

**Valuing Individuals:
Transforming Participation in
Chronic Kidney Disease
Peer Review Event Report
10 May 2016**

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Peer Review Event - Introduction

The TP-CKD second Learning and Sharing Peer Review Event took place in Birmingham on 10th May 2016.

This event provided further opportunities for the units in cohort 1 to meet in their teams of patients and clinical staff to build on the principles of co-production that they have been developing locally, and to share the successes and challenges they had experienced in implementing 'Your Health Surveys' within their units.

The programme for the event was shaped and planned by patients and clinicians who had attended the first event in November. Their involvement ensured that the principles of co-production were at the forefront and the lessons from previous event informed the planning of this one.

The sessions during the day were mainly interactive with a lot of group work in unit teams and also in mixed teams across cohort 1 to make sure learning was shared as much as possible.

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.

Even with careful planning there were some issues raised on the day concerning the sound quality and some of the sessions within the programme that perhaps gave out mixed messages regarding co-production – such as splitting patients and health care professionals into separate groups after lunch. But overall the feedback was very positive with patients and professionals enjoying the chance to meet one another and share ideas in a relaxed way. All of the comments and feedback have been captured, discussed with the planning group and will be used to inform future planning of events.

The main aim of the day was to bring together patients and clinical teams from cohort 1 to share and discuss their learning from the programme so far. This included the challenges and successes of implementing the PAM and PROM (Your Health Surveys), the impact of co-production and what the priorities and next steps were for individual units and how these lessons could be translated to advice for cohort 2.

The second aim was to share information from the programme with the units, such as measurement data and what the next steps might look like regarding this.

The Programme

The programme for the day included presentations, mixed unit work, renal unit group work and split patient / health care professional group work. Patients from the programme were asked to support and facilitate teams throughout the day. Each unit was asked to come prepared to the event with information about their experiences to date as part of the programme including 5 challenges, 5 successes, advice they would give to Cohort 2 and the impact of co-production on implementation.

We started with Richard Fluck welcoming everyone to the event, describing how excited he was about the programme for the day.

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

Session 1 – Programme update and purpose of the day

Rachel Gair, person centred care facilitator, gave a brief overview of what person centred care is and how patients can be supported to become activated and achieve outcomes that enhance their everyday life. She gave examples of different approaches used by units in cohort 1 of how they implemented Your Health Surveys and had begun to embed them within everyday practice.

Session 2 – Renal unit mixed group peer support session

The purpose of this session was to build on the concept of ‘buddy units’ by gaining further learning from the experiences across all teams by mixing them up.

The session was started 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 immediately generated energy in the room from which further discussion and sharing developed.

A facilitator was allocated to each table which comprised 10 HCP and patients from across cohort 1. In the first half of the session the facilitator encouraged sharing and engagement of all individuals involved making sure that there was full interaction and all voices were heard. This part was unstructured and more about engagement and confidence building.

The second half of the session focused on the challenges and solutions that had been experienced by the teams.

The facilitator prompted groups with the following:

- Did you feel involved in the process of measurement after attending the event in November – how were you involved (group meetings, emails etc.)?
- Have there been any barriers to starting surveys or spreading surveys to wider population in unit?
- What have been responses of fellow patients and colleagues to the programme – has there been good support?
- What are views on Renal Unit Package and timings (posters, leaflets, RUG etc.) and are there any changes you would suggest?

Paper and pens were provided to encourage individuals to make notes on points that could be shared with their own unit teams during the follow-on session.

Session 3 – Renal Unit team work

For this session renal units regrouped in their unit teams in order to take the learning from the previous mixed group session, along with their pre work to draw out some key points and set some next steps that the unit team could take away with them.

We asked the units to provide us with some of main **challenges** that they have faced as part of the programme, here are some of the things that they as a team came up with:

- Concerns about sustainability and resources
- Patients asking what’s going to change and what’s happening with the results
- What happens to the data? After clinic, how will the data be feedback to patients and how will the data be used in the long term?
- Too many areas used initially so best to focus on quality not quantity and grow from there
- Staff duties, time, resources
- Clinicians too over-stretched already, hard to get things rolling
- Embedding with whole team – really need to get every in from day one
- The time needed and the sustainability
- Making sure everyone was aware of how great the programme is and what it will do
- Getting commitment from the beginning – important to launch properly so everyone is engaged and knowing what is happening from the start
- Faster feedback – 3 months too optimistic, should be 6 months

We also asked them to share some of the main **success’** from the programme, and this is what they said:

- The use of patient volunteers and sustainability
- Involving patients in own care
- Group work

- Co-production and patient empowerment
- Seeing PAM returns after the hard work put in
- Delivery of programme with limited resource – using patients
- Getting it done – waiting returns in clinic
- Patients all thought it was a great idea, very receptive and good uptake
- Arming patients with the resources to be activated
- Involvement in World Kidney Day / Hospital Open Day – advertised the programme locally in hospital, comms and public
- Working with patients as partners
- Surveys in clinic opened up conversations in the consultations

Finally, we wanted to find out from them what happens after this event, what happens next...?

- Nottingham - Making expectations clear – where/when and potentially create own unit specific leaflets
- Coventry - Get second group involved (July) and set up self-support team through volunteers
- Kings – move forwards but keep it simple
- Sheffield – get more patient volunteers for support
- Bradford – increase volunteer force and suggested simplifying language in survey
- Newcastle – more patient involvement and engagement and target a wider spread
- Derby – get buy in from across the whole unit and potentially create unit specific posters, leaflets and literature
- Birmingham – focus on specific areas. Go smaller and use the tool in consultations
- Plymouth – re promote and get some new recruits
- More patients / volunteers to help create sustainability
- Outcome and results to be feedback to patients and clinicians so not to lose momentum
- Re-promote / re-launch
- Start small and build up

Session 4 – Programme updates

This session was split into 3.

1. Fergus Caskey gave a brief overview of the CS-PAM data returns from cohort 1
2. Ron Cullen gave an update on how PV is being developed to allow patients to access the results of their PAM and PROM alongside clinical data.
3. Dave McHattie co-chair of the Intervention Work stream provided an update on Interventions Toolkit that is being developed.

Session 5 – Specialist patient / professional session

The patients and healthcare Professionals were invited to divide into 2 groups and asked to discuss the following and this was their response

- **What’s gone well** – communication between staff and patients. Reduction of barriers. Equality. Teamwork. 50/50 role (patients / clinicians)
- **Involvement** – much more inclusive. Shared decision making. Patients encouraging other patients to complete the Your Health Survey
- **Surveys** – too many questions. Still waiting for feedback. 3 months is too frequent, repetition. Timing needs to be considered. Communication is critical.
- **Patient volunteers** – needed. Success when implemented. Needs to be advertised so that patients know about it. CRB checks.
- **Experience** – Get staff involved from the beginning. More time. Data protection.
- **Anything else** - Concerns about patients feeling depressed when seeing results. Renal Unit Pack feedback: Posters too small, but the Renal Unit Guidance (RUG) is hugely important, patient information leaflet to be localised. Anxiety about what to do with the results. Patients were asking and feeling that they didn’t know why they were doing it. Keen to fill in but need to be encouraged.

To end the day, we asked all the teams what advice (based on their experiences and learning from the TP-CKD Peer Review Event) they would give to Cohort 2. Here’s what they had to say:

- Embrace co-production, allow the patients involved to administer surveys, speak to clinicians / spread the work, co-chair actions groups and chase up actions etc.
- Keep it simple – target a co-located group of patients, use existing systems (e.g. the questionnaires already regularly administered) and keep going!
- Involve patients in helping to complete questionnaires (training – join staff / patient)
- For your first group, choose carefully (manageability, staff, time, and support from all)
- Complete the front page initially and give it to patients completed (NHS number, RU etc.) to ensure complete information is sent back
- More patient involvement
- Start small and think carefully about where best to start
- Working Groups should be built – MDT Team with patients and an admin lead
- Preparation! Think about the ground work – preparation and education first
- Use Rachel and the TP-CKD Programme’s team for advice and guidance
- Get staff on board as early as possible and create timelines
- Use your patient population and embrace co-production, allow the patients to be involved in the administration of surveys, speak to clinicians, spread the work, co-chair action groups and chase up actions.

Feedback from the event

Thank you to all who took the time to complete the Peer Review 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 4.30

Overall the average score for relevance was 4.36

Organisation: 4.68

Venue 4.48

Catering 4.45

And finally some of the comments received from across the event

*Fantastic event! Lots of food for thought. Good luck for Cohort 2 and to the programme.
More time – too much of a rush after lunch*

Thank you very much for the day (Patient)

*I would like to highlight the feedback of the data from CS-PAM as it was so important for my role. Thank you for a great day. Thank you also for the timings of the day. The meeting in November felt rushed and full, whilst today felt calmer and we were able to talk things through more thoroughly by having fewer tasks to complete (or so it felt!).
(Healthcare Professional)*

Very interesting and fruitful day (Patient)

*Today has re-motivated us!
Thank you
(Healthcare Professional)*

*Very valuable day. The different breakout groups were very helpful! Useful to get the early results
(Coventry)*

*Enjoyed the table planning – was good to communicate with staff and patients from other areas. Was also insightful to speak to peers at the end of day – good for comparison and sharing learning.
(Healthcare Professional)*

‘THINK KIDNEYS’

Photos from the Day

