

Learning from... patients and professionals working together to improve kidney care

Practical examples from four leading quality improvement programmes

LEAD AUTHOR: Professor Martin Wilkie MD FRCP Sheffield Teaching Hospital NHS Foundation Trust, Sheffield, UK

CO-AUTHORS: Amjid Ali, Andy Henwood, Catherine Stannard, Claire Corps, Dela Idowu, Kirit Modi, Nick Selby, Ranjit Klare, Sonia Lee and Tracey Rose.

Contributor profiles

Amjid Ali was diagnosed with Chronic Kidney Failure in Oct 1987 at the age of 20 and spent 23 years on home dialysis before receiving a living related kidney donation in May 2011. He is Partner and Project Lead for the 'Transplantation in Islam' initiative for NHS Blood and Transplant, and BAME Engagement & Inclusion for Kidney Care UK.

Andy Henwood is a transplanted Haemodialysis patient and considers himself a patient advocate. He was the Patient Lead on the Shared Haemodialysis Care programme and a contributor to the Kidney Services Improving at Scale report. Andy is also the co-founder and Co-Chair of the newly created Kidney Patients Involvement Network (KPIN).

Catherine Stannard is a Quality Improvement Programme Manager, working for the Kidney Quality Improvement Partnership (KQUIP). She works in partnership with renal units, kidney patients, clinicians and academics, supporting national quality improvement initiatives and change programmes to improve the lives of kidney patients in the UK. She is currently working with renal teams in the East and West Midlands to improve the quality and uptake of home dialysis, as well as supporting the national paediatric network.

Dr Claire Corps had a renal transplant as a child in 1980 following two years of haemodialysis, and a liver transplant in her twenties in 1997, both of which still work extremely well. She now works as a Senior Research Scientist working in the field of Organ Preservation for Transplantation at the University of Leeds and St. James's University Teaching Hospital, Leeds. She has worked on patient and public involvement on many projects both regionally and nationally. Claire co-chaired the Measurement Workstream in the TP-CKD project and has continued to help evolve the Kidney Patient Reported Experience Measure ever since.

Kirit Modi is a kidney transplant recipient. He has been involved in promoting organ donation and supporting kidney patients for many years, in a voluntary capacity. He is President of the National Kidney Federation (NKF), a founding member and Hon President of NBTA (National BAME Transplant Alliance) and Chair of the Lister Area Kidney Patients Association (LAKPA). Kirit is also Chair of the Jain and Hindu Steering Group on organ donation (JHOD), has frequently spoken to the All Party Parliamentary Kidney Group and has written two Manifestos for Change; one on BAME issues and one on living kidney donation. He is a member of the project board for two NHSBT programmes; the Community Investment Scheme and the Living Transplant Initiative.

Professor Nick Selby is a clinical academic with primary interests in Acute Kidney Injury (AKI), Magnetic Resonance Imaging (MRI) of the kidney and the haemodynamic consequences of dialysis. He led the development of one of the first e-alert systems for AKI in the UK and is clinical investigator on several investigator-instigated studies in these areas including the Tackling AKI study and the AFIRM study. Since 2011, Dr Selby has been awarded peer-reviewed grant funding from NIHR, MRC, the Health Foundation, Kidney Research UK and British Renal Society, and he has published over 80 peer-reviewed articles. Dr Selby has several national and international AKI roles.

Martin Wilkie is a consultant renal physician with a particular interest in supporting individuals to take a role in their own dialysis care. Martin lead the Shared Haemodialysis Care programme, co-authored the recent Kidney Services Improving at Scale report, was Editor in Chief of *Peritoneal Dialysis International* until this year, and a strategic lead for Yorkshire and Humber NIHR Clinical Research Network, leading a project on mechanisms to enable participation in COVID research for people from BAME communities.

Dela Idowu is the founder of Gift of Living Donation, an organisation that works to raise awareness of living donation in the Black Community. She is the author of *More Than a Match*, a book she wrote after coming forward as a living kidney donor for a family member. She is also the writer and producer of *We Are Family*, a living donation educational film.

Ranjit Klare is a Quality Improvement Programme Manager for Kidney Quality Improvement Partnership (KQUIP) working in the North East of England. She works in partnership with renal units, kidney patients, clinicians and academics, supporting national quality improvement initiatives and change programmes to improve the lives of kidney patients in the UK. Ranjit has 11 years of experience of operational and strategic management within the Public and Charitable sector.

Sonia Lee - Working out of the Sheffield Teaching Hospital NHS Foundation Trust Sonia Lee was the programme manager for the Health foundation funded Shared Haemodialysis Care (SHAREHD) Scaling Up programme having previously, and for the majority of her career, managed large scale software developments in the private sector. She led and co-authored the *Kidney Services Improving at Scale* report and is a member of the Health Foundation Q community.

Tracey Rose has been actively involved in the kidney community for the past 25 years since her eldest daughter was diagnosed with End Stage Kidney Disease as a teenager. Since then both her daughters have undergone three kidney transplants for a still undiagnosed kidney condition although her son is not affected. She is a living organ donor with personal experience of all aspects and impacts of kidney disease. Tracey has been Trustee of Kidney Research UK, patient member of NHS Renal Clinical Reference Group, and taken part in several Quality Improvement and research projects.



This paper summarises a webinar we presented on July 14, 2020, in which 150 patients and professionals discussed key questions around the practical aspects of working collaboratively together to improve kidney care.

Our learning was based on a report that examined four improvement programmes in kidney care, focussing on the learning around effective patient participation.¹ Our panel included individuals who had participated in those programmes, as well as additional members with considerable experience in this area. We developed and tested key questions relating to aspects of patient involvement that came from the report, and supplemented the work with insight from a focus group with wider stakeholders that was held in May.

The objective of the webinar was for patient partners and healthcare professionals (HCPs) to talk about what it feels like to work together in an improvement programme in kidney care and to understand the challenges, the successes and enablers to patient participation. Below we summarise some of the questions and the responses from the panel members with the goal of drawing attention to the webinar which you can listen to.² The full transcript of the webinar is also available to view online.

Questions and answers

Q: What are the benefits of involving patients in the setup and running of a programme?

TR: Patients are the people who are going to be affected by change. Although medical professionals will have their opinions, it's the patients who know what they want and what works for them.

AA: I was approached and invited to support the ASSIST CKD project at an early stage. As a patient this was very reassuring. Patient involvement can be more value adding if we are given the opportunity to help co-design programmes of work based on lived experience. All of my feedback, guidance and constructive challenge was positively received. Ideas and suggestions were discussed in a manner that encouraged me to be an active participant.

Q: How can involvement be tailored to the availability of the participating individuals?

TR: We tried to involve patients with different backgrounds and skill sets – e.g. Amjid had financial expertise and we had a GP who was a dialysis patient. Also, it was important to have widespread geographical representation and to ensure members' opinions were valued.

Q: What are the most effective ways to involve people from a range of backgrounds?

AA: Involving and securing patient involvement from diverse backgrounds is essential but can be difficult in practice. From my experience, patients can be concerned that they are being asked to participate purely as a 'tick box' exercise. Project leads must reach out to patients in a manner that demonstrates a respect and understanding of cultural differences.

Q: What are the benefits of involving more than one patient?

AH: The last thing we want is for a patient to think that they are tokenistic – we need to make sure that there is more than just one patient engaged in the programme. Equally, the inclusion, diversity and cultural make up of that of that group is important; age, gender, ethnicity and social background. The more patients and the breadth of experience you have, the better representation you will have to help guide the programme. We also need to consider that patients inevitably suffer from illnesses, sometimes at short notice, which will deplete patient representation. Being an only patient can be a lonely place with no one to turn to for help or guidance.

Q: What is the right balance of patient representatives to healthcare professionals? How do you strike that balance?

KM: There is no magic number for the right balance. We need to ask the question as we go through the project: are we giving equal voice to the patients and have they got a leadership role?

Q: What things should we consider when we are identifying potential patient roles?

AH: It's a bit like when you are having a job interview – the patient and the clinician (or researcher) needs to have a clear understanding of what is expected of the patient and what the programme involves. It's important to say from the beginning that patient should not be seen as a free resource – they are not just there because they are free – their time is golden time.

AA: Being clear about the 'ask' of patients is key to success. Introducing a 'Balance Scorecard' that clearly states the aims of the programme of work and the broader context in which the work sits is beneficial. This helps all participants keep focus and helps to identify areas where there is a knowledge gap. Patient involvement should be on the basis of mutual trust and respect. The primary role of the patient should be confirmed at the outset; Advisor, Information Source or Critical Friend. This will help define their role and degree of influence across the programme of work.

Q: Everyone is different - how do we identify an individual patient's strengths and support them to gain confidence to use them?

TR: I really talk to people in the beginning – we have separate patient group meetings and encourage people's views, skills and opinions, to make them feel confident...the more you get involved in this kind of work, the more confident you become.

Q: How can we help patients gain the skills they don't have so they can be more engaged and add value to the programme?

AH: The idea of the Kidney Patient Involvement Network (KPIN) was that we would start with few patients who had experience and share those experiences with less experienced patients or carers – we are not a training provider, but we

are looking at how we can support simple aspects like confidence, engagement and involvement practices for those that would value some help.

Q: Did you know what you were letting yourself in for? Was it more or less what you expected?

CC: When I was asked if I was interested in being involved in Transforming Participation in Chronic Kidney Disease it seemed like a great idea – it was looking at patient outcomes and experiences and I was using these measures in my work. I thought great – no problem – we can do this. But it was so much more than just analysing data...we had to decide which patient reported measures we were going to use... initially the professionals said 'it's ok we'll do this and then we will come back to you (the patients)' – which of course the patients were not too keen on. They said 'no, its about our experience, let us tell you what we want'. Neither of these were going to work so we eventually agreed to sit down together, write down what we wanted and look for common trends...We compromised and we worked together.

AH: I recall walking into a room of clinicians for the first time. Whilst it was daunting it was something I was used to – that said, there are a lot of patients and carers who are not used to doing that; and if not handled correctly the experience can be very off putting.

NS: We can always get better – each time we do a project or a research study we will find something that we can learn from and improve upon the next time.

MW: I had no idea – I was very nervous as I thought if I organised a meeting with lots of patient partners they would start to tell me what they really thought and I would get into serious trouble.... however I quickly learned that whenever we took a patient partner with us to a meeting, the patient story was the thing that really turned the heads of the people we needed to influence – they made such a huge difference.

Q: Do you think that the sudden familiarity with zoom and other video conferencing tools as a result of COVID-19 will change the accessibility of renal patients to get involved? How can this be harnessed?

KM: There is a huge revolution in terms

of virtual ways of working and this will continue for the foreseeable future. I was invited by The Vanik Council UK, to a webinar they organised – this was a combination of religious, entertainment, yoga and health issues. I was quite apprehensive about turnout, but we had 250 people on a Sunday afternoon taking part – I spoke about the change in transplant law from a Jain perspective, and they produced a YouTube video of this so 1,000's of people have now heard it. None of those 250 people would have dreamt of using zoom 6 months ago. This is really a revolution.

Q: Within your programme what peer support was available? Did it work? Could it have been better?

AH: The type of peer support comes down to how much involvement you have at the beginning (understanding the various types of support available), which may well define how you setup the peer support within the programme. It cannot just be two people talking to each other – it needs to have some thought and meaningfulness. It cannot be something that you just slam together – you can do as much damage through bad peer support as you can good.

Q: Is it possible to re-design kidney care in conjunction with kidney patients? Where are the best examples?

NS: We can learn from how the patient voice is really embedded into the research world now. Quality improvement (QI) is in that grey area between delivery of health care and research – but there are some good examples of how patient groups and patients take roles throughout the design, development, oversight and leadership of research projects and all of those messages apply to the structure and the working of QI as well.

Q: To what extent are HCPs ready and willing to give patients an equal voice and allow them to have a leadership voice in improving renal services?

KM: We know from patient surveys that Shared Decision Making is an area of development nationally and that we have a long way to go to meet the ambition of 'No decision about me without me'. A cultural change is needed both among HCPs and

patients for us to achieve this. In this context, enabling patients to have an equal voice in improving renal services is a challenge. We need to have frank dialogue about how we can achieve this and both kidney patient groups and HCP groups need to take responsibility for making this a reality.

There are some examples of good practice we can learn from. One is the Community Investment Scheme (CIS) which is led by NHS Blood and Transplant (NHSBT) to empower BAME community groups to promote organ donation in targeted communities.³ The Advisory Board for the CIS consists mostly of BAME patients. The Board has responsibility for determining how this funding should be targeted and advertised, it goes through all the applications received and makes decisions on the successful ones, it helps to monitor and support individual projects and helps evaluate the impact of the scheme.

Q: How do you build and maintain trust?

AA: For BAME participants in particular, building trust and confidence in a QI programme comes through actively promoting equality of opportunity for all and ensuring no one receives less favourable treatment. Having a clear framework or 'balance scorecard' that clearly defines the objectives and measures on a single page document written in plain English ensures that everyone understands the ask and helps the participant prepare appropriately for meaningful engagement and dialogue.

Recognising that success depends very much on the Project Lead's ability to demonstrate a respect and understanding of the cultural differences and different lived experiences. Relationships built on mutual trust, respect and responsibility encourage active participation and create a sense of value for the participants.

Q: What structures should we have to enable longer term support for patient partners?

AH: There are some patients who, once they have done elements of their involvement, then that's enough, they are quite happy to move on with their lives; for others, perhaps their interest has been raised and they wish to help further. One of the things that KPIN are looking at is how we can capture that experience and how we can look after patients who wish to remain involved with programmes or activities in the future. It was thought that if they joined a patient network then they could share their experiences and skills, learn from others and view more opportunities as they arise.

Reflection

DI: I sum up my reflection of the webinar in three key words – Change, Collaboration and Commitment.

CHANGE

Now is the time to change the narrative and encourage patients from all communities to get involved, especially patients from BAME communities and those from a range

of social backgrounds. They have powerful voices that can effect change at a variety of levels. This will enable patients to add their voice to key decisions that are being made.

COLLABORATION

Working in collaboration with patients is vital, as is the diversity of patients, as this will build better healthcare structures and systems, improve quality of care and remove many of the institutional barriers which have created health inequalities in BAME communities.

COMMITMENT

We must be committed to ensure that patient involvement is not just a buzz word but a key priority to improving the quality of care for patients. The strength of that commitment will take healthcare providers, organisations and patients all working together.

I believe that the webinar must be the catalyst for change if we never want to witness the crisis and health inequalities that affected the Black and Asian communities during the pandemic – and if we say Black Lives Matter. We have the opportunity to bring about change but it is important that we focus on the solution and not the problem.

The solution cannot be token gestures of promoting people from BAME communities into higher positions or commissioning yet another report on systemic racism and health inequalities, there needs to be a complete reconstruction of the current healthcare system for things to change, and this can only be achieved at a government level through policies and more funding. It can no longer be a question of 'the system is not broken so why fix it?' The system is broken and it needs fixing urgently - and the answer to that is patient involvement.

For a recording of the webinar, full transcript, information on the panellists and the *Kidney Services: Improving at Scale* report, visit the following website: <https://kpin.org.uk/learning-frompatients-and-professional-working-together-to-improve-kidney-care/>

References:

- <https://www.thinkkidneys.nhs.uk/kquip/hub/kidney-services-improving-at-scale-qi-learning-report/>
- <https://kpin.org.uk/learning-frompatients-and-professional-working-together-to-improve-kidney-care/>
- <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/19105/community-investment-scheme-progress-report2.pdf>

Summary of key learning points

