

KPIN Kidney Services: Improving at Scale Webinar (held on 14 July 2020)

Transcript

Welcome & introductions

Hello everyone and welcome to this webinar we are very excited to share with you this afternoon.

This webinar is around patients and professionals working together to improve kidney care. I'm Martin Wilkie and I'm a renal physician in Sheffield and along with the team who you will meet and with others we have been working on looking at aspects of patient participation in 4 quality improvement (QI) programmes across renal and we will be talking more about that as we go through.

This webinar involves our patient partners and colleagues talking about what it feels like to be a patient participating in a QI programme within renal and to understand the challenges and the successes the enablers around that. So that is what I will lead you into shortly.

It's really been a journey coming to this point we have worked out way to a series of questions canvased and involved a group of people and distilled ones we think are really important to answer but of course this is part of an ongoing dialogue and we are very much looking forward to your involvement too.

Next slide please.

We have on this webinar today 285 delegates or registrants. Of whom 58 are patient partners which is excellent. 65 registrants are from Black and minority ethnic groups and we think that is very important too. I'll update you more data on who the registrants are as we go through.

This slide gives practical housekeeping points – we will be dealing with questions during the discussion session at the end. Please put your questions into the question and Answer button which you can find at the bottom of your screen and we will collate those - you can vote on questions as you see them to move a question up and give them a priority

Some questions will be answered during the webinar if they are practical and our team can respond to you otherwise we will pick them up during the discussion at the end

If you have any technical issues put these in the chat box and we will try to resolve those promptly.

Just to say IT can be a pain – there are things you can do if your IT is not working properly like logging in and logging out and we will go onto mute during apart from those who are speaking. Now my privilege to hand over to my co-chair Claire Corps who will introduce herself and the rest of the wonderful panel that we have her this afternoon so thankyou Claire

Introductions (2:57)

Thankyou Martin, Hi my name is Claire Corps and I have been a renal patient since I was 8 years old. Following 2 years of conservative treatment and 2 years of haemodialysis I had a kidney transplant and I celebrated 40 years of that the other week. So it is still going strong. I now work as a Dr of research science in the department of transplantation at Leeds and over the years along with lab work I have done clinical trials working on several projects to do with QI both regionally and nationally and as such I am a person who can see both side of the coin sop to speak and as such have been asked to sit on several boards such as UK renal trials network and KQUIP.

As Martin said I am one of the co-hosts but I would now like to introduce you to our panel – so to start with Sonia.

Hello – my name is Sonia Lee. I was the Programme manager for the Shared haemodialysis Care programme working with Martin and Andy who are on this call for the last 4 years. I also managed and co-wrote the Renal Services: Improving at scale report and so really pleased that this learning is being shared with so many of you here today.

As the daughter of a renal patient who dialysed at home and had a kidney transplant back in the mid 80's I grew up with the impact of renal failure not just on my father but on the rest of the family especially in terms of what eat at meal times but also the mountains of medical paraphernalia that was stored in open shelves in what was my bedroom before I was kicked out and it became the dialysis room.

The world is constantly moving, sometimes slowly and sometime like at the moment very very fast and continuous change is inevitable so for me being involved, listening and helping to draw those voices together to move in the agreed direction of travel of patients and professionals is what being a programme manager in health is actually all about and why I am honoured to be here today – thankyou.

Thankyou Sonia I would now like to introduce you to Andy.

Hi my name is Andy Henwood and firstly I would just like to thank everybody for giving me the opportunity for being involved with this presentation and the build up to it. I'm a kidney patient and have been a kidney patient for now about 13 years or so – I had a short time on pre-dialysis, 4 years on haemodialysis, and then have been transplanted ever since. Through after I suppose about a year of being on dialysis I then got into being a patient representative for various quality of life aspects for patients started on the shift which involved the hospital and then it evolved into doing aspects for and within the region and local implementation groups. I then moved onto being a patient partner specifically within the shared haemodialysis care programme – the first one which was Yorkshire and Humber and that ran on for about 2 years after that we had a little bit of a break where I went back into doing as much of the things that I could for the hospital and then was asked again by Martin to be involved with the scaling up programme called shared haemodialysis care or SHAREHD and that was very much about trying to encourage patients to be more active where they wanted to be in their own care and to maybe let some of the healthcare professionals release some of that responsibility to those patients that wanted it. And on that second programme I was the patient lead so. Part of that has opened our eyes in terms of how can we help patients to become more involved hence we have since come up with and co-founded the Kidney Patient Involvement Network (KPIN) which you can see on the screen behind me for which I am co-chair. SO once again thank you and I am also privileged to be here today.

I would now like to introduce Amjid please.

Good afternoon everyone, my name is Amjid Ali and I am a kidney transplant recipient. I was diagnosed with Chronic Renal Failure at the age of 20, with no history of kidney disease; I spent 23 years on home haemodialysis before receiving a living related kidney donation from my nephew in May 2011. As a dialysis patient I was fortunate enough to maintain a full-time role and spent 26 years at HSBC. I took early retirement in June 2012 based on medical advice.

My work today and what has led me to being here today is on the back of the role I have with NHS Blood and Transplant which is Partner and Project Lead, Transplantation in Islam initiative on behalf of NHSBT is what brought me to the attention of Tracey Rose who invited me to support her and the team with the ASSIST CKD project. Securing an updated religious edict on Organ Donation in Islam in June 2019 and my contribution as an Advisory Panel member on various health forums that I sit on has also led to my appointment as Partner, BAME Engagement and Inclusion Lead, Kidney Care UK.

I hope that my contribution on the various health initiatives that I have had the privilege to support has helped to increase awareness and understanding of the value of engaging patients from diverse backgrounds. And It's a wonderful feeling to be able to give something back to the NHS in light of all that they have done for me and my family and its an honour and privilege to be here today.

Thankyou Amjid I would now like to pass you over to Tracy.

Hi thankyou very much Claire. My name is Tracey Rose I have been actively involved in Kidney Care for the last 25 years when one of my eldest daughters was a late diagnosis and had end stage renal failure. I have 3 grown up children now and 2 of them have had 3 transplants between them so over the period of 25 years I have been involved in Peritoneal dialysis, home dialysis and I have been a living kidney donor myself which was 20 years ago. I have been really involved because I am someone who needs to ask lots of questions we still don't a diagnosis for my families kidney failure and that led me to ask lots of questions and I became involved with Kidney research ULK and was a trustee there for 6 years. As a result of that I also became involved in some of their quality improvement patient projects and research projects. At that stage when I was first asked to become involved I had no idea what quality improvement was, I had no idea what scaling up was, but I have been delighted to be involved in a few projects and latterly was the CKD patient lead on that.

I think one of the points that people forget is that kidney patients and not just kidney patients they very often have important role behind them and other attributes and skills which also add the voice of patients and their roles and how they can be really important on really changing the scale , changing the pathways of kidney care and making it better for patients everywhere and I think nobody should be scared to think that their voice does not matter because every bodies opinion is vital and nobody can be better than the patient who is actually receiving care.

Thankyou Tracey I would now like to introduce Kirit.

Hello everyone my name is Kirit Modi I am a transplant recipient my first transplant was a living donation from my wife and my second one was form a deceased donor. I am the president of the National Kidney Federation (and Chair of the Lister Area Kidney Patients Association) and as most of you will know NKF is the largest Kidney patients' charity run by patients for patients in the UK. Firstly I have gained a great deal by offering my support – my health has been good because of the transplants – on a voluntary basis for many years. Just to give you a couple of examples I believe in change and through the NKF and the support of the all-party parliamentary kidney group I led on the writing of 2 manifestos for change one on living donation and one on BAME matters and I think both have resulted in improvement for kidney patients. I have obviously gained a great deal personally – a great deal of satisfaction that my health has enabled me to give something back to support other kidney patients. Thankyou.

Thankyou Kirit I would now like to introduce Dela.

Thanks Claire good afternoon my name is Dela Idowu I am the founder of Gift of Living Donation. This is an organisation that I setup after coming forward as a living kidney donor for my brother. We mainly raise awareness of organ donation within the black community. I am the author of "More Than a Match" a book that I wrote about my journey and my family's journey as a potential living donor and all the emotions and the different things that go into that. I am also the writer and producer of "We Are Family", a living donation educational film that talks about kidney failure in the black community. Last year we organised the first ever event in the UK where we brought together over 200 black living donors across the UK so primarily our work is to raise awareness of living kidney donation in the Black Community and has worked in collaboration with a number of health care providers to effectively engage black patients with CKD.

Thankyou and finally I would like to introduce Nick Selby

Good evening everybody my name is Nick Selby I am a professor of Nephrology at the University of Nottingham and a consultant at the Royal Derby Hospital. It is a great pleasure to be here and I have got to admit that it is a first for me presenting in a webinar so looking forward to it. I think the reason that I am involved in the panel tonight was that I was the chief investigator for the Tackling AKI study. This was a Quality Improvement programme that was designed to improve standards of care for patients who sustained acute Kidney Injury and that was a programme that was rolled out across 5 UK hospitals within the framework of a research study so we could also evaluate the effect of that. So thank you and looking forward to taking part.

Thank you Nick we will now start with a presentation by Sonia please looking at the background to the report which we are going to talk about. Over to you Sonia

Background (14:45)

We have to thank the Health foundation for providing funding for a unique opportunity to write a report that pulls together learning from 4 Scaling up projects that have run over the last 5 or 6 years. Scaling up is where a proven local initiative is taken and deployed to further sites in the belief that similar benefits should be able to be obtained but also with the recognition that this may not always be quite so easy as at first thought.

So briefly to explain the 4 programmes, firstly is Tackling Aki – (Acute Kidney Injury). This programme was to improve hospital AKI recognition and care delivery. It has 3 components (1) an electronic detection and alert (2) a care bundle of actions to follow when the alert was triggered (3) an education programme for staff. The specific approach was first deployed in Derby Royal Infirmary and patient involvement was primarily via local patient groups in the hospital teams that deployed the intervention.

ASSIST – CKD was at the opposite end of the kidney pathway. This was a computer programme and training that was deployed in laboratories. By tracking graphs of kidney function using the estimated Glomerular Filtration Rate the detection of potential early Chronic kidney disease could be spotted and the GP notified that action was needed. The objective was mainly to reduce 'late presentation for renal replacement therapy'. It had been developed and used at the Heart of England NHS trust. At the start this programme recruited a large patient involvement group and specific a patient lead to work with the programme all the way through.

The third programme was Shared Haemodialysis Care which was a collaborative of trust teams working to routinely offer patients the opportunity to participate in component tasks related to their haemodialysis treatment in the dialysis centre setting. Key elements of the intervention are a patient competency record, staff offering patient support and training to achieve personalised goals. It was initially developed in Yorkshire and the Humber within the 'closing the Gap programme. Patient participation in this project was by a patient lead working as part of the programme team all the way through and with each trust having a patient advocate who came to the learning events with their team. During the day this group formed their own forum to take forward specific considerations. And play these back to the wider groups.

And finally Transforming Participation in Chronic Kidney Disease was funded by NHS England and run as part of the Renal Registries Think Kidney programme. This looked to support patients build the skills and knowledge and confidence to self-manage their health. It was a slightly different programme to the other 3 in that it did not take a specific local initiative and scale it up rather it developed a toolkit and measures such as the Patient Reported Experience Measure that are now reported on nationally each year. Their programme really placed patients at the heart striving for a 50/50 representation and all workstreams and the programme board was co-chaired with patient and clinician.

Between these programmes the whole pathway of renal services was covered from early detection of trends in primary care to acute Kidney injury in the emergency care setting but what we found was that there were consistent themes across all these programmes that we drew together into 5 key chapters in the report: Definition of the change, implementation of the change, evaluation of the change and management of the systems and processes surrounding the programme. The fifth theme and the one we are covering today focused on involving patients together with front-line professionals.

Martin: Forgot to tell you a couple of points – this webinar are being recorded so it will be available later to listen to

Want to explain you what QI briefly we use the acronym QI – quality improvement basically describes mechanisms to try to improve the quality of care and we are focusing on how we do this in kidney services and why involving patients as partners really strengthens us in doing that. So now I am, going to start asking question to members of the panel you have already given us questions but we will use our pre-prepared questions but we will pick up anything else at the end I hope.

Panel Questions - part 1 – Setting up and making it work

Our first session is about setting up and making it work. So to Tracey and then to Amjid

“What are the benefits of involving patients in the set-up and running of a programme? (25:13)

Tracey: I think as Amjid said in his introduction we were (1)at a very early stage of the Assist CKD process even before the funding or even part of the funding application that went to the health foundation.

I think that was very important as because patients are the people who are going to be affected by this so although medical professionals will have their opinions really the patients know what they want and what works for them

And what often what some small changes can make so what we get out of a programme is what goes in at the beginning so we really need tailor that to what patients think is important to them and I don't think I can really over state that enough.

So that's exactly what we were trying to do with the Assist CKD project both Amjid and I have experiences of late presentation to GPs or GPs not probably reacting as we would like so the key criteria for me was to really to highlight to GPs how important it is to look at the eGFR so if we could so if we could though the system that Assist CKD was scaling up if we could improve GPs in primary cares knowledge of what to look for and make it a highlight then it would help patients not 'crash landing' in secondary care but really to try to improve how their care path works so they didn't get in at the far end as there are lots and lots of evidence which shows that if a patients is caught early with kidney disease then their outcomes and criteria and everything about their process is better. We can make them feel better the whole way through or even in lots of case not get them through to the end stage kidney disease and that need for a transplant or dialysis.

Anything we could do to guide (1) the project to that criteria was what was important to me and why we were involved at an early stage.

Martin: Now pass to Amjid

Amjid : just like to echo what Tracey has said about how I came onboard I was invited at a very early (1) stage when the business case was being put together and feel I was able to help on a couple of fronts both as a patient with my lived experience (2) of unfortunately being diagnosed very late and this was generally to do with the fact that my heath was very good all the way through and I didn't really show symptoms till the very end at which point I insistent on a blood test which showed I was had chronic renal failure that was 3 decades ago and I hope that there have been some learnings about that and GPs have are now more active about recognising this in certain BAME (3)groups earlier on.

Double edge to my approach was my background I have in finance and strategy. Coming from a banking background looking at the proposal document and actually seeing it for the cost benefit analysis of doing the work rather than just as a patient - it was nice to be able to share that feedback with Tracey and the team

What is nice for me was that I felt engaged (4) throughout the process and I think that is important for any patient involvement that we are recognised and valued for our contribution and that any suggestions that we make - if they are not used there should be a reasonable explanation as to why as that is what would keep the individual on board so I felt it was a great opportunity and I was glad to assist.

Martin: thankyou you bring you particular strengths and experiences to the project and that is key.

The next question is going to Nick and then Kirit

“How do we achieve patient representation at the programme concept period? When the programme is less defined how can patients help at that stage?” (25:25)

Nick: this follows on quite nicely from what Amjid and Tracey were just saying that early involvement in any project is crucial. Also the landscape has changed (5)over the last few years so if you think back to the start of the TAKI project was in 2015 and the design phase was even before that and I think if you compare that time to where we are now I think that the appetite and acceptance that patient involvement is crucial and extremely valuable has really become much more widely accepted. That's important because hearing the patient voice at the point when you are planning and designing (1) studies really gives that opportunity for those inputs to change and shape the project.

So what does that mean practically so from my side when leading and designing it means thinking about patient involvement early on and then the second practical thing is that many renal units and research groups have active patient groups that meet 2 or 3 times a year specifically for this process so we can hear what is important (2)and put questions to the group so when we are trying to do this it's important that the questions are not broad but that we actually think about areas of the areas of the project where the patient voice is going to be really important for that. Then that over time develops and it build the relationship and the regular working becomes more efficient and easier and just simple things really like co-production of materials that are going to be patient facing are the simple things you can start with alongside the imputing of ideas into a project.

Martin: Thankyou Nick so now I'd like to pass to that question onto Kirit.

Kirit “ Yes I think that is very important to involve patients at an early stage the main reason for doing that is so that patients can influence and shape the project and also is important that have can have an equal say in the project and not an afterthought (1) (4)—so the question is how do we do that ? what I would say is that we are very fortunate as we have 51 Kidney Patients Associations up and down the country and they are all members of the National Kidney Federation but one way of getting the right patient is to contact you KPA locally and if you don't know who they are contact the NKF. We need to make sure that the patient are representative (6)so for example if the project is on project about dialysis you need the dialysis patient to be the representative person you don't need somebody who has had a transplant or has no experience of in dialysis

I am particularly keen that representation means that we need to think about equality and therefore patients from BAME background and patients from lower socio economic class that is very important and sometimes we struggle to do that.

But we also need to think about the practical issues so when we involve patients in long terms projects like the ones we have been talking about we need to make sure that these patients are paid for their time and that any travel costs or so on met and these need to be built into the funding (7)right from the beginning.

And how do we make sur that patients have full access to the various meetings and so on and one of the advantages of virtual meetings is that it will be easier for some patients to participate in the projects than they did in the past. In conclusion I would say involve patients early but they must be valued and they must be supported. (1) (7) (4)

Martin: Thank you Kirit so can I now ask Tracey

“How can involvement be tailored to the availability of the participating individuals?” how do we do that so that people are best able to participate given their availability? (30:50)

Tracey: I think I can best answer from how we went about setting up the patient groups for ASSIST-CKD we tried to have a group that was spread geographically across the UK so it covered most of the renal units that we possibly could we had a group of 10 (8) at the beginning with 6 mainly active members . We tried to involve patients with different backgrounds and skill sets (6) as Amjid said he had a specific skill set in finance and we also had a GP who was a dialysis patient. We tried to cover all the bases with that but we also tried to make sure that not everyone had to attend everything so there were different workstreams within the project everyone was able to answer things via emails some we able to attend meetings and some weren't. We tried to factor that all in so that every bodies viewpoints (6) were well heard so their skill set as a patient and behind the scenes within their areas that others patients they knew in their area to be able to include their opinions were covered I think that was very important.

Martin: thankyou Tracey I would like to ask Amjid then

“What's the most effective ways to involve people from a range of backgrounds?” (32:20)

Amjid: I am a little bit limited in what I can say about Assist CKD but would like to talk to that point regarding the work I have done with NHS blood and transplant and more recently in Kidney Care UK. Now if I look at the way that we engaged the communities with organ donation with Islam, and looking at BAME engagement in general, then what's absolutely key is being able to demonstrate a respect and understanding of the cultural difference and the importance that plays in the decision making process for individuals (3). What's absolutely key is that people buy from people - sharing my journey and lived experience (2) as a patient has helped to build relationships with stakeholder groups and enabled and encouraged them to participate and come forward.

In terms of the other work being very clear about the ask - what's in it for the patient or the stakeholder my approach has been to be very clearly using a simple 1 page document - a balanced score card on that you clearly state what the aims and objectives (9) are, what the parameters are or the framework of the project or piece of work that you are doing and that ensures that people are able to contribute effectively when they go off track it means you can bring them back on board and what that does is it keeps the group focused and I think that the climate we are living in where inequality and disproportionality (6) is at the forefront of everyone minds it's important that we are absolutely clear about what is the outcome we are trying to achieve so that particularly vulnerable groups don't think like it is a tick box exercise (8).

Martin: Thankyou Amjid that was very clear and very pragmatic. So now my next question is to Andy

“What are the benefits of involving more than one patient? How many patients should we involve and how do we decide about that?” (34:30)

Andy: I think that Kirit and Amjid have covered quite a few of these already including Tracey so I will briefly just go over a few points. The last thing we want really is for a patient to think that they are tokenistic (8) so we do need to make sure that there is more than just one patient that is physically engaged in the programme itself. Equally diversity and culture (6) of that group its as much about age and ethnicity as it is about anything else and clearly that then helps with the direction of the programme and

the representation of the programme and how those links develop. There is this aspect in relation to being able to hold the programme to account in relation to the more patients that you have and the breadth of experience that you have of patients which is then helping you to guide the programme in particular ways which is perhaps more generic than specific in other words it covers the patient group you want it to cover.

We also have to consider of course that although well we are very dodgy people in many ways in that we suffer from illnesses relatively quickly and quite shortly. (8) So the more patients that you have you can actually look after those individuals that are not very well you can perhaps work out some way in relation to keep them involved but we have to be mindful that this is one of the aspects of engaging a patient. Equally it can be a lonely place - you can have a load of people who are sat around a table for example at a meeting who can talk to each other who go away and they network with each other whereas the patient will go and they have no-body else to talk to they just have clearly their peers that they can talk to when they go back to the unit if they are a representative but they still have nobody else to talk to so the more groupings you have. Sonia mentioned earlier on that within the shared care programme we had on the learning days where the healthcare professionals came together – the day was a co-produced day - but there was a time when the healthcare professionals had their time and us as patients had our time and that was invaluable so that's why you need a reasonable number of patients a third to 50% at least.

Martin : Thank you Andy that's great I am just picking up a comment that has come in from Michael Reese saying that “involving more patients in a project can help to overcome the perceived power imbalance between researchers and the researched” (6) particularly when the later are in the minority groups - I think that is a very important observation Michael. What I would like to do then is ask Kirit to put this one to you

“What is the right balance of patient representatives to health care professionals? How do you strike that balance?” (37:45)

Kirit: I think there are important principles here really and the first principle for me is that the voice of the patient should be equal to that of the healthcare professionals on the project. (4) And often that is not the case. And secondly which again is difficult to achieve is that patients should have a leadership role (10) within the project because they bring expertise which may be different expertise from the healthcare professional but they do bring strengths to the project so their voice must be equal and they should have a leadership role those are important principles. How do we achieve that something some people say is go for a 50/50 balance with half the members of the project group are patients and the other half consists of healthcare professionals if that works that's fine but there is no magic number you 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. And you also have to accept that we are patients our health changes regularly and therefore we have to be prepared those patients who are on long term projects that their health will suffer from time to time and that they may not be able to continue. So we do need a large pool of patients to be involved throughout the project. (8)

Martin: thankyou Kirit coming back to Andy then

“What things should we consider when we are identifying potential patient roles?” (39:30)

Andy: So we can talk quite a lot about this – in one ways it's a bit like when you are having a job interview so the patient and the clinician (if it's a clinician or researcher) needs to have a clear understanding of what is expected (9) of the patient and what the actual programme involves. I think it's important to say from the very beginning that the patients themselves should not be seen as a free patient (resource) they are not just there because they are free - their time is golden time (7) really so it is important. It's about making sure they are happy when they are going to come in and join the programme. Some of that is not trying to oversell what the programme is trying to deliver (9) or what the patient engagement is going to be and trying to get a good understanding from the patient in relation to how they understanding what you are talking about in relation to the patient. It's a bit like some of this engagement with motivational interviewing. When there are some more basic questions about when and how with this effect their treatment – how it will impact on their family life – what skills in relation to what you have talked about do they think they have to offer –

what skills do they think they do not necessarily have but that they would like and so what skills can you help them to develop. And I will give a brief example of that shortly and then it comes back to other areas that we have been talking about before like where are the meetings, how often are they held, are they online, where does the agenda stuff come from, how and what will people understand when they are reading the agenda, and various other aspects like travel expenses are they pre-paid or reclaimed so there is a whole raft of various things. Equally its important to try where you have a group of patients to perhaps identify with the patient where there are other patients involved in the programme as you may be able to offer some coaching from that for specific patient within that programme or there are other patients that you could do that with. This is one of the roles of KPIN would be very much about trying to help to do that. Will they be mentored by more experienced patients? So there is a raft of different things you need to look at and you need to consider and there is also this thing about if the patient starts to feel uncomfortable or isn't quite sure that it is what they thought it was how can you help them so what is your communication how do you link with that specific patient and will they be treated like a team member (4)I suppose in many respects.

But the quick example I wanted was what started with the first shared care programme (closing the gap) and then went onto the second one where actually as a patient and as a patient lead I was involved in every training activity that the healthcare professionals were involved with within that training and a lot of that was done with providers from the health foundation training they were both great fun very enlightening but it actually brought the team together (4)not the healthcare with the patient coming in from the outside so engaging, involving and making the patient really feel that they are part of that engagement process.

Martin: thankyou Andy - Amjid any other additional points when considering identifying patient roles? (43:15)

Amjid: thankyou Martin. I have had the pleasure of working across a number of workstreams looking at engagement in particular from a BAME communities so if I can share a couple of examples. The key thing that I would say which reinforces the point that Andy has made is that its vitally important to state at the outset what is the purpose and the role of the patient or the stakeholder that you are trying to engage. (9) Is it that of advisor, is it that of information source, is it there as a critical friend. Because setting that out at the outset will help define their role and the degree of influence that they have and that will kind of dictate the way they engage and behave. For me I think – the biggest challenge for me at the moment and I see this as a challenge and also as a great opportunity that COVID-19 has highlighted so much around health inequalities and disproportionality and I think that the webinar today which is talking about patient involvement I think this is now a critical time for all healthcare professionals to take this information away and recognise that we can't look at patients in silos and we have to look at – particularly with BAME multiple co-morbidity issues that effect each other. What is the best way that I feel as a patient that I would want to be engaged is rather than having everyone coming to me as an individual group is for them to partner up and come to me as a wraparound that's telling me that if you've got this issue then we can signpost you immediately to the other and being able to share my lived experience (2). That way will give me that degree of comfort and reassurance that you've genuinely got my interests at heart because otherwise I think potentially; we could lose a key stakeholder group in the whole process.

Martin: Thankyou Amjid so in a sense what you are saying is that enabling people to navigate through your experience is a real strength. Tracy I would like to ask you then "Everyone is different - How do we identify an individual patient's strengths and gain their confidence to use them?" (45.32)

Tracey: I think that the main criteria really looking into the groups that I have been working in as a patient member or lead on is that I really talk to people in the beginning we have separate patient group meetings so we do try and encourage people's views encourage their skills, encourage their opinions to make them feel confident (4) (1) (9). It really explains through the different workstreams what they will like to be involved with not just telling them what we want them to do. In that I think we can encourage different points of view and different voices and encourage people's personal development. Because I think this is what the process is, I speak for myself but I

think others on this group that it's all part of our development. I think the other thing is the more you get involved in this kind of work then the more confident you get in being able to undertake those roles (11)– so sharing that confidence (11) I think is key.

Martin: Thankyou Tracey so just to finish this section off I just want to pass over to Andy and ask him if he would just tell us a bit more about

“How can we help patients gain the skills they don't have so they can be more engaged and add value to the programme?” (47:10)

Andy: Yeah I mentioned before and I think this being a theme really across where we are at the moment is that it is not easy to get patients to be involved and there are some barriers that patients see in relation to being involved there are patients that are enthusiastic about being involved but how do they do that. Equally for those of us that are experienced and not ashamed to say that for a lot of people I never knew before we started doing this because again we live in our own bubble so I would often meet 2 or 3 patients that I knew they were always the same patients and they are good to talk to but you never get anyone really that can be a regular friend. So that's why we came up with the idea of the Kidney Patients Involvement Network that we would try and start with very limited patients who had experience and try to share those experiences (11)– we are not trying to be a training provider but we are trying to look at how we can provide these simple aspects like confidence, engagement, involvement practices that are there to try and help people to be engaged and at the same time create this mentoring, coaching programme where there are people on here who could mentor me on various aspects of what we are doing and equally for those who want to be involved where that experience could go across to other patients or carers that particularly want to be involved in specific service development, research or quality improvement programmes. So that's why we started with KPIN and clearly some of this we are just touching on in relation to patient involvement and we are hoping really to try and help people like yourself and Nick and the others that are listening in relation to trying to help them to get patients involved. We all want to have a meaningful role (9) - we all want to make an impact rather than just sit there and be a token patient sat there and that is really what KPIN as Kidney Care UK as Kidney research UK and other providers are trying to do but we are just trying to do this through experiential learning to do that.

Martin: Thankyou Andy that's great that's a very comprehensive answer so I'd now like to hand over to my co-chair Claire who is going to take us into the next session.

Panel Questions – Part 2 – Expectation Management

Claire: Thanks Martin we are not going to look at the area of expectation management and whether or not what we expected is what we got! So the first 2 questions I would like to touch on to start with myself they are

“Did you know what you were letting yourself in for?” and “Was it more or less what you expected?” (50:00)

Having been a renal patient since childhood things were very different back then and we were encouraged to do as much and know as much as we could. So we were involved right from the go. So when I was asked if I would interested in being involved in the transforming participation in Chronic Kidney Disease this seemed a great idea especially since it was looking at PROMS and PREMS that's Patient Reported Outcome Measures and Patient Reported Experience Measures. Well as it happens I was using them in my work so I thought great – no problem – we can do this. But it was so much more than just analysing data. First of all we had to decide what PROMS we were going to use so we worked together to look through them. I was on the measurement workstream which was looking a finding PROMS and a PREMS that we could use nationally and to put them out annually that we could see whether or not things changed for patients. We could then perhaps what was happening in certain hospitals that were not happening in other hospitals so that we could mentor one hospital with the other or things like that – even it might have been within the same hospital between satellite units that things change. We just wanted to have a look but first of all we had to come up with these. So we looked through all the PROMS that there were for Kidney patients and we had to work out which one was best. In the end we found 2 or 3 which put together covered the majority. That was actually quite easy compared

to the next step which was coming up with the brand new Patient Reported Experience Measure. Here was the nub of the problem – initially several of the professionals ‘oh its 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 come up with it and we will tell you what we want on it’. Neither of these was going to work so we eventually agreed to all sit down together. Everybody wrote down what they thought was wanted and then put together and see if we could work out what the trends were and these are still going strong today (2)(well the PREM certainly is because I am involved in it) but it changes annually we are still on a learning curve. But we compromised and we worked together (4)and decisions made together made it a lot easier.

So Andy pass over to you

Andy: Just going to start by a point that Tracey made earlier on as if we look at patients as people (9) and we look at what their background is as well as what their treatment is and what they are coming in for and they aren’t just Kidney patients then not only do we have patients who are more confident in relation to what they are doing but was also have patients whose roles or their jobs actually are quite inventive in themselves. They will have a considerable amount of experience in themselves. When I first started I recall walking into a room of clinicians whilst it was still daunting it was something I was used to that said there are a lot of people who are not used to doing that. Equally when I first started as a patient representative you immediately start to find out where some of these holes are and these were quality of life hole and these are quite simple things like televisions, Wi-Fi, security and allowing people into a building and when we went onto start on the Shared Care programme the first one - I had absolutely no idea what that involved. I felt confident enough to be doing it and I felt confident to be able to tackle some of the aspects as they came along but the program itself was helpful. But there was a lot to learn and its one of these things that you get very good at the end but actually the programmes finishing by the time you become impactful. (11)

The second one which I did which was the SHAREHD programme yes I knew exactly what was coming – to a degree – you can never guarantee that you know exactly what was coming and I will say part of that is that you know what is coming from the patients (being their representative is a bit like being a Union representative) as well as from the healthcare side of it. So I am fortunate but to start with I was a little bit more confident than maybe some other are but actually the second programme I knew what was coming.

Claire: like to ask Nicks views on this subject

Nick: So I guess this is from the other side of the fence from the medical side of how you plan to manage expectations and I think the first thing to say is that we can always get better and each time we do a project or a research study each time we do something we can learn and improve how we get the patient involvement right. (11) It’s also a changing perception really and it’s quite important to say that from a professional side it’s really valuable to hear that patient voice so we do want to involve patients so it shouldn’t feel awkward and sometimes that takes a little bit of time to build that relationship (11). If there are any of our Derby PPI group on this webinar tonight just to say thankyou and how much we do appreciate that input and as time goes on and your patient group becomes more established and you heard with other comments from around the panel confidence grows, skills improve over time. I think that part of that skill set is knowing what’s going to be involved with certain projects so yes there is the explaining and the being very clear – I think Amjid’s I page scorecard at the start of a project is a great suggestion but also by being involved in projects you learn experientially (11)what types of things might get asked and which you are comfortable with. Also from a healthcare professional point of view always try to ask questions in a way that its easy to say NO or actually that’s too much or the ask is too great.

Claire: Martin briefly would you say what you think

Martin: Yeah I just want to say that for me - did I know what I was letting myself in for? No I had no idea – I was very nervous as I thought if I organised a meeting with lots of patient’s partners they would start to tell me what they really thought and I would get into serious trouble. And actually what happened was that people started to talk about what mattered to them (2)and their stories were so powerful that that really made the impact so whenever we then took a patient partner with us to a meeting the patient storey was the thing that really turned the heads of the people we needed to influence and they made such a huge difference.

So over the years I have been so persuaded that hearing it form the patient perspective (2)is the way to start any piece of work because that really is what makes it relevant. Thank you, Claire,

Claire: Thank you for that Martin, now going back to Kirit could you answer the question

“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?”(59:28)

Kirit: I think we all know that Zoom has had a great impact across our society we know that virtual social interactions amongst family and friends are now normal. (5) We know that our consultations with GPs and with hospitals are by phone or by virtual video we know that community events like religious services and so on are taking place through Zoom. So clearly there is a huge revolution in terms of virtual ways and this will continue for the foreseeable future. Now I wanted to give you one example - there is a programme called the community investment scheme funded by NHS B&T (Blood & Transplant) and currently there are 25 projects led by BAME communities across the country where people are doing amazing work in their own community talking about the change in law on organ donation. I am please to say there are a number of people who are participating in this webinar today and I want to first thank them for what they are doing. I was invited by one of these groups, the Vanik Council UK, to a webinar they organised this was a combination of religious aspects, entertainment, and yoga and health issues. It was only a few weeks ago and I was quite apprehensive then we had 250 people on a Sunday afternoon taking part - I spoke about the change in law from a Jain perspective because that’s what their focus was and they produced a YouTube video of this so 1000s of people have now heard it. I bet not one of those 250 people would have dreamt of using zoom 6 months ago. So this is really a revolution. I accept totally that whenever new things happen there will be people who will be left behind. So we need to make sure that we don’t challenge the inequalities as some people will not have IT facilities and so on and how we cater for them. But my view Claire is that lets embrace this revolution – and zoom whenever we can.

Claire: Thanks Kirit.

Martin: Thankyou Claire for that very interesting section. I would like to change the running order slightly Dela has been listing to what we have been talking about and I would like Dela to make some observations form what she has heard from her perspective and then we will go back to some of our questions after that. So Dela can I open the floor for you please.

Guest Speaker Dela: (1:02:34)

Been listening to all that been said and I will probably sum up my reflection in 3 words - Change, collaboration and commitment – now is really the time to change that narrative and the conversation with regards to patients involvement and the issue that we have patients from all communities but more importantly that we have patients from the BAME (3)community and also patients from the lower social economic groups. They have powerful stories they have powerful voices and I think those stories and those voices can really bring about change. (2)

But I also think it's important that patients get involved in key decision making so that they are part of the decision making and that decisions are not just being made on their behalf (1) – I think that's important. But I think the most important is that when you involve patients it empowers them it gives them that empowerment to be able to voice their suggestions and what they feel is important. (11)

I think in well in terms of collaboration and working with patients it's important and I think it helps us build a better health service when you involve patients in terms of diversity we'll have more diversity (6) within the workplace and also I believe it builds better systems that will allow us to improve the quality of care. But I think it will also help us to remove those institutional barriers that actually created this health inequality. And we saw the impact that had on the BAME community during COVID-19 and it's those things that I feel patient involvement could break down some of those barriers. (12)

Again I think that to have all of that in place it will take commitment not just from health care professionals but from all of us as a team I kind of feel that today can be that catalyst for more patients to really get involved but it will take that commitment I feel; from all of us. (13)

7 years ago I came forward as a living donor for my brother to be honest I don't know why I offered cause when we were growing up my brother wasn't really that nice to me I had to do all his household chores as well as mine but truthfully – actually I was a no brainer for me to come forward as a living donor for him but sadly I wasn't compatible and I couldn't continue the process.

But I had 2 choices I could put that down to experience and move on or I could use my experience to raise awareness of living organ donation within the black community and I chose that - I just chose to use my experience (2) to raise awareness of living donation within the black community because it wasn't something that people talked about I would say 99% of the people that I spoke to say I was coming forward as a living donor didn't have a clue about what living donation was. So I set up Gift of Living Donation (GOLD) and we worked primarily within the black community to raise awareness. I wrote a book about my experience called "More than a Match" and it really just talked about our journey especially from a black perspective I was coming forward as a living donor. We also held the very first event last year and we brought together across the UK all the black living donors together. It was great to see black living donors share their experience in terms of what their experience was for them

But if I'm going to end for me it's like we don't want to repeat and we don't want to see the health crisis and the health inequalities that affected the BAME communities during the recent pandemic and if we do say that Black Lives matter then we have to focus a lot on the solutions (12) and not the problems. We know what the problems are. We don't want the solutions to be just gestures (13) where by ok let's promote BAME people into higher positions or really commissioning another report on racism within the professions but it will take a reconstruction of the whole healthcare system but we can't do that unless patients get involved so I think that is key If change is going to happen it has to have patient involvement (4) – I would say be the change that you want to see. Thankyou

Martin : thankyou Dela that was very powerful and the point that you make is well made that if we want a more equal health care system that it means working more collaboratively together with patient partners.

Panel Questions – part 3 – Working together and culture change

So the next question I want to explore is around peer support because peer support really is a means of trying to help people to work in this way and perhaps I can put the question to Andy

"Within your programme what peer support was available? Did it work? Could it have been better?" (1:08:30)

Andy: Well the answer to that was quite simply yes but did we have peer support yes we did and I think again it comes down to how much involvement you have at the beginning (1) about how you setup the peer support (11) within the programme. It cannot just be 2 people talking to each other so it needs to be some meaningfulness behind it. And also Kirit mentioned at the beginning about sometimes patients - when I first did the shared care programme I was a dialysis patient but when it came to do the 2nd one I was a transplanted patient but that does not mean to say that I forgot all about Haemodialysis but it just means I'm not current in that specific process so therefore what we did within that within the 19 hospital we had 19 patients or more than 19 patients if we could have done which were an inclusive group of patients. We started by having these group sessions together at various time throughout the programme that then morphed itself into having online groups and we were doing the mentoring through the online groups. And it didn't take very long before actually the group itself was mentoring itself on line on WhatsApp and indeed that continued to this day and the programme has been finished for some 18 months or so. So again within KPIN that is one of the priorities that we have its to how do we produce a simply mentoring programme which is not onerous as we cant afford that we cant take lots of people time but how can we do that in an effective way ? So it is important it does need some thought and it can't be something that you just slam together because you can do as much damage through peer support (11) as you can good.

Martin: So we need important mechanism to make that work well but it can work very effectively thank you Andy. SO the next Question goes to Nick – here is a really challenging question for you

“Is it possible to re-design kidney care in conjunction with kidney patients? Where are the best examples? Is it possible to do so?”(1.10:58)

Nick: Yes it is - that's an easy one Martin I guess that why we're all here because that's what we believe in so it's an easy question to answer like that but as we all know it's far more challenging to do it in real life. I do think that some of the learning that we've got from the health foundation funded projects that you and Sonia have brought together in the report together really bring some different aspects of how to do that and quiet different approaches of how to do that together (4) and I think it would be really nice to consolidate that learning and keep working on the important messages and refining them including in forums like this to really distil that out. I think the other area that we can learn from maybe is how the patient voice is really embedded into the research world now and QI is in that grey area between delivery of health care and research at the other side but really there are some good examples of how patient groups and patients really take roles throughout the design (13) , development, the oversight and the leadership of research that all of those messages apply to the structure and the working of quality improvement as well so yes I think the answer is yes and as we go forward and acknowledge that it is something that we will hopefully see more and more of.

Martin: so it's a journey and we are on it and there is a long way for us to go but absolutely essential. So I have a key question that I would like to share with Amjid and that is

“How do you build and maintain trust?”(1.13:06)

Amjid: Thank you Martin this is absolutely key and as I mentioned earlier we live in unprecedented and uncertain times there are lots of concerns for all patients of all communities and as Dela has beautifully articulated if we are talking about real change and sustainable change then it requires real commitment (13). One of the things that I have learnt in the various pieces of work that I have been involve in is that we have to look at patient engagement as the beginning of the commitment to pursuing a more comprehensive engagement we have to think about building it on mutual trust, (14) mutual respect and mutual responsibility. I think it's about helping to empower to build that sustainably. For me personally you have got to be able to feel the change one of the things that I can share with you is that when I spoke to this group and came on board you know I was a patient for 23.5 years on dialysis and I never spoke to another patient in all that time – I didn't join a Kidney Patient association I didn't reach out to any of the charities – now being involved I now know how much support is out there how much is available and I thinks its really important that everyone

health care professionals support agencies look at the way that they communicate (11)– how they engage and how they build that trust and confidence with all communities not just BAME but all communities and that for is what I have taken away in more recent weeks from having had this conversation.

Martin: thankyou very much Amjid for your comprehensive answer – Kirit can I just ask you to highlight perhaps how the NKF helps with that?

Kirit: Yes I think they have been a couple of questions Martin about KPAs and I want to pick those up because as I have said we have got 51 Kidney Patients Associations up and down the country – they are run by volunteers like me and others and some are doing very well and very active and so on whereas others are struggling. So one of our roles as the National federation of KPAs is to offer them support and advice. It's not an easy task because sometimes you'll have half a dozen people on a local KPA working over many years struggling to find new members and to move forward and so on. So what we have done recently, just in the last few months, is that we have appointed within the NKF a KPA liaison person so his job (his name is Mark Davies and many of you will know about him) His job is to support KPAs so there were a couple of questions about KPAs which are struggling and we are here to help you and in fact as I have said as president of the NKF which I took over fairly recently we are now examining a strategy for the NKF moving forward particularly in light of COVID and one of the things we are looking at is how can we support the KPAs better so that they can be empowered (12) to engage with the wider kidney community that they need to do at this critical time.

Martin: Thank you Kirit that is great so our last pre-prepared question if you like I want to give to Andy and that is

“What structures should we have to enable longer term support for patient partners?” (1.18:00) thank you Andy.

Andy: I am certainly not aware of that many people of patients that when they had gained all that experience and got through the programme that they were then just suddenly released and that experience was in some ways lost. Clearly there are some patients that once they have done elements of it then that's it they are quite happy to go and go onto things that are better. One of the things that we were looking at was how can we capture that experience (11) and how can we look after it so one of those was with the Kidney Patient Involvement network. Once the relationship has been built and people know and they have learnt from each other then there is this aspect of trying to use patient on other aspects. Now whether the second programme they go on they have somebody with them so they are teaching them so it's a bit like a handover in many respects so that's the only way that I know of really doing it. Clearly everyone has their own contact lists but once patients have gone within a reasonable amount of time then they're interest is lost.

Martin: right thankyou Andy that's great we are now going to move into the discussion session and pick up some of those questions that you have presented to us.

Q&A (1.18:37)

Martin: I like this question from Martin Cunningham

“Is it always possible to lump all kidney patients together into a single pot? Is it not true that the cause of kidney failure can throw up specific issues? Do those specific issues get addressed? (6)

What I am interested in here is in the individuality of the patient experience so perhaps I can ask Tracy to have a go at this question if she would like to?

Tracey: I think its 2 things really I want to say firstly clearly no patient is the same as another patient and the adage of no decision about me (1) (6) without me is very true. As we are evolving as a society and as patients are getting more involved - my 87 year old mother in law was recently poorly and agreed to some additional chemotherapy and when we said why did you do that she said well he's a doctor you can't argue with him and I think that kind of attitude is changing (5) we're happier and all feel more able and confident to question doctors about things.

One thing in the renal service which I think and my daughters have found very helpful is specialist nurses because sometimes they seem a little bit more approachable They seem to know almost as much as the doctors about patients and procedures and treatments and outcomes and I think that is very important.

The other thing is to really change or to think about the way you go about your appointments whether you are a GP or in secondary care - instead of sitting down and looking at your computer looking at blood results or whatever look at the patient ask them how they are and what's bothering them that day trying to start up a dialogue and what the patients individual need are as opposed to treating them all the same (5)

Sometimes they might say just some little odd snippet to you about how they are feeling that you realise means something completely different and just small tweak in their treatment or the way you speak to them or their drug regime or another points can make a massive difference to that patient they can go away a lot happier.

Claire: question from David Coyle for Andy

“Patient role profiles can help clarify expectations burden of work and provides legitimacy to patient role. It can also be a baseline for assessing patient involvement quality and impact (9). Interested in views of panel

Andy: I know David quite well and I actually need to thank David as he was one of the co-founders of KPIN. One of the things that we were finding and particularly when I started on the shared care programme with Martin was its ok to try to explain being a patient lead (10) but what does that actually mean and the amount of time I spent on the internet as there was nobody else to talk to about what sort of things should we have - I knew in my head, from my work, what type of things I needed but couldn't find anything.

But some of those things were what we were talking about before like making sure that patients have guidelines for example in relation to what they are doing and what the expectation is as if they are not doing what you want they to do they are not in the right place at that particular time so where do you go? We had patient champions for example so were there any patient champion guidelines? (12) There weren't any so had to write them.

There are a variety of different guidelines which are helpful for people to look at – we currently have things like working groups, patient advisory groups so what are the boundaries and how do people know what you mean when you say those words.

Again that's what KPIN is trying to do is to bring those examples and put them in one place so it stops that hour of looking to try to find something so that you can pick something, adapt it to your circumstances and then use it.

You cannot underestimate how much time that actually takes to physically do that.

Claire: this is a question for Dela and Amjid

“How can we make things so they are clear and transparent so that people from other than the white population will trust what is written?” (14) (3)

Amjid: If I may use the example of the work I have done in the work on behalf of NHS Blood and transplant in terms of securing and updated the religious edict from an Islamic perspective. One of the key things I found is why I waited so long for an organ off the organ donation register. From a Muslim perspective it was really down to fact that most members of the Muslim community don't understand the Islamic position from a faith perspective. What we couldn't do was to go out and assume was that everyone knows everything about the faith and assume everyone understands the jurous-prudence behind the decisions of a scholar. (12)

What we did early on was to build a stakeholder base (12) and that included Scholars, Iman's, clinicians, community organisations, patients, individual influences and sought the insight that we needed to understand where the pinch-points were, where the blockages were and develop an updated edict that addressed all of those concerns.

Building that trust and confidence you have got to be able to first have to listen, truly understand, reaffirm the position you have taken with your stakeholder base and then develop the solution or the product or package that you are putting forward back in the manner that shows transparency. (14)

One other thing I would like to say - we put a lot of emphasis for the need for patients to come forward one of the key signpost areas for that is in primary and secondary care and I think the question we should be asking ourselves here as well is how can we better support our GPs and secondary care clinicians in understanding how to broach the subject with their patients to order to come forward and be part of a programme and be involved in Quality Improvement (11)

Because that's where I missed the opportunity in the time that I was a patient. No body ever asked me 'Amjid would you like to contribute your ideas and thoughts your feelings about how you feel you have been treated as a patient'. It's only now that I am involved in the process that I can see that door has already open and has been open for years. Just think we need to do more to support everybody in the process not just one stakeholder group. (12)

Martin: so I'm going to ask one more question for Sonia

"How do we differentiate between volunteer and paid roles?"

Sonia: So we can differentiate between paid and unpaid but it's very much about what is said at the beginning when setting up the programme. Clearly when setting up at the start need to consider what you are doing with involvement of patients and ensure that you have built that into the financial model for the programme and not ignored it that's the first clear thing (7). Right at the very beginning need to think about how many, where, what and how patients need to be involved in the same way as you would for clinicians, nurses with any other elements and build it into your model.

And then make sure that the expectations (9) are set so that people understand what those roles are going forward.

Summary (1.28)

I realise that they are still questions we have not answered but the sands of time are flowing past

Essentially we have had a really energetic conversation we have heard the answers to key questions and we have had conversation with the wonderful panel and that really important this afternoon

The points that we thought we key that we need to pick up on we have put these in the slide set we have shared with you and also in the report. I am just going to go through these.

In terms of patient partnerships in these kinds of projects make sure that you involve more than one patient representation (8) that's absolutely key and Involve patients early (1) during the concept stage so that they can influence the design of the project

It's really key that you describe the patient role clearly (9) so that people know what involved and what they are expected to be doing

It is essential that we are genuinely representative (6) of people from a range of backgrounds so that we can hear the different perspectives of service users and how that should influence the development of the service. It's really important that we have review mechanisms (9) so that people can hear how they are getting on and can get the support they need to develop their potential going forward enabling you to match involvement to motivation (2) understanding people particular skills that they bring.

Be clear about expenses and remuneration (7) and make sure that this is clear upfront and that it is not difficult for people to get access to the expenses that they need - it is important it is not bureaucratic

Consider the accessibility of meetings (5) and indeed zoom has made a big difference to that and we can work with much larger groups of individuals. But we still need to be conscious of the barriers as not everyone has access to the IT we are using today for example.

Develop peer support (11) and mechanisms to support people so that they can gain in their confidence. Foster co-production more broadly in other words working together to develop the goals that we are aiming for.

Then of course it's important to consider the longer term patient roles (11) as well the patient partners we have been working here have built experience over many years and they are a tremendous asset to us working together to develop the services and this did not happen overnight that requires long term support.

Close

So now I'd like to turn to our final slide that give you highlights of many of the partners that have been involved in this work and these are resources for you to look at and think about and groups for you to link with as well as dates for your diary.

For me at this point to thank all of our participants, to thank KQUIP for supporting this, the health foundation for funding the report that we wrote – our patient partners for joining us in this panel and really energetically and clearly telling us what matters in this work and enabling us to take it forward together. I really subscribe to what Dela said there that without genuinely involving patient partners going forward we won't be able to make our health care service more equal and more accessible and everyone believes this strongly.

Thank you to everyone.