

# Participation of patients and carers in Quality Improvement: lessons learnt from the ASSIST-CKD (Chronic Kidney Disease) project

Rose T<sup>1</sup>, Harwood, S<sup>2</sup>, Lumsdon A<sup>2</sup>, Thomas N<sup>3</sup>  
<sup>1</sup>ASSIST-CKD Patient Project Team (PPT),  
<sup>2</sup>Kidney Research UK,  
<sup>3</sup>London South Bank University

## Background

The ASSIST-CKD quality improvement project, managed by Kidney Research UK and supported by The Health Foundation, focuses on scaling-up an intervention that reports kidney function (eGFR) graphs over time to primary care. The aim is to identify patients at highest risk of CKD progression - a simple concept which not only offers value for money but also a real chance to improve renal patient journeys.

Using this system, one NHS Trust in Birmingham has reduced the number of patients starting dialysis by 16% and has the lowest percentage of patients presenting late for dialysis in the UK (associated with poor outcomes and greater cost). GP feedback has also been very positive<sup>1</sup>.

The project involves around 20 renal units, 25 pathology laboratories and their surrounding GP practices, covering an estimated population of over 11-12 million people. The first 4 sites commenced graph reporting in Autumn 2015 with the others starting the programme in stages up until early 2017.

## Integral participation to improve the patient journey

We know that patient involvement is comprehensively associated with a study's success & benefits.<sup>2</sup> Patients have been involved from the earliest stages of this project, and members of our UK-wide Patient Project Team (PPT) are now making a key contribution throughout the project, helping spread and sustain the intervention as well as ensuring changes to service delivery and patient outcomes as the project evolves.

## A pioneering approach

Members of the PPT offer unique and valuable insights through both personal experience of kidney disease, including two who had late referrals to secondary kidney care, as well as their wider commercial and professional experience. They are 'informed' advisors, helping achieve success and adding real value by maximising every milestone through an effective external communications plan as well as contributing to purposeful and controlled governance to help deliver longer-term sustainability. See some of their stories below:



Amjid Ali, was on dialysis for over 23 years before receiving a living related kidney donation. Now retired, he was previously a career banker and has had extremely valuable input into the development of a cohesive project business case to local commissioners, supporting participating renal units seek ongoing funding to support the intervention.



Rob Finnigan, underwent a transplant in 2003. He is a member of the project's Evaluation Advisory Group and is also helping shape the Communication workstream strategy. He is drawing on his experience with the Greater Manchester Kidney Information Network and is working with both local kidney patient groups and renal unit's media teams on how best to promote the project to maximum effect. Rob shared his personal kidney journey and the impact late referral has had on his family, at a project learning event which was very effective in giving the biochemists involved a better understanding of how CKD can impact patients.



Ama Basoah is a locum GP and long term dialysis patient. She is member of the project's Advisory and Dissemination Board, and is giving practical and effective guidance as voice of primary care - what happens on a daily basis in GP surgeries which can impact the success of the project.

“When I shared my patient journey at a Cardiovascular Disease Network GP renal event, it highlighted to me the importance of sharing personal experiences with primary care specialists to increase understanding of the challenges of being a renal patient. It also added to the work I do on behalf of NHS Blood and Transplant with Muslim faith leaders and community influencers to increase awareness and engagement amongst the diverse Muslim communities in the UK.”

“By sharing my experiences of living with kidney disease, and the physical, social and psychological effects it has on those affected, I hope to raise awareness of the often devastating impact a diagnosis can have. If the ASSIST-CKD project can prevent even a small number of people from developing kidney failure then it will be worth every penny spent and every man hour worked on it.”

“I am at a stage where I may be able to help patients and families who may have or be at risk of kidney disease as I am both a patient and a GP.”

## Discussion

Kidney Research UK has input from patients and carers throughout our many approaches to research and including quality improvement projects. A key aspiration of the PPT group for ASSIST-CKD is to identify key learnings which can be used in future projects as a template for patient and public participation. This includes role descriptions and payment for PPT members, and full integration of the PPT into project activities. This will be augmented by careful evaluation of the true impact of the PPT which will be vital to sustain such involvement in the future.

## Further information

For further details on the ASSIST-CKD project please contact [assist@kidneyresearchuk.org](mailto:assist@kidneyresearchuk.org) or visit: [www.kidneyresearchuk.org/assist-ckd](http://www.kidneyresearchuk.org/assist-ckd)

References:  
<sup>1</sup>Rayner HC, Baharani J, Dasgupta I, et al. SA. Does community-wide chronic kidney disease management improve patient outcomes? *Nephrol Dial Transplant* 2014; 29(3): 644-9

Early detection  
Improved care

ASSIST-CKD:  
A person-centred  
system that highlights  
patients at greatest  
risk of end stage  
kidney disease

Saving money  
Saving lives

### Benefits to GPs

- Identifies small number of high risk cases prompting earlier referral
- Prevents inappropriate referral and reduces on-going hospital follow up of patients with stable kidney function
- eGFR report signposts to CKD guidelines, referral options and offers specialist interpretation

## A symbiotic voice across all the project's workstreams...

“this is the first time associations with study success have been identified for patient involvement. Researchers might now consider ways to involve patients more comprehensively as this is associated with study success”

<sup>2</sup>Impact of patient involvement in mental health research: longitudinal study.  
Ennis and Wykes: *Br J Psychiatry*. 2013 Nov;203(5):381-6

## Patients telling their own stories and sharing their experience so that others don't have to do the same in the future.

Project supported by:



**Kidney Research UK**  
Funding research to save lives