



Email Update for Transforming Participation in Chronic Kidney Disease

Message from Richard Fluck

Welcome to the first email update for TP-CKD. We will send one every two months to help us keep up to date on progress, people, news and results. As co-chairs, Jonathon Hope and I plan to alternate writing this introduction. If you have any ideas about how to improve the newsletter, e.g. ideas for content or something you'd like to share with the wider group, contact Annie (email address below).

Over the autumn it's been good to hear from Rachel Gair about the increasing involvement of our first cohort of renal unit teams. This was reflected by attendance at the excellent Learning and Sharing event last month. It was great to see so many of you there and the day was charged with energy and enthusiasm for the work you are doing. I don't believe I've been to an event quite so oversubscribed before and while that caused a few logistical problems, we managed to meet our objectives for the day. You can read the report on the day by clicking [here](#). Thank you to everyone who attended and made it such a successful day.

I've been thinking about the programme and its aims. This programme is about involving people in their own care and giving them more control whilst changing the dynamic of the clinical teams to adopt a coaching role. It was great to see the relatively even split between those coaches and the people living with CKD. But, while the idea of co-production seems fairly straightforward it seems to me that this new way of working is very different and achieving it quite complex. First there's the cultural shift that's needed to change the way in which clinical staff work and view their patients as patients become partners in their care and involved in decision making. This can only be achieved through engagement and involvement – helping everyone understand what the programme is all about – for the individual, for the team and for the organisation. Strong leadership will make this a reality and I saw great examples of that in the room. And a leap of faith will be required for many given how new this way of working is, and our hope for improved outcomes for people. That is why sharing the experience and learning is so important.

I was struck at our event last month by the different nature of the relationships we need to develop for co-production. While it's easy to say that everyone has an equal voice, it's not always easy to achieve. Equal does not mean the same – everyone needs to bring their knowledge and skills into solving this conundrum. People with CKD have to radically rethink their relationship with their clinical colleagues so that they become confident enough to take part and have their say. And from the other perspective, the clinicians in the teams have to be prepared to accept what they hear, and to listen and be open to ideas and views which could be considered to be criticism. This makes us all equally vulnerable and that's where the difference lies, but at its heart is mutual respect. Having those honest conversations will drive the change we all aspire to.

Richard is Co-chair of the programme, NHS England National Clinical Director for Renal and Consultant Nephrologist at Derby Teaching Hospitals NHS Foundation Trust

The First Cohort of 10 Renal Teams

Rachel is working with each of the renal unit teams over the next few weeks to help with development of project plans and kick starting the local work. Most teams have now completed the Learning Needs Analysis and are starting to look at their 30-60-90 project plans.

Resources for the programme

Leaflets for patients are available now, and posters for renal units will be available very soon. We will contact project leads in each unit when they are ready.

The website went live on time and we'd like your comments and suggestions on how we can improve it, so please get in touch. Our plans for the site include creating a page for each renal unit team, outlining what they are doing, their progress, what's changing and people's views on the work. We will send out a template for each unit to complete so that we have all the information we need easily accessible on the site.

We also want to develop some case studies for the website. But they won't be typical case studies – they will be 'activation stories'. It would be great if the stories include a wide variety of perspectives – not timelines of people's experience of living with CKD, but more about the difference that becoming an activated patient can mean. We'd also like to include renal unit's staff views on the programme. If you'd like to volunteer please contact Annie – the more we share about the difference activation can make to lives, the more impact the programme will have. It's also about sharing the experience of involvement in the programme and the learning.

In time it would be great if we can have regular updates from each renal unit team so that we can share progress and experiences in this email update.

The Workstreams

Measurement The 10 renal teams in the first cohort are preparing their pilots of the measures – PAM, PREM, PROM & CSPAM and most will be starting this work in January. Work involves putting systems in place to capture the data, the learning and the experience and the feasibility. Success is also dependant on cultural shift, leadership and inclusion, which we recognise may be the most challenging part of the programme.

Intervention The team meets just before Christmas and is working over the next six months to develop a toolkit of interventions, the first of which will focus on staff in the renal teams to look at how we can change the concept of the consultation to include an element of coaching. Renal teams – clinicians and lay members will also need tools to help them respond to the first results from the CSPAM surveys.

Commissioning The first face to face meeting of the team is in January, but the focus for their work will be outcome based commissioning which will be influenced by the work of the other two workstreams and the renal teams. More info to follow.

Edited by anniemtaylor331@gmail.com please send me feedback, comments and ideas for content. If you would like to contribute an article for the next update it will go out at the end of February.