

KPIN Kidney Services: Improving at Scale Webinar (held on 14 July 2020): Question and Answer Transcript

Participants outline replies:

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Theme	Question / comment	Panellist	Answers
Involve more than one patient	Andy , how difficult was it to get other patients and staff to become engaged and were more resources required?	Andy	Yes it is difficult, but it depends on the desire to co-produce activities with patients. Part of this has to be about having patients involved at the very beginning and being able to talk to other like minded patients and convince them of the benefits of being involved; then supporting and listening to them when they are involved and actually helping to solve some of their issues.
		Sonia	Agree with Andy - we ran a '3rd' wave and asked all trusts to submit a request if they wanted to get involved - we had 6 places and actually had 18 submissions.
		Andy	It did require more resources - we designed our own (taken from various attempts) for both HCP and patient. These are on the Shared Care website and will be on the KPIN website.
	A greater number of patients involved in a project can help overcome perceived power differences between researchers and researched (particularly where the latter are minority groups)		...this is a very good point and very true.
Be clear about expenses and remuneration	Any advice on volunteer roles versus paid roles when developing patient roles?	Sonia / Andy / Tracey	I've been involved in projects and programmes on both sides of this - but happy to discuss more options Good information on this is available at KPIN.org.uk. - with detail on payment for patient involvement.
Be genuinely representative	How about patients who because of their background, life experiences or health (both physical and mental) faced significant barriers to participate in group work/co-production activities? How did you engage and involve them? For example Looked After Children, Young People Leaving Care or Travellers?	Sonia	That is a very good point and possibly not one that was done as well as could have been within the programmes covered in the report. But as confidence grows that involvement and inclusivity is possible then finding ways around these barriers is possible. It is – as Amjid said – about working with that particular group or individual to understand who are the influencers and how to build a trust that will enable co-production. Not easy and not a simple one size fits all fix.
	Getting adequate representation is important but in reality only few usual suspects turns up. Most KPA membership itself lacks diversity and engagement to hard to reach voices	Kirit	I agree this is a challenge for us. As Chair of the Lister Area KPA, it is my responsibility to reach out to patients to encourage them to take on roles within our KPA and we had had some success with this. We have also been successful in having patients/carers from BAME background on our committee but this is a priority for the NKF and we are considering how we can address this. We clearly need more patients from BAME background as role models.

Be genuinely representative (continued)	Why do you think Black patients and Donors do not participate as Representatives? Is trust an issue?	Dela	Black patients don't participate as they are often made to feel that their input is not valuable. We need people to be involved in order for the problems to be identified and fixed. We also need to understand what how and why they think their input is not valuable?
	Thank you for showcasing some fantastic work and for rightly highlighting the issue of patients from BAME backgrounds and those from more challenging SE backgrounds. What are your thoughts about how we include older and frailer patients and those who will never be able to benefit from a transplant or a home therapy in designing the service as their voice is so often not sought and rarely central to service design - many thanks	Andy	Involve them. We have a patient working with KPIN who is the other side of 80 and is going to prove to be invaluable. Life is rotten for many people but if we do not involve those that want or would like or indeed need to be involved, then their time on treatment is going to be depressing. We should be inclusive at all levels!
		Sonia	Perhaps a bit of work on how clinicians or staff communicate with patients to ask for their help may be the key here. The other consideration is the annual PREM (Patient reported Experience Measure) survey that is annual and should go to all - all patients have the opportunity to complete that and the results are seen nationally with comparisons being made between centres.
	It's important when talking about representation to understand that BAME is not a monolith, so patients from all minority ethnic groups should be represented because the contributions are uniquely different and valuable to provide a diverse service. I'm sure Dela would have pointed this out if asked.	Martin	I absolutely agree. There are major disadvantages in the BAME term - it clearly covers a range of communities with different characteristics. However, that is the term that is used widely and it is difficult for us not to use it.
Match involvement to motivation	As a patient and now a qualified youth worker working and supporting young people through their health but also as a renal lifer would like to help with how life can change for them and tips and tricks I've picked up.....but again no idea how to do thissorry not a question but I think it's an example of how sometimes patients with skills and experience sometimes don't know how to engage and get involved	Andy	I think it sounds that you are doing lots already. I would just say to keep getting involved - perhaps contact KPIN or your local Kidney Patient Association will be good points of contact and/or tell your consultant you want to get involved www.kpin.org.uk
Foster co-production more broadly	I've emailed KPIN now and I am part of my KPA but it seems my KPA is about to be dissolved as lack of interactions with patients engaging	Kirit	NKF keeps regular contact with all its KPA members through Mark Davies, our KPA Liaison Officer. We know about the KPAs which are struggling and provide them with all the support we can. Our aim is to increase the number of KPAs which are members of the NKF.
	To what extent are HCP ready and willing to give patients an equal voice and share leadership with them?	Andy	Not easy but do-able. The more patients we have involved who are able to make a valuable and impactful contribution through co-produced work then the easier it will be. "We should celebrate the skills that patients have, not feel sorry for the illness they live with".

Foster co-production more broadly (continued)	How do we implement our ongoing shared care programme during this current climate?	Sonia	We have been truly inspired by the ways that teams have been innovative with shared care during this current climate. We have heard of teams starting or extending their shared care programme specifically to enable their patients to have the choice of going home during lockdown /shielding periods for example so they do not have to come into the hospital setting for their dialysis. The use of virtual meetings and social media means it is quite easy to share ideas with others or to ask for support from other staff or your own patients perhaps. I suggest you look on the shared care website https://www.shareddialysis-care.org.uk or contact tania.barnes1@nhs.net who will be more than willing to discuss things with you.
	Besides the 51 full NKF Member KPA's across the UK that Kirit mentioned, I have also identified there are around 25 other KPA's who are not currently fully affiliated to the NKF.	Kirit	Mark is right. We are encouraging Kidney Patient groups which are not our members to join the NKF. Our membership has recently gone up; from 51 to 53!
Involve patients early	Difficult question for nick: what is the one single thing that you find challenging working with patients to improve the service?	Nick	Difficult to answer in a single point! However, I think the hardest thing is establishing initial engagement from a situation in which there are no established structures. This is the part that requires most effort and time, and also the point where trust is still being established (at later points, conversations become more natural) and other ways of working (e.g. via email) become possible. Once a group is established, it gains its own momentum.
Develop review mechanisms	One way to build trust, is to have an equality policy for all programmes. It is a legal requirement for all public bodies to have an equality policy, with a publish action plan. So their could be an equality policy for each programme which Amjid's suggestion would accommodate.	Amjid / Andy	For BAME participants in particular, building 'Trust & Confidence' in a Quality Improvement 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 is able to prepare appropriately for meaningful engagement and dialogue. Recognising that success depends very much depends on the Clinical and Project Leads ability to demonstrate a respect and understanding of the cultural differences and the different lived experiences. Relationships built on mutual trust, mutual respect and mutual responsibility encourage active participation and create a sense of value for the participants. We also have other ways for example 'Terms of Reference' for patients that are involved, induction processes, team building activities etc. Everyone involved needs to understand and demonstrate 'respect and understanding' of each other's cultural difference and lived experiences.
		Sonia	This is a really good point that we will pass onto The Health Foundation as a suggestion that they build that into their bid process. KQUIP could also perhaps look to build a template that programmes both national and local could use.