

# Transforming Participation in Chronic Kidney Disease

ARAL RECIPE



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**CASE STUDY** 



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#### **Unit Name**

Royal Derby Hospital

#### **Unit Programme Leads:**

Joanna McKinnell:
Consultant Nephrologist
Cath Johnson: Renal Nurse
Consultant
Peter Naish: Patient lead

## What we wanted to achieve:

"To inspire, encourage and empower both patients and staff; thus increasing collaboration in kidney disease management.

This is in line with the already well established ethos of the whole Derby team – no decision about me without me"

### What we did:

#### Background:

Development of a working group with a patient and clinical co-lead acting as champions. Our unit had inherent senior management support from the beginning and was committed to Shared Decision Making. Dr Richard Fluck, consultant nephrologist at the Royal Derby Hospital was the National Renal Clinical Director and co-chair of the TP-CKD Programme. The Clinical Director was also supportive and attended our first working group. The programme was led locally by a consultant, renal nurse and patient lead but we had wider support and commitment across the unit.

"It was fun - there was a buzz at every meeting and that helped in the motivation. Lots of laughter. We had leadership not hierarchy."

# The role of the co-productive working group:

How did you form your working group/what were the processes behind how your working group ran the programme locally? How often did you meet—who attended...?

- The group was formed from a large group of staff and patients who went to the first programme event
- Where our group recognised gaps in our strengths, we co-opted other people, for example a pharmacist, an IT specialist, the trust communications team and the patient volunteers group
- The patient champion at this unit really drove the programme forward, keeping records of action plans and following up next steps with team members
- Derby was asked to present at the Peer Assist event in May 2016 and our presentation concentrated on co-production and building a strong working group

"We went away feeling re-energised and ready to get on'

"the most positive part was taking the time to sit down together and look outside of every-day operational management"

# **Challenges:**

Challenges around the working group—patients dropping out, difficulty in convening meetings—things going off the boil—working co-productively / keeping motivation—how did you re-motivate?

- Delays in data returns from the UK Renal Registry to Derby meant momentum was lost.
   The data infrastructure was not in place soon enough to keep up with local enthusiasm
- Whilst there was a core group of seven, members of the working group came and went during the two year programme
- The needs and purpose of the working group changed quite often and there was a lack of consistent focus

"The initial two year programme was achieved through a commitment to co-production and immensely enhanced by that. Once that ended the focus moved to the unit's procedures and patient involvement turned into consultation/sounding board. In our working group co-production really worked as a short term "task and finish" exercise for working out solutions/ suggestions at the patient/staff interface, but not necessarily for applying them"

#### **Outcomes:**

Is the group still running and in what guise?
What was positive/what were the sustained outcomes from your working group and the programme more generally?

"The group is in abeyance at the moment. The focus of the work is on internal procedures - embedding processes, ensuring paperwork is not lost, analysing the results... I think this will go on for about two years before there is sufficient stability and data to make it worth involving patients again. That will mean re thinking what the role of the group is at that time. The sustained outcomes are:

- 1. As a model of what can be achieved through this approach it was a major success
- **2.** Changing the culture within the unit I suspect there is still some way to go for most units. <u>CS-PAM</u> would be worth a separate follow up project on its own
- **3.** Patient activation, quality of life and medical outcomes time and data will see how successful this approach has been"

For further information and resources on Transforming Participation in Chronic Kidney Disease please visit www.thinkkidneys.nhs.uk/ckd