient's level of knowledge, skill and confidence ( Patient Activation Measure) and quality of life ( Patient Reported Outcome Measure) using data collection methods.

As we move into phase 2 - spread and sustainability - we welcome Cohort 2 on board, who are beginning their implementation of 'Your Health Survey', assisted by the learning we've captured from cohort 1 units.

### What we have achieved in phase 1

More than 1000 patients across the 10 units have successfully completed and returned surveys to the UKRR.

Individual 'Your Health Survey' returns are available to clinical teams via an excel spreadsheet which is sent to the unit lead, and patients are able to view their personal results on Patient View.

All renal units in cohort 1 have recently received a centre and cohort level report. This report presents data collected at the end of phase 1 from the 10 renal units participating in the TP-CKD programme, and includes data received from the units between March 2016 – August 2016.

These reports provide us with novel information on pre-dialysis and renal replacement therapy (RRT) patients with CKD in England. For the first time patient activation, symptoms and overall health can be evaluated and benchmarks established. You can view the overall report [here](#).

### Key messages

- Many people living with CKD completed the survey, with more than half of them doing it themselves, without needing help from others. This is a promising starting point for using the survey on a wider scale.



- One in three patients reported feeling overwhelmed by their illness, and felt that their doctor made the decisions about their health. At the same time, a similar proportion said that they had the knowledge, skills and confidence to feel part of their health care team.
- Many patients felt they lacked the confidence to work out solutions when new health problems arose and did not feel able to maintain lifestyle changes.
- More than half of all patients who completed the survey reported experiencing lack of energy. Poor mobility, pain and difficulty sleeping were also very common.
- Half of all patients had at least moderate problems with mobility and with carrying out their daily activities.

### Event overview

An event for cohort 2 was held on November 8th in Birmingham. This was a very positive day where cohort 1 shared the challenges and learning from implementing 'Your Health Survey' and their experiences of participating in the programme. A full report from the day is available via the Think Kidneys website [here](#).

The day was facilitated by patients and staff from cohort 1 and what was really exciting was experiencing the principles of Peer Assist and co-production really working in a practical sense. This created an energy and 'buzz' in the room that was different from previous events.

Thank you again to all those that attended and participated in this event. The feedback from both patient and clinical teams was that that it really was a very positive and energetic day.

### Cohort 2

Following the success of the Cohort 2 event we are now welcoming a further 6 units into the programme. At the event we asked the 6 units to begin work on their 30-60-90 day action plan. We have asked that between now and January they start to develop their implementation working group and engagement within the larger unit team, with the aim of starting measurement in January 2017.

### Phase 2 - Spread and Sustainability

Phase 1 of the TP-CKD programme has culminated in robust benchmarking PAM/PROM data and the development of a process within the UKRR to support the feasibility of collecting this data and returning it to clinical teams and patients.

Phase 2 will use the Health Survey results to explore and test what interventions may improve the knowledge, skills and confidence in both patient and clinical teams. We will also see if improvements in patient activation are associated with improved overall health and decreased symptom burden.

The TP-CKD team would like to work with units to help them really use and understand the data. In the New Year we will be offering and facilitating a workshop for teams to explore ways to use the data to start changes in conversations and behaviours.



Patients and health care professionals from the Intervention Workstream have developed an Intervention Toolkit. This toolkit gives an overview of recommended interventions, the benefits of using them and signposting on how to access them. It lists, with some details, methods of working with patients to help improve activation. A copy of the Interventions Toolkit can be found [here](#).

### PREM

The UKRR has been delighted with the response from the first national pilot of the PREM – 41 of the 52 units in England returned surveys with 8,801 returns being analysed. The results from the PREM will be made available to the clinical directors via a closed section of the UK Renal Registry website this month. Once the data has been reviewed by each unit a full report will be published on the website which will be available to anyone (March 2017). The report will be promoted on the BKPA's and Think Kidneys' websites and will enable renal units to assess their performance and compare results regionally and nationally.

**The Website** [www.thinkkidneys.nhs.uk/ckd](http://www.thinkkidneys.nhs.uk/ckd)

If you get chance to visit the website you will see lots of changes to content – particularly our personal stories. If you would like your story or thoughts to appear on the website, please email Rachel Gair who would be happy to work with you to get it published - [rachel.gair@renalregistry.nhs.uk](mailto:rachel.gair@renalregistry.nhs.uk)

Finally we would like to thank everyone who has been involved in the TP-CKD programme over the last year for your support and enthusiasm, and we look forward to working with you in 2017.

**With all good wishes for a happy Christmas and a prosperous New Year!**

