

**Valuing Individuals:
Transforming Participation in
Chronic Kidney Disease**

Cohort 2 Learning and Sharing
Event Report

8 November 2016

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Cohort 2 Learning and Sharing Event - Introduction

The Transforming Participation in Chronic Kidney Disease (TP-CKD) Learning and Sharing Event for Cohort 2 took place in Birmingham on 8th November 2016.

The programme invited 6 delegates (a mix of patients and clinical staff) to attend the event, from each of the following Cohort 2 renal unit teams:

- Royal Sussex Hospital, Brighton
- Southmead Hospital, Bristol
- St James Hospital, Leeds
- Churchill Hospital, Oxford
- Royal Stoke University Hospital, Stoke-on-Trent
- New Cross Hospital, Wolverhampton

The aim was to share the learning and experiences from cohort 1 to guide and support the implementation of 'Your Health Surveys' across the new cohort. A patient and clinician from each of the five units from cohort 1 shared the challenges and successes they had experienced with the implementation of Your Health Survey and participating in the TP-CKD programme. Current data from the patient activation measure and patient reported outcome measures were shared with the audience. The afternoon then focussed on developing a 30-60-90 day Your Health Survey implementation plan for each renal team in cohort 2.

The event provided opportunities for the units in cohort 2 to meet in their teams of patients and clinical staff and to begin to build on the principles of co-production. The programme for the event had been shaped and planned by patients and clinicians who had attended the first two events in November 2015 and May 2016. Their involvement ensured that the principles of co-production were included, and the lessons learned from the previous events informed the planning of this one.

Not only was the programme for the day co-produced, but the sessions were presented and facilitated by patients and health care professionals as equals. This approach shows the TP-CKD

programme’s commitment to building and developing the principles of co-production so that it continues to underpin all that we do.

The Programme

The programme for the day included presentations from the UK Renal Registry on the data from the surveys, along with presentations from cohort 1 on their experience of being involved. The day also included renal unit group work. Patients and professionals from cohort 1 and from the programme team were asked to support and facilitate teams throughout the day.

We started with Karen Thomas (Head of Programmes, UK Renal Registry) and Jonathon Hope (Patient Co-Chair, TP-CKD Programme) welcoming everyone to the event, describing how excited they are about the TP-CKD programme and the progress it has made as well as the day’s activities.

You can view the slides from the day by clicking [here](#).

Session 1 - Aims of the day and overview of the programme to date

Rachel Gair, person centred care facilitator, gave a brief overview of the TP-CKD programme to date, the context, what person centred care is, and how patients can be supported to become activated and achieve outcomes that enhance their everyday life. Rachel gave a brief update on the lessons learnt so far in phase 1 with cohort 1 which has focussed on measurement. She then gave an outline of phase 2 focussing on spread and sustainability.

The session ended with an ‘ice-breaker’ which involved each person in turn in the team asking the person next to them ‘I bet you have never...’ and then recounting something revealing that they as an individual have done. The aim of this was to move beyond the value judgements that we sometimes make without thinking and to start the day as equals bringing our different qualities and experiences to the event. This generated real energy in the room from which further discussion and sharing developed.

Session 2 - Data and cohort 1 experiences

The purpose of this session was to provide an overview of Cohort 1's data and to hear about the experiences from some of the units involved.

Retha Steenkamp from the UK Renal Registry began with sharing the aims and some of the initial data from Cohort 1 PAM / PROM and CS-PAM survey returns. All 10 units in Cohort 1 have submitted survey returns. 358 staff members in total completed the CS-PAM and 1,053 patients have completed the PAM / PROM survey. The summary and key findings can be found within the slides from the day [here](#).

The session then continued with presentations from five of the cohort 1 units.

- Dr Ramla Mumtaz and Peter Forest, patient lead from Bradford presented on their implementation of the PAM / PROM / CS-PAM surveys, data handling, and next steps.
- Helen Ritson, Young adult worker and Rachel Fraser, pharmacist from Freeman Hospital, Newcastle shared the challenges of implementing the surveys into both their Young Adult patient group and transplant patient group and how they sought help and support. .
- Peter Naish, patient lead and Dr Joanna McKinnell from Derby focused on the development of their working groups and how they rolled out the survey using small cycles of change.
- Eleri Wood, consultant nurse and Agnes Gogognon, patient lead shared some of the challenges in getting started and how they overcame them and Agnes presented on the role of the patient volunteer.
- Dr Jyoti Baharani from Birmingham Heartlands in her informal presentation recommended that Cohort 2 focus on a specific group of patients when starting implementation rather than try and do it across the whole pathway. She also raised the issue of language and felt that a significant proportion of her patients were excluded from participating as English is not their first language.

Session 3 - The importance of communication

During this session Annie Taylor, communications advisor for Think Kidneys presented on the importance of communication. She shared information and advice on how to use comms, the

value that it can bring and why it is so important. Examples of case studies, blogs and press releases from Cohort 1 were available on the day for Cohort 2 to look at. You can also find these resources on the [Think Kidneys](#) website.

Session 4 - Quality improvement and change management

Rachel Gair presented a brief summary on quality improvement cycles, after-action learning and peer review / peer assist.

Session 5 - Implementation and 30-60-90 day plans

In this session we asked each unit from Cohort 2 to start to develop a 30-60-90 day plan based on a quality improvement approach – starting with small cycles of change and spreading. They were encouraged to use the learning shared from Cohort 1 to develop these plans. Examples of the 30-60-90 day plans from Cohort 1 were shared with Cohort 2 to offer ideas along with examples of After Action Learning tools.

We then asked each team to share 5 minutes feedback covering the following:

- What group of patients do you propose starting with?
- What do you see as challenges?
- How will these be overcome?
- What do you have in place that you can develop further – links with KPA, patient + clinical champion, working group etc.
- What support would you like from TP-CKD team?
- What’s your key message to take back to your team following this event?

Feedback from the event

Thank you to all who took the time to complete the event feedback form. Your comments are appreciated and will be evaluated and used for future reference.

We asked you to rate each session of the day on a scale of 1 to 5, for interest and relevance, where 1 = not at all interesting/relevant to your role, and 5 = extremely interesting/relevant to your role. Here’s how the sessions rated.

Overall the average score for interest was **4.41**

Overall the average score for relevance was **4.41**

Average score for ‘organisation’ **4.55**

Average score for ‘venue’ **4.64**

Average score for ‘catering’ **4.52**

And finally some of the comments received from people who attended

Very useful day to learn from others and share experiences from Cohort 1

Really interesting day. Found information helpful and informative as feedback and for progress forward in my role for TP-CKD in the future

As a professional from Cohort 1 it's very useful to see how this has evolved since our first sessions last October. Talking to Cohort 2 was very helpful as aid and insight into our own development, limitations and area in which we're performing well. THANK YOU

Good to hear patient and other units' experiences from cohort 1. Felt like the tool became 'practical' as people discussed their experiences and benefits. Explanation of the PAM very useful. Good ideas learned for implementation; patient gave good advice. Patients inspiring and supporting

Excellent day, answered a lot of questions. Good to have names, emails, contacts etc. An interesting concept which we feel with support, we will be able to implement

Useful day looking at how to implement this project. Very useful to meet with staff and patients from other units and share experiences