



## **Transforming Participation in Chronic Kidney Disease**

**Learning and Sharing Event – 18 November 2015**

### **Report on the Day**

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The Transforming Participation in Chronic Kidney Disease (TP-CKD) programme will develop a person centred approach to care. People will be supported to build their skills, knowledge and confidence to better manage and make decisions about their own health to improve their quality of life.

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#### **Introduction**

The Learning and Sharing event presented several opportunities for everyone attending this event. The first was that this event brought together the first cohort of renal unit teams, comprising people living with CKD and clinicians, and the Transforming Participation in Chronic Kidney Disease team (comprising members from the UK Renal Registry, NHS England's Patient Centre Care Team, lay members and clinical experts). Getting together for the day provided everyone with the chance to learn more about the programme, its aims and objectives for the coming months.

The second opportunity was for the renal unit teams – patients and clinical staff - to start to work together, in most cases for the first time, to explore how they are going to deliver the programme by developing the relationships, knowledge, skills and ultimately services, for the benefit of patients. This way of working is what makes the programme innovative and different.

The chance to develop an understanding of co-production was the third opportunity for everyone. Co-production is what makes the Transforming Participation in Chronic Kidney Disease (TP-CKD) programme unique. Co-production is about more than involving and engaging people, or asking for views, opinions and perspective. It's about truly working together to create something new and different that meets everyone's needs and improves the lives of those who are impacted by the disease and the service overall. In a spirit of partnership and equality and by valuing everyone's contribution, the TP-CKD programme has the potential to have an impact on many lives.

A number of challenges beset the day but we worked flexibly to ensure we got through the programme and importantly, teams had the chance to work together on their plans. Trains

were disrupted by the weather which meant we were late starting, and the day was oversubscribed in terms of numbers of people attending. While this was an excellent indication of the level of interest in the programme, it did cause some difficulties as space was severely restricted in the room we occupied for the day. A number of people fed this back to us and we will work to ensure this doesn't happen again.

The main aims of the day were to learn about the TP-CKD programme and what it intends to achieve, to learn about our gaps in knowledge and how those gaps might be filled, and, very importantly, for the teams to start planning their work for the next few months.

The programme will make use of a number of surveys to measure patient activation, experiences and outcomes as well as clinical support. The resulting data will provide renal unit teams with the information they need to work with people to become more activated by developing the skills, knowledge and confidence they need, and to improved services.

### **The Programme**

*All slides for the presentations for the day are available by [clicking here](#).*



We started the day with a welcome from Patricia Muramatsu on behalf of NHS England and the Patient Centred Care Team, who talked about the importance of the TP-CKD programme and ran through plans for the day.

### **Session 1 – Overview of the TP-CKD Programme – The Co-Chairs**

Richard Fluck, National Clinical Director for Renal Disease for NHE England, TP-CKD Programme Board Co-Chair, and Consultant Nephrologist, Derby Teaching Hospitals NHS Foundation Trust followed. Richard described what 'activation' is and what it can mean to individuals developing the skills, knowledge and confidence to make informed choices about their care, to be a partner in their own care and to self-manage their condition. He talked

about how the ‘activated’ person is more engaged in doing things that prevent ill health, in being involved in activities that are more likely to keep them healthy, in managing their own health condition, and in wanting to know all they can about their condition.

Richard continued by describing the aims and hypotheses of the TP-CKD programme which are to determine the following -

- Can we gather PAM/PROM/PREM/CSPAM measures routinely? These are the questionnaires completed by people with CKD and clinicians which demonstrate how active a patient is in management of their own care. For a full description of the measures please [click here](#).
- Is the PAM related to PROM/PREM/Clinical Measure results? This will explore whether patient activation has an impact on the outcomes for an individual, reflecting their experience of care.
- Can we bring in interventions that will increase a patient’s activation, segmented by PAM status? In other words are there resources, such as tools, information and education that can help people become more activated (engaged and involved) in their own care

Richard described the ‘mission’ for the day – *“How are you going to introduce patient activation measures (PAM) and clinician support for PAM measures (CSPAM), patient reported outcome measures (PROM) and patient reported outcome measures (PREM) into routine use within your departments?”*

Jonathon Hope, TP-CKD Programme Board Co-Chair followed, sharing his personal excitement about the potential for the programme, as well as his own journey of living with kidney disease for many years and how his life changed as he became more involved in his own care and ultimately more activated.

Both Richard and Jonathon described the ‘skills, knowledge and confidence matrix’, which shows the relationship between the level of activation of the patient as well as the level of activation of the clinician to show how and where their positions can meet for best effect in terms of outcome for the patient.

## **Session 2 – Programme Methodology, Rachel Gair**

Rachel is the Person Centred Care Facilitator for the TP-CKD programme and she began by describing the changing ‘doctor –patient’ relationship to become patient centred. She went on to describe how patients are experts as a result of their experiences; that the approach now needs to be “working with” rather than “doing to or for”; that the programme needs to help people develop the skills, knowledge and confidence to help them take more responsibility with the right level of support to reach the goals they aspire to so that they can achieve lives that are independent and fulfilling.

Rachel provided more detail on PAM/PREM/PROM and CSPAM and how they are used, the challenges, some of the practicalities, giving examples from existing work. She described 'Peer Assist' as an important element of the programme. This will help renal unit teams to learn from each other – to share experiences, knowledge and insight to develop ways of helping each other, problem solving together and sharing progress.

The 'Peer Review' process will be used to check how well a team is doing with their work on the programme. One of the important elements of this process is the quick identification of mistakes so that they can be rectified quickly and effectively and improvements suggested and made as appropriate. The timescale for implementation of the programme was then described with actions recommended for each of the next six months. Rachel's role as Person Centred Care Facilitator for the programme will include support for each of the 10 renal team units in the first cohort and she will also be recording what went well, what worked less well and anecdotal experience of implementing the programme. This is so that learning can be captured and made available to renal unit teams joining the programme next year, ensuring no one is reinventing the wheel and experience is valued and built on for the future.



### ***Session 3 – Health Foundation Approaches to Improvement, Helen Crisp, Assistant Director of Research***

Helen introduced the Health Foundation's approach to improvement and patient centred care, describing the theory and their research based approach. Helen outlined some of the resources available which will be of use to the renal unit team. All of the resources are online and can be accessed by [clicking here](#). They include 'Measuring Patient Experience', 'Helping People Share Decision Making', 'Helping People Help Themselves' and 'enabling People to Live Well'. She went on to describe methodologies and how implementation might be achieved. Helen suggested that if we only read one thing it should be 'Person-centred care:



from ideas to action'. She also described ways to evaluate work to see what has been successful and change that has been delivered, providing tips for writing the project up.

#### **Session 4 – Learning Needs Analysis – group work led by Richard Fluck**

Due to the changes we had to make to the programme during the day, the Learning Needs Analysis session was curtailed and renal unit teams were asked to complete the posters on just two of the stations instead of the planned 10. The renal unit teams had access to the results of the online survey about learning needs to review. The remaining eight topics for the learning needs analysis will be completed by the teams over the coming weeks, but each team was asked to highlight very briefly what they had discussed and agreed was the most important point. As we would expect there were some common themes which emerged from the feedback and these included the following;

- Designing the improvement and managing the change, including barriers to getting people involved and engaged
- Recognising the patient journey and the impact this has
- Keeping the focus on co-production and learning together about working together. Patient engagement – importance of using the right language
- Getting engagement and supporting people. Getting the engagement right with the wider team before the support can begin
- Evaluating the work – managing qualitative evaluation, especially if it's not what you want to hear
- Challenges of resourcing – negotiating people and time allocation to get up and running effectively
- Communication – keeping it simple, clear, easy, useful and not overwhelming.



### Session 5 – 30 – 60 – 90 Day Planning - Karen Thomas

Feedback from attendees told us that this session was the most interesting and important session of the day. That's no surprise given that this session was for renal unit teams to gather initial ideas and focus on how they are going to implement the TP-CKD programme. The templates were completed by each team and then each team was 'buddied up' with another team to share where they are at in their thinking and to start the peer assist process. Following this plans were revised and one key message was shared with the whole group from discussions and the plan.

Again some themes emerged from the renal unit teams which are captured here.

- Our focus has to be on understanding patient needs – this is the main objective of the programme – a reminder that the vision and the focus is around patient need.
- We have to start with engaging clinical colleagues to make sure everyone understands what, why and how we are going to do this.
- We will start a pilot with PAM deciding in one part of the service which will be very valuable before rolling out. We've identified 2 patient groups to pilot this work with. We'll do a pilot and evaluate the usefulness of the PAM survey. We will consider how practical it will be to do the survey every 3 months and manage the data.
- We will learn from the experience of other teams who have used this. We have a project meeting planned to work out roles and responsibilities as well as patients we may start with, then we'll roll out.
- Engagement, engagement, engagement - we want to roll the programme out to a new area every 30 days.
- We want to work with our patients to spread the word and get co-production going. Patients will help us to get the questionnaires to patients. We will use patients as volunteers to drive this.

Richard closed this session explaining next steps. The link to the online Learning Needs Assessment survey would be emailed for those who didn't manage to complete it before the event. The results for each unit will be returned in a couple of week to each renal unit team.

Rachel Gair will organise to visit each team soon, to support the development and delivery of the 30-60-90 day plans. We agreed to share the slides from the day which can be accessed [here](#)

Richard asked for feedback on the new website when people have had the chance to see it at <https://www.thinkkidneys.nhs.uk/ckd/>. This site is for the programme to own and ideas for content will be very welcome. In the next few weeks we will develop web pages for each of the renal unit teams so this is a site for the programme to own and influence how it is used.

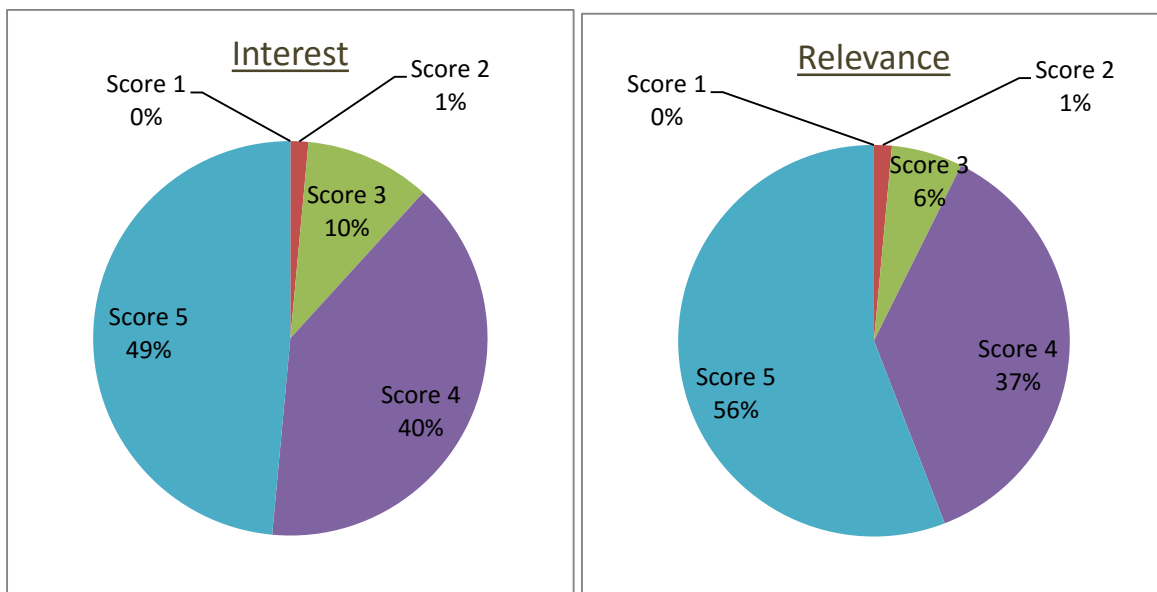
## And finally – feedback

Around 70% of delegates completed the feedback form. And while we had a number of comments about the lack of space and noise in the room – due entirely to the unexpected number of delegates as previously explained – the day was very well received and there was a definite buzz and energy in the room as teams started working together.

From the evaluation forms – Ratings are based on a 1-5 scale for interest and relevance, where 1 = not at all interesting/relevant and 5 = extremely interesting/relevant to your role.

### The overview session of the TP-CKD Programme

The average score for interest was **4.4** and for relevance was **4.5**



### Here are some comments from delegates.....

“As a CKD patient I am all for self-care so welcome any help with this”

“Brought staff and patients together from our renal team to discuss ideas. Most important thing is to put the patient first”

“Anything which improves the care which we can give to patients and help us to meet their needs has to be crucial. It reminds us why we do the job we do”



**Feedback on the 30-60-90 Day Planning Session**

The average score for interest was 4.3 and for relevance was 4.4

