

First Trial Using the Patient Activation Measure in Plymouth

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Caroline Adams is Chronic Kidney Disease Healthcare Assistant and is heavily involved in the Transforming Participation in CKD programme in her kidney unit in Plymouth Hospitals NHS Trust. Caroline captures here the change and learning they have experienced in being part of the programme by describing the team's 'after action learning'.

“Plymouth renal unit is excited to be taking part in a new programme to help people with chronic kidney disease. The programme is called Transforming Participation in Chronic Kidney Disease. Studies show there are benefits for patients who are actively connected and working with clinicians to manage their care.

The Trial

Two weeks prior to a nurse led CKD clinic, a random group of nine patients were selected. Within their appointment reminder letter a ‘Think Kidneys’ leaflet, a PAM questionnaire and covering letter were posted to each patient.

The clinic had two clinicians and two expert patients to support the process. The PAMs were collected and handed to the clinicians prior to the patient being seen by them. The patients were thanked for their participation and informed of the reason for the survey and what the process of the appointment would be, and that we intend to feedback our results in individual letters to them at a later stage of the trial.

Date	11/02/16
Venue	Main outpatients department
Sample group	CKD patients x 8
Team	Clinicians - Jen McDermott and Ceri Watkins Expert patient volunteers - Sarah Yearling and Andy Demaine HCA - Caroline Adams

Below is an After Action Review of reflected views from across our team after our first session.

What did we expect to happen?

- On the whole we were not sure what to expect but thought there would be more problems than we experienced
- Patients would bring completed questionnaires and for the volunteers to resolve any questions in the waiting area prior to clinic
- Probably not all patients would remember to bring their completed surveys.
- Possibly a few DNAs.

What actually happened?

- 6 of the 8 patients completed the PAM questionnaire prior to arrival at the clinic and required little or no assistance.
- One patient was a late add on to the clinic therefore had not been sent any info other than their clinic appointment. On arrival the patients were asked if they would like to participate

and were given the PAM questionnaire and an explanation about the trial which they were happy to complete.

- One patient was visually impaired and slightly hard of hearing. They had filled out half of the questions and required help from the expert patients to finish. This took about 20 minutes.
- One patient needed reassurance that she had completed it ok.
- One patient had asked at outpatient's reception where to hand the survey. The reception team presumed it was a friends and family survey and the patient therefore posted it in the friends and family post-box.
- We had no DNAs
- Two patients asked if the mobility question applied specifically to their renal related health or their whole health including other health issues. They were not sure how to answer this.
- Three patients did not fill in their unit name as did not know what to write. Answers Inc. Kidney/Derriford/Plymouth??
- All patients had positive reactions to the PAM trial.
- Whilst patients were waiting we asked how they got on completing their surveys and if they had any questions.

What did we learn?

- It was a positive exercise for all involved.
- Environmental factors need to be considered. Each team may encounter different issues depending on location.
- There was no privacy to support patients on answering questions as the waiting space outside the clinic room is in close proximity to other patients and can be overheard by everyone. This is not ideal as the nature of the questions is of a personal and confidential manner.
- There needed to be clear direction where and who to hand in the PAMs to.
- We needed to inform the reception team that we are also running a survey and how to redirect patients.
- Patients found the mobility question slightly ambiguous.
- Clinicians needed to add post it notes with their thoughts as they didn't want to write on the PAM directly.
- Patients queried whether they needed to include their other health issues on the responses or answer only from a renal perspective?
- Time frame - it worked well sending out the PAMs in the post a fortnight prior to the appointment.
- Patients said that their answers varied from one day to the next.
- Patients suggested there could be space to write additional supporting comments to some answers.
- Patients requiring support to complete form would heavily impact the normal speed of any clinic. Additionally the clinician evaluating the PAM and explaining the process required extra time. A double clinic time slot should be considered.

What will we do differently as a result?

- Confidentiality is very important to consider and a solution for this will be discussed by entire team
- Inform the patient to hand their survey to the nurse that calls them through to clinic
- We need to inform outpatients department of our survey to avoid confusion

- Possibly add a contact number in the covering letter for patients to call with any queries or questions in relation to their survey. This should hopefully reduce time taken within the clinic appointment
- Put a box on the outcome form to indicate if the patient would prefer the letter directly addressed to them or the GP
- Consider a page for additional comments
- Consider a frequently asked questions page to help support patients
- Consider a place for the clinicians to write notes.”

Caroline Adams
Chronic Kidney Disease Health Care Assistant



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