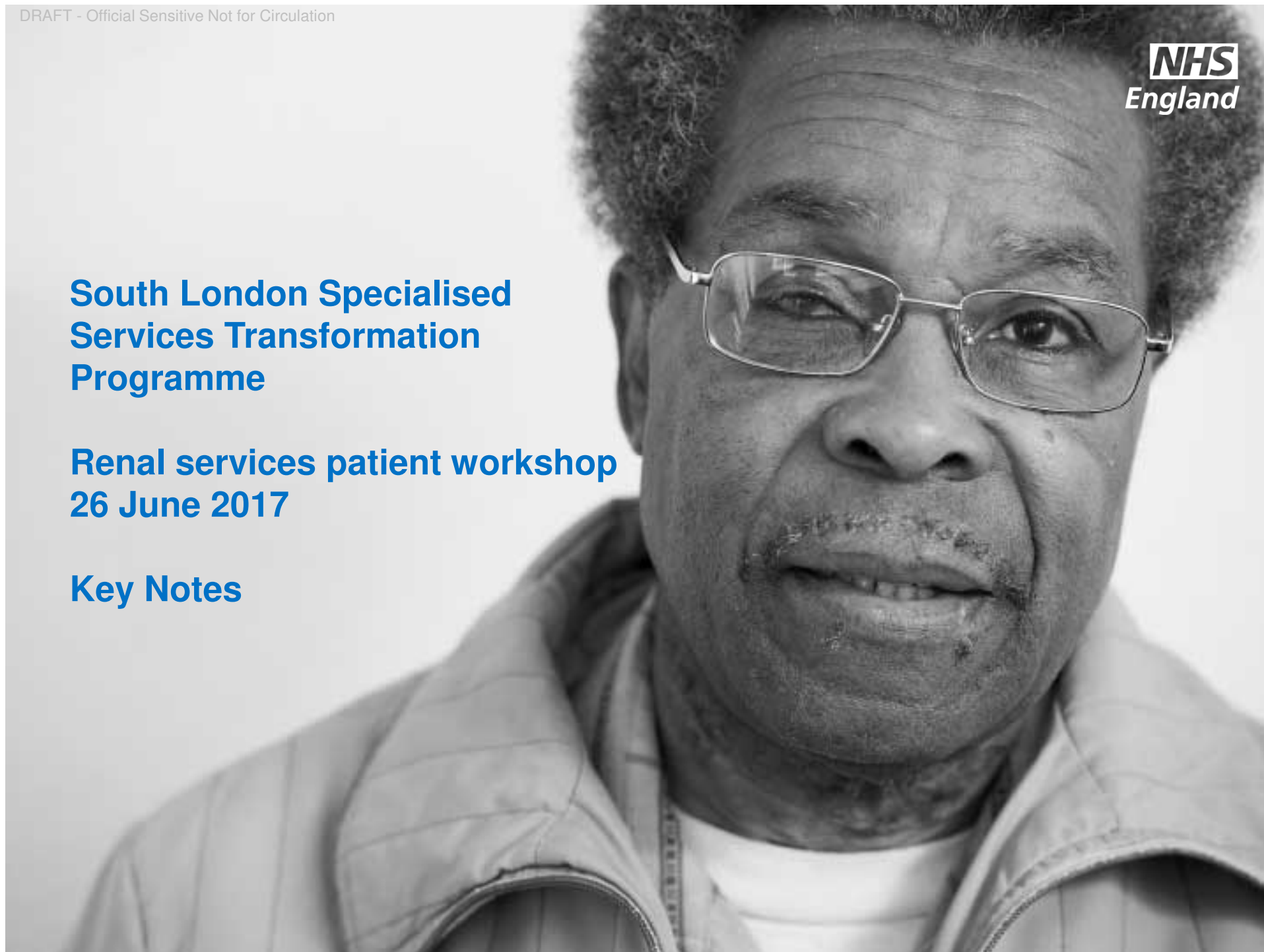


# **South London Specialised Services Transformation Programme**

**Renal services patient workshop  
26 June 2017**

**Key Notes**



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## Overview of the paper

- This paper provides a summary of the information collected at a patient workshop that took place on 26th June 2017.
- Before this information is shared, an overview of the programme's objectives and work to date is provided, in order to provide some context to this patient workshop and why it took place.
- The methods used to invite patient representatives to this workshop are outlined and an overview of the workshop's agenda and is also shared.
- Relevant information (including demographic data) relating to the patients who attended the workshop is outlined, to inform the reader and programme team of whose opinions have been heard and are being communicated within this paper.
- The main content of this paper communicates the key feedback that was received from patients who attended the workshop, particularly when considering the eleven proposed opportunities for improvement (or "interventions").
- Finally, this paper summarises the next steps for the renal workstream of the programme.
- **The programme team would like to take this opportunity to thank all the patients who took the time to contribute to the workshop.**

## Context of the patient workshop

### Transformation Programme

We have some excellent, world class specialised services in south London, but there is still room for improvement in terms of quality, performance and value for money. There is also significant population growth pressure on specialised services and if we do not make changes now, then the current level of service provision will be unaffordable by 2021, given the increased demand from the population. It is recognised that there is an opportunity to deliver improved value and outcomes through closer collaboration between providers in south London.

In autumn 2016, a programme of work began to improve how effectively specialist hospital services are provided across south London. This programme of work has been labelled 'The South London Specialised Services Transformation Programme' and it sits within the context of wider Sustainability and Transformation Plan (STP) work. The programme aims to ensure that the future provision of specialised services in south London is both of high quality and financially sustainable through to 2021 and beyond.

NHS England has defined success factors for this programme as below:

- *Patient experience:* To redesign services that where possible, support patient led care. Patients, carers and families are sufficiently informed and supported to make the best choice for them, regarding their treatment.
- *Quality:* To provide optimal safe quality services – services are provided in line with recognised best practice standards and recommendations made from previous quality reviews are addressed.
- *Value for money:* To bridge the gap between the rate of growth in service funding allocated and spend. This will require effective use of drugs/devices, demand management and appropriate intervention rates

An analysis and evaluation of current acute/ hospital specialised services provision across South East London (SEL), South West London (SWL) was undertaken – both clinical quality and financial affordability were considered within this analysis. The numbers of patients coming into south London from Kent, Surrey and Sussex to access specialised services was also analysed. Kent, Surrey and Sussex are being considered within this programme of work because approximately a third of patients that receive specialised services in south London actually live in these areas.

In order to identify which clinical services it was most sensible to focus initial transformation efforts on, a prioritisation exercise was undertaken. Renal services are one of five specialised service groups that has been prioritised as an area of focus within the programme.

### Clinical workshop

We thought that a sensible place to start in order to identify areas of opportunity for improvement, working towards the programme's objectives was to ask lead clinical staff that work within renal services in south London. After all, these individuals work in these services everyday. Therefore, in February 2017 a workshop was held for the renal service group, in order to identify opportunities for improvement. The Medical Directors of Epsom and St Helier University Hospitals, Guy's and St Thomas' NHS Foundation Trust, King's College Hospital NHS Foundation Trust and St George's University Hospitals NHS Foundation Trust were asked to identify clinical representatives from their organisations to attend the workshop. These organisations were asked to provide representatives because they are the major providers of specialised renal services for south London, Kent, Surrey and Sussex. Most of the individuals who attended this workshop were doctors (usually Clinical Leads) and Heads of Nursing within renal services at the previously mentioned hospitals.

## Context of the patient workshop

In addition to clinical representatives from these organisations participating in the workshop, Dr Neil Ashman, who is a well respected clinical expert in the field and who does not work within south London also attended (a neutral party from an organisational perspective).

The workshop ran very effectively and attendees displayed a willingness to work in collaboration. Attendees were encouraged to share their thoughts on ways in which renal services in south London and the surrounding areas could be made more sustainable – considering both short and longer term changes. Numerous opportunities (or ‘interventions’ as they will sometimes be referred to), were identified by clinicians at the workshop. Following the workshop the programme team went on to have many in depth discussions with appropriate stakeholders (including more renal clinicians), in order to further develop the suggested opportunities and to ensure that the details were well understood. These follow-up discussions were complete by early April.

All of the ‘interventions’ were then evaluated by the programme team and Steering Group to determine whether they were aligned to the programme’s objectives, were suitable for implementation and whether it would be helpful to further analyse the implications of introducing each intervention by undertaking a modelling exercise. The opportunities/ interventions were also evaluated when considering the associated timeframe for the changes to take place and the time for them to deliver benefits. The assessment indicated that certain interventions could potentially be implemented within the next 12-18 months and could be viewed as ‘do now’ opportunities, releasing shorter term benefits such as improved value for money and/ or improved patient experience. Other interventions would take longer to implement, with benefits realisation seen in the longer term. The full evaluation process was informed by the follow-on clinical and

non-clinical meetings that took place, and has been reviewed and approved by the Programme’s Steering Group . This evaluation process led to a shortlist of prioritised interventions, to be considered further.

Modelling work was undertaken for each of the shortlisted interventions to provide an idea of how things would be different if the intervention was implemented (i.e. if the proposed change took place). This modelling work provides an estimate of the financial implications of implementing each intervention, when considering the whole healthcare system.

Whilst health system leaders involved in the programme had assessed the shortlisted interventions as being positive for patient experience, quality of care and value for money, we recognised the importance of hearing renal patients thoughts about the proposed interventions. With this objective in mind, a renal patient workshop was planned.

The workshop was originally due to take place in early May 2017, but due to a general election being called and the associated purdah period, we were advised to postpone to workshop until after the election. The patient workshop took place on 26<sup>th</sup> June 2017 and this paper is the write-up from the workshop.



## Workshop overview

## Workshop Attendees

- The workshop took place on Monday 26<sup>th</sup> June 5pm- 7pm at Skipton House, Elephant and Castle, London.
- Kidney Patient Associations from across south London, Kent, Surrey and Sussex were invited to attend the event. In addition to this, clinicians from renal services at Epsom & St Helier, Guy's & St Thomas, King's College and St George's Hospitals were asked to invite approximately ten current patients from their services whether they would be interested in attending (and a letter was drafted to support clinicians with this invite (please see appendix 1). The full list of Kidney Patient Associations that were contacted about the event is shown in appendix 2.
- Patients were sent materials prior the workshop, so that they could gain an understanding of the programme's objectives, the work undertaken so far and of the interventions that would be discussed with them at the workshop. The pre-read materials contained a short version and an optional longer, more detailed version.
- **20 patient representatives attended the event. Of these patient representatives there were:**
  - **11 males and 9 females**
  - **12 people who indicated that there were currently receiving renal hospital services in south London (5 attendees said that they were not and 3 attendees did not answer this question)**
  - **6 individuals who live in south east London, 4 individuals who live in south west London, 4 individuals who live in Kent, 4 individuals who live in Surrey and 2 individuals who live in Sussex**
  - **14 attendees who stated that they are a member of a Kidney Patient Association (KPA) and 3 attendee stated that they are not (3 attendees did not answer this question).**

## Workshop Attendees

All 20 patient representatives who attended the event completed an equalities monitoring form. The ethnicity and age data can be viewed below.

Ethnicity	Number
White English	13
White Welsh	1
Black Caribbean	2
Black British	2
Indian	2
<b>Total</b>	<b>20</b>

Age Group	Number
25-29	1
45-59	9
60-69	4
70-79	4
<b>Total</b>	<b>18</b> <b>(2 attendees did not answer this question)</b>



## Workshop Attendees



Other than patient representatives, workshop attendees included:

Name	Position	Organisation
Peter Andrews (PA)	Consultant Nephrologist & Clinical Director	Epsom and St Helier University Hospitals
Jeremy Bishop	Transformation Lead, Specialised Commissioning	NHS England
Annabel Dallen	Transformation programme support	NHS England
Robert Elias (RA)	Consultant Nephrologist & Clinical Director, Renal Services	King's College Hospital NHS Foundation Trust
David Game (DG)	Consultant Nephrologist & Clinical Service Lead for Nephrology	Guy's & St Thomas' NHS Foundation Trust
Daniel Jones (DJ)	Consultant Nephrologist & Renal Care Group Lead	St George's University Hospitals NHS Foundation Trust
Neil Kennett-Brown	Programme Director, South London Programme	NHS England
Fiona Loud (FL)	Policy Director <i>(also a renal patient)</i>	Kidney Care UK (previously British Kidney Patients Association)
Silvia Novo	Programme Officer	NHS England
Nicola Payne	Assistant Medical Director, South London	NHS England
Jane Ritchie	Programme Officer	NHS England

## Workshop Agenda

The workshop took place over 2 hours and the agenda is outlined below.

Subject / Activity	Time	Lead
Arrivals and refreshments	16:45	
Introductions, programme overview and objectives	17:00	Neil Kennett-Brown & Annabel Dallen, NHS England
Home dialysis, vascular access and transplant	17:10	Fiona Loud, Kidney Care UK <i>(formally known as British Kidney Patient Association)</i>
Summary of proposed improvements (or 'interventions') and the opportunity for patients to ask clarifying questions	17:20	Daniel Jones, David Game, Peter Andrews & Rob Elias, (renal service clinical directors from south London hospitals)
Group activity: Patients share their thoughts on proposed interventions <i>(Session to include a 5-10 minute comfort break)</i>	17:40	Smaller groups – table facilitators
Group activity: Patients given opportunity to provide broader feedback, e.g. what works well versus what could be improved in renal services?	18:35	Smaller groups – table facilitators
Groups to feedback key discussion points to wider group	18:45	Nominated table leads
Next steps	18:55	Neil Kennett-Brown, NHS England

## Introducing the interventions

Patients had been provided with pre-read materials which outlined the interventions. At the workshop attendees were provided with a verbal summary of the interventions by the renal clinicians and then were given the opportunity to ask clarifying questions within the larger group. The four renal clinical directors/ leads responded to the clarifying questions that were asked. Patients were also given the opportunity to ask further clarifying questions when they broke out into smaller groups as part of the activities.

## Group activities

The room split into four groups for the group activities. As well as patient representatives, each group contained a renal clinical lead and at least one programme team member, both of whom facilitated the table discussions.

Within the group activities, patients were asked to provide feedback on each of the ten proposed opportunities for improvement (or “interventions”). Patients were asked to consider:

- Whether they think the intervention would benefit patients (when considering both patient experience as well as quality of care received)
- Whether they have any other feedback or comments relating to each intervention (e.g. to highlight any areas that you think could be explored further)
- What they thought were the highest priority interventions.

Although the majority of the group work sought to hear patients feedback about the proposed interventions, patients were also given the opportunity to share broader feedback about their experience of renal services in south London with the group.

The programme team member on each table also took notes from the discussions. Patient feedback about the ten proposed interventions is documented on the following pages.



## Patient feedback on the proposed interventions

## Overview of patient feedback (detail on following pages)

Intervention	Key concerns raised?	Next Steps
Intervention 1: Ensure that patients have the information and support they need so that they can decide upon the best treatment option for them (e.g. dialysis, transplantation and home/self-care)	<ul style="list-style-type: none"> <li>Ensure that good practice patient information/ documentation is produced and shared (i.e. is not duplicated slightly differently across hospitals).</li> </ul>	<ul style="list-style-type: none"> <li>Helpful feedback which we will incorporate.</li> </ul>
Intervention 2: Maximise the number of patients who are well informed about the different care options available to them as they approach end of life, and the implications of each, so patients receive the most suitable care for them at the end of their life.	<ul style="list-style-type: none"> <li>It is crucial to ensure that staff are providing reliable guidance to patients and their families, in terms of likely outcomes with the various options.</li> <li>This needs to be handled very sensitively, building on the lessons learnt, to ensure patients are at the centre of decision making.</li> </ul>	<ul style="list-style-type: none"> <li>Fully agree and we will be ensuring training and support is in place for staff.</li> <li>We will seek advice of Kidney Care UK in order to have the right approach</li> </ul>
Intervention 3: Introduce 'virtual clinics' (dedicated time slots for specialist renal hospital staff and GPs to discuss the care of specific patients) and electronic 'trigger tools' to flag high risk patients.	<ul style="list-style-type: none"> <li>Whether GPs would make the wrong decisions and/or patients would miss out on important tests.</li> <li>Need to look at financially incentivising the behaviour.</li> </ul>	<ul style="list-style-type: none"> <li>We will be involving GPs in developing this, and this will be joined up with intervention 1, so we have clear pathways defined.</li> </ul>
Intervention 4: Improve the overall standard of home-dialysis training quality and efficiency, with a view to increasing home-dialysis uptake	<ul style="list-style-type: none"> <li>The option of having only one private sector provider to deliver training was considered a risk. Home haemo was also discussed – with a range of providers including NXStage, Gambro, Fresenius etc. Patients should still be provided the option of whether or not to do home dialysis.</li> </ul>	<ul style="list-style-type: none"> <li>We already have one provider (Baxter) supporting PD, and it works well.</li> <li>Patient choice remains our priority.</li> </ul>
Intervention 5: Pool/ share and better utilise existing south London dialysis units	<ul style="list-style-type: none"> <li>Existing patients often have relationships with people at their current dialysis unit and may be reluctant to move.</li> </ul>	<ul style="list-style-type: none"> <li>This is about offering choice for those who are having to travel from home past one unit to go to another</li> </ul>

## Overview of patient feedback

Intervention	Key concerns raised?	Next Steps
Intervention 6: Create centralised, high volume vascular access centres to undertake complex and non-complex vascular procedures	<ul style="list-style-type: none"> <li>Location of the centre and whether it would have good travel links.</li> <li>Good support for the this, if the unit can provide good timely response, especially for urgent cases, people will travel to get access issues resolved</li> </ul>	<ul style="list-style-type: none"> <li>Helpful feedback which we will incorporate.</li> </ul>
Intervention 7: Increase collaboration within renal transplantation services	<ul style="list-style-type: none"> <li>More detail around the extent of collaboration being proposed was requested (e.g. if consolidation to one site patients wanted to know more detail).</li> </ul>	<ul style="list-style-type: none"> <li>We agree that further work is required and if we want to proceed we will need to define this more fully and then engage</li> </ul>
Intervention 8: Standardise renal service processes across south London hospitals, particularly focussing on improving referrals from GPs to tertiary/ specialist centres.	<ul style="list-style-type: none"> <li>No concerns were highlighted. The importance of upskilling GPs, in particular around detection, was supported and emphasised.</li> </ul>	<ul style="list-style-type: none"> <li>Helpful feedback which we will incorporate.</li> </ul>
Intervention 9: Create a standardised, pre-emptive transplantation protocol which follows best practice, to ensure a consistent approach across south London, Kent, Surrey and Sussex	<ul style="list-style-type: none"> <li>No key concerns relating to this intervention were raised.</li> </ul>	
Intervention 10: Introduce collective purchasing (i.e. join up procurement) across South London hospitals where beneficial to do so.	<ul style="list-style-type: none"> <li>That the cheapest items should not always be purchased. Quality matters.</li> </ul>	<ul style="list-style-type: none"> <li>We agree and quality is part of our procurement. We also want the best price.</li> </ul>
Intervention 11: Increase nephrology input into District General Hospitals	<ul style="list-style-type: none"> <li>No key concerns relating to this intervention were raised.</li> </ul>	

## Overview of patient feedback

Attendees generally showed good support for all the interventions. Different groups prioritised different interventions and so it is difficult to reliably conclude which interventions are considered to be more of a priority overall.

That said, the interventions that attendees generally viewed as real “no brainers” and things that should be actioned quickly without the requirement for much further discussion were interventions 1, 3, 9 and 10.

Interventions 3, 8, 11 are all about upskilling staff elsewhere in the system (be that GPs or in District General Hospitals).

## Patient feedback on the proposed interventions

**Intervention 1: Ensure that patients have the information and support they need so that they can decide upon the best treatment option for them (e.g. dialysis, transplantation and home/self-care).**

- Many patients felt this intervention was sensible. “This ones a no-brainer really.”
- One patient said: “There was an assumption (with the doctors) that I knew what I wanted without really knowing anything. I was left to do my own research on the internet. But there were more scare stories than what the average pathway looks like. I looked on Google at what a fistula looks like and saw the most horrific ones come up first. I told my friend not to look at them.”
- “There are probably, going across the hospitals, up to 16 patient information leaflets available.” Others agreed that it’s important to stop re-inventing the wheel and others commented that there’s a huge variation in the quality of information available.
- One patient highlighted the cost involved with producing material.
- FL highlighted that, through the renal associations, there is a project focused on producing patient information and looking at the standard of patient information. They’ve created a range of documents to go through processes. They will be producing with the Renal Association <http://www.renal.org/> about 10-12 leaflets a year; additionally they have a wide range of leaflets <https://www.kidneycareuk.org/about-kidney-health/order-or-download>.
- One participant said she was scared of the prospect of transplantation, so it took her 3 years to go onto the transplant list. People highlighted that support has been improved in this area. For example. Cancer Canterbury support network runs sessions where you can talk to doctors and expert patients. The group highlighted the importance of having access to expert patients.
- One participant mentioned that when she did dialysis there were no TVs in the room and they had to raise funding for blankets. The experience was totally different from other members of the group and PA confirmed that the default standard for a dialysis unit is to provide televisions, blankets, air conditioning and refreshments.
- There is a really good peer support programme run by a consultant nurse at King’s who is very passionate and gifted in this area, and has done some presentations to other KPAs as well. This emphasises the need to have right people and share best practice.



## Patient feedback on the proposed interventions

**Intervention 1 (*continued*):** Ensure that patients have the information and support they need so that they can decide upon the best treatment option for them (e.g. dialysis, transplantation and home/self-care).

- The patients recognise the variation that currently exists.
- Patients recognised that there is currently repetition, and realise that we could have a more shared approach to producing patient information. Patients felt there are lots of similar documents/ leaflets produced by each Trust (and yet there are also some gaps in information available too). This is duplicated effort and spend.
- Good discussion about renal patient view <https://www.thinkkidneys.nhs.uk/ckd/patient-view/> , which is a tool that enables patients to see their results, but also to share it with others. This really helps patients with self-management and information and it also reduces duplication. Apparently 50% of renal patients use it but some aren't aware of it.
- "In the initial stages of our experience within renal we found information and understanding difficult to obtain and, remember, we were bewildered by the situation. My daughter was diagnosed after an emergency admission and we were told the prognosis was life threatening. So our experience might be different to patients who had been diagnosed early and had the opportunity of support and information. If the inconsistency is apparent then we would welcome the development of a consistent and a better informed approach from the very outset."
- Peer support perhaps needs to have a role juxtaposed to clinical interventions. Pathway driven models of assessment and treatment create specialist hubs and so any given clinician might not have the knowledge of a particular treatment or intervention. Also clinicians do not have the lived experience of being a renal patient.
- Home/self care needs to be introduced sooner rather than later to patients before they become dependent on staff. A managed transition to it is crucial.
- Standard information brochures & online information would help considerably.
- Special care should be given to "crash-landers" I didn't see any structured approach to these people unlike those who go through the AKC programme clinics. They are particularly ill-informed, scared and vulnerable.

## Patient feedback on the proposed interventions

**Intervention 2: Maximise the number of patients who are well informed about the different care options available to them as they approach end of life, and the implications of each, so patients receive the most suitable care for them at the end of their life.**

- Most patients felt this intervention seemed sensible.
- One patient highlighted that nobody at the workshop was at end of life. He commented that it's the mental capacity (of the patient) that's important to consider. Does the person have the capacity to make decisions? They may have dementia.
- Another group member responded to say that if people have younger family members, perhaps they could make that decision for them (when the patient lacks capacity). Group were unsure whether that's appropriate or not.
- DG highlighted that clinicians can usually talk to patients and their families in advance of dementia/ mental capacity being an issue.
- Was some discussion about how this intervention links with frailty.
- Some patients felt it is important to assure patients that this intervention is not driven by cost reductions, although that might be a helpful consequence.
- DG informed his group that there was a project in Gloucestershire about the take up rates for dialysis. By applying comorbidity rules rather than clinical judgement, more people would have had dialysis, not less.
- Patients in one of the groups linked this discussion in with the first intervention. They were generally supportive of this, and lots of the points discussed for intervention 1 were relevant e.g. sharing information sheets across Trusts and ensuring the right people are in these important roles.
- "We agree that patients should be given information regarding treatment options especially as they approach a stage where end of life is apparent. We have reservations about the ability of some nursing staff and would want strict guidelines set in place with thorough training and specialist staff to support patients in making decisions."
- One patient was concerned about whether the body starts to swell and the patient starts to feel uncomfortable if dialysis is stopped. The clinician on the table reassured her that patients would not feel more uncomfortable than if they were on dialysis.
- Two patients on one table discussed the fact that they have already discussed with their loved ones that there will come a time when they say "no more" (treatment).

## Patient feedback on the proposed interventions

**Intervention 3: Introduce ‘virtual clinics’ (dedicated time slots for specialist renal hospital staff and GPs to discuss the care of specific patients) and electronic ‘trigger tools’ to flag high risk patients.**

- There was very strong support from all groups for this intervention.
- Group felt we need to ensure that we improve training of primary care clinicians (links with intervention 8) and that this intervention supports this.
- Supportive of ideas of nurse-led clinics, instead of multiple visits, and joining up diabetes and renal care services.
- There are lots of examples of duplicated tests – and one patient highlighted that for his diabetes, sometimes he is chased by 3 different bits of the NHS for blood test results.
- DG, DJ and PA informed their groups that hospitals get paid to see patients by the number they see and that currently hospitals receive more money for face to face appointments than virtual/ electronic appointments. Therefore, it was felt that NHSE would need to incentivise virtual appointments more, relative to the face to face appointments. Patients said that seemed logical. The clinicians, as well as patients, felt that virtual clinics are a sensible way forward.
- Some patients wanted to hear a bit more detail on how this intervention would work. DG explained that a GP can send a referral to the renal unit and the department will then instruct the GP on what to do next and whether the patient needs to be seen by a specialist. DG explained that it would mean that the wait time for people who actually do require face to face specialist services would go down as a result.
- One patient had a concern around the safety of this intervention but the clinicians said that if it is managed properly it would be as safe.
- “Why is this not happening any how? Surely most patients are initially referred from their GP so why is there not regular contact within disciplines, especially where high risk patients are receiving treatment.”
- One of the groups queried how long it would take GPs to receive a response from the renal specialists. Would it be more or less instant or within 24 hours? The view was that within 24 hours would be helpful. There was also some discussion from this group about whether one renal doctor would be assigned to provide responses to GPs, and there would be a rota in the hospital for this. DJ advised that each hospital will probably need to consider the best approach for them and suggested that NHS England might have a steer on this. DJ thought that at St George’s it would work well if consultants provided responses to GPs within 24 hours and fitted this in around their other work, e.g. set aside time in the day to respond in writing.
- There was a comment that the person in the hospital who is liaising with the GPs needs to be qualified enough (i.e. not a junior).

## Patient feedback on the proposed interventions

**Intervention 3 (*continued*):** Introduce 'virtual clinics' (dedicated time slots for specialist renal hospital staff and GPs to discuss the care of specific patients) and electronic 'trigger tools' to flag high risk patients.

- On the topic of technology, there was some discussion about 'Patient View' and some patients felt it is fantastic. It allows patients to see their blood results on their own computer often the same day as the test. It's great for home dialysis patients. Some patients had the system that also gives you online access to your hospital letters and they thought that was great too. Not all hospitals provide 'Patient View' and apparently this is because it required 'open source' which some Trusts deem insecure.
- One patient was a little anxious about whether this intervention would mean some patients need to see a specialist but do not get to see one. She was concerned about whether this could be dangerous and mean the patient misses out on additional checks/ tests. She highlighted that GPs would need to have high capability (and be very well upskilled) to ensure they are making the right decisions about when to refer onto specialists.
- There was the comment that existing kidney patients can be hesitant/ reluctant to visit GPs for advice because they quickly start to become 'expert patients' and know more about renal/ kidney issues than some GPs.
- There was also the comment that some GPs can be reluctant to ask specialists for advice and they don't like revealing that they don't know the answer or that they need some help. Thus, would this pose a risk to the intervention?
- It was highlighted that many patients will not see the same GP more than once and so it's rare that a GP will not come to know the detail around any one renal patient's care.
- One patient supported this intervention as an additional solution to slowing the progression of Chronic Kidney Disease, not a substitute for required referrals. His GP told him it was 16 years since she had had renal specific training. There should be good links to the RCGPs. There was supposed to be an education programme for GP's over the last few years, but he didn't come across any evidence of it in SW London/Surrey.
- Within large global IT services companies, technical communities often run competency networks which could act as a useful knowledge management model for developing GP special skills within larger practices.
- All the points about quality, process, governance, skills and service level agreements make sense for such a new approach.
- Patient view should be seen as a key component in empowering patients to take more control over their treatment. It is the information "life-blood" for home therapies, diet and fluid management and other aspects of CKD that patients should be responsible for.

## Patient feedback on the proposed interventions

### **Intervention 4: Improve the overall standard of home-dialysis training quality and efficiency, with a view to increasing home-dialysis uptake.**

- Overall patients were supportive of this initiative.
- Baxter training (single centre at Kew) is a good example of this for PD.
- Important that this isn't seen as a cost-cutting initiative, but one about supporting patients and independence (there has been some miscommunication on this in past). Having home dialysis really enables greater freedom to travel.
- There are a few challenges in terms of time to get the home set up and adapted for home haemo, and one patient mentioned that on occasion supplies have been an issue (too much stock in patients house).
- FL expressed that there can be unintended consequences of home dialysis, e.g. people feeling isolated and lonely. There are many ways of addressing loneliness e.g. Facebook groups. They're really good. We've (Kidney Care UK) got a closed Facebook group of 5,500 people. Lots of people contact us for explanations, some people miss the contact at the unit.
- A patient in another group said that some people, including herself, would prefer to go to a dialysis unit because of the social factor; those attending dialysis at the same time and the nurses become as part of the family. She also mentioned it would be good to have local back up and phone numbers for any central specialist centre.
- A couple of patients expressed concern about having only one provider to deliver an essential service is – they felt that was risky and it's sensible to have back-up.
- There was also some concern about lack of personalisation if the team is centralised. When there are problems it's good for the team to know who you are and in a centralised team it takes time for them to know you.
- Most patients in one of the groups felt that home dialysis is a better and cheaper option but everyone agreed that patients should be given the choice of whether they do it. It was also highlighted that some people are not able to do it, or they are afraid of needles.
- PA highlighted an issue with the lack of incentivisation for current providers to provide training.

## Patient feedback on the proposed interventions

### **Intervention 4: Improve the overall standard of home-dialysis training quality and efficiency, with a view to increasing home-dialysis uptake.**

- PA asked if patients would be willing to travel further to a Home Dialysis Specialist Centre for training. HD was very important for those at the table because it provides a better quality of life and patients said they would be willing to travel further to a Specialist centre to receive good quality training. One member said longer travel would potentially have an impact on her job but agreed that she would be willing to do so if that meant a reduction in training time i.e. 4 weeks instead of 6.
- “Yes. Good. Do it. More information and training needs to be put in place so that patients entering the renal system who will need dialysis at a later time will become familiar and confident with home dialysis and use that regime when the need for dialysis is part of their treatment.”
- There are obvious reasons to encourage patients to home dialyse: improved outcomes; greater flexibility regarding care management and the cost benefits should be cheaper than in unit dialysis. Teaching adults to learn new skills and adapt behavioural patterns is a learnt skill. It is an absolute requirement to ensure training is mindful of the significant body of knowledge related to adult learning styles.
- I'm a strong advocate for home therapies. Done APD, CAPD & home HD. So education to speed take-up is welcomed. Don't let isolation become an issue. Use venefor and other procedures to maintain Face to Face contact. Skype, Facetime or similar should be standard for all home patients. Make sure there are dialysis facilities for carer respite where applicable (e.g. when they need to go on holiday without the renal patient). There is a big difference in the psychology of PD & Home HD and that in turn is affected by whether the patient works or not. Also stability of condition matters. Making patients who are unstable fear being forced into it would be a mistake. Sell the benefits but say it's not for everyone.
- Training for HD takes longer so travel more of an issue. For PD I picked it up in a day and the Baxter telephone support is excellent so it wouldn't have mattered where it was. HD needling techniques and machine troubleshooting takes much longer. That took months. Whether you work or need hospital transport will also be factors in how you look at where the training is.

### Intervention 5: Pool/ share and better utilise existing south London dialysis units

- Patients were very supportive overall, though there is the challenge of ensuring IT joins up so that results are shared back to the patients main hospital, and making sure the advice given to patients is part of a single system. Overall this will be tackled if we can have an integrated renal service across SWL or SEL (which supports the idea of greater collaboration work between SGH and ESTH).
- It was highlighted by more than one group that some patients have an allegiance to a particular place and can be protective of their own hospital. Patients already on dialysis have friends at particular sites and relationships with the staff. Existing patients also have trust in the centres they have been using. Thus, patients should not be forced to change units. Was noted that this intervention would work particularly well for new patients.
- One groups consensus was that the nurses and other patients are a constant and vital support network, whereas doctors move around. Existing patients in one of the groups said they would be happy to change to attend their local unit.
- DG highlighted that he has seen patients from far outside the local area travelling to Guy's London Bridge for dialysis and the transport is paid for by the CCG. This is expensive and unnecessary and perhaps the NHS can't afford to pay for unnecessary costs.
- There was discussion around the fact that, at the moment the patients have choice about where they will receive dialysis and that maybe new patients should be told where they will be having dialysis (and this should be closer to home).
- There was a comment about the importance of managing and co-ordinating the process well so that this intervention will be successful. It's important to remember that sometimes patients do not attend their dialysis at the last minute, meaning their slot is vacant. It's important that this intervention supports the ability to fill the slot.
- Sharing makes sense. Kingston is a shared centre (run by ESTH) used by SGH patients as well. But don't forget support structures such as IT. How do blood results get from one Trust's lab to the others patient databases? Manage any changes. Every centre runs things differently. Different processes, efficiency levels, medication and protocols. Patients exposed to these can become very nervous. There should be a standard change/induction approach between centres/Trusts.
- There needs to be a system for where there is a breakdown of trust between the patient and a particular centre.
- This is an example of an intervention where it is not fully clear what sharing means. If for example no new capacity can be built before all shared capacity is utilised, this could mean an increase in travel distance or a continued reliance on temporary dialysis facilities e.g. Kings & George's trailers.

## Patient feedback on the proposed interventions

### **Intervention 6: Create centralised, high volume vascular access centres to undertake complex and non-complex vascular procedures.**

- Patient felt centralised vascular access centre were a good idea because this is generally a one-off event (not regular) and if we get improved outcomes from this, then it's very good and patients would be prepared to travel. Some of our patients in the group were from outside of London and already have to travel quite far for access at one of our hospitals. The challenge comes if there would need to be regular visits.
- Patients felt this was a very good idea, particularly if it means reducing waiting times and/ or patients not having to receive multiple procedures unnecessarily.
- If you woke up with an aneurysm on a fistula you should be able to walk-in (to get treatment).
- The issue of proximity was discussed and transport. "If close-by that's great, but if you need to get transport and it's bad, it's better that you can access this service from your own unit." It was highlighted that the centre needs to be near a transport hub/ have good transport links.
- One patient queried what would happen to the existing vascular access services in hospitals.
- One patient thought it was a good idea but queried where the centre would be.
- Whether it was important for patients to have a choice of provider was raised.
- There was a query about whether this would be considered a 'major change' in service which would require public consultation.
- "I don't really care where it is so long as it's efficient."
- "It' about what's at the end of the rainbow that counts."
- One patient raised the question about whether one centre would have the capacity to see all patients. The feedback from the clinician was that the centre would need to be large enough for this and should increase overall capacity, compared to existing service provision across south London.



## Patient feedback on the proposed interventions

### Intervention 7: Increase collaboration within renal transplantation services

- One of the groups only discussed this intervention briefly. The patients wanted to know what is really being proposed here - they felt that it is unclear and they required more detail regarding the specifics in order to be able to properly comment. For example, is consolidation into only one transplant centre what is being proposed, or just improved collaboration in other respects? General view of patients in this group was that they are happy with current service. This group included a number of our patients who had had a transplant (one of them had had 3).
- Again, the importance of having good transport links was highlighted.
- The centre will need an intensive care unit and radiology, they need to think about the complications and interdependencies. People now have got other problems, they don't have perfect hearts.
- There's an argument that there needs to be an element of competition.
- The details regarding repatriation back to other hospitals were queried and discussed briefly.
- Patients in one group queried how much it would cost to consolidate two centres, and whether there is evidence it would be financially beneficial.
- This would all get fixed by virtual clinics, which would really help to ease the overcrowding issue (imbalance between demand and capacity)
- One centralised transplant service would better serve patients better enable clinical staff, their expertise and experience.

## Patient feedback on the proposed interventions

### **Intervention 8: Standardise renal service processes across south London hospitals, particularly focussing on improving referrals from GPs to tertiary/ specialist centres.**

- The group agreed that this intervention seems sensible.
- Patients recognised that there is variation of practice and agreed there is a need to be more consistent (links to intervention 1 as well). Patients were keen to have more consistency and best practice shared.
- GPs are not experts. Recognising the early stages and referring patients to specialist in the early stages is key. “In our experience, opportunities were missed in the early stages of my daughters diagnosis.” This patient felt that more training for GPs is important.
- Little to discuss due to few details. Superficially it makes lot of sense. Just needs much more definition. Clarity over who will develop this, how will it be rolled out. What are the objectives beyond standardisation.

### **Intervention 9: Create a standardised, pre-emptive transplantation protocol which follows best practice, to ensure a consistent approach across south London, Kent, Surrey and Sussex.**

- Patients generally agreed with this intervention.
- One patient felt we need to ensure that fast-track donors are supported and there aren't any unintended consequences.
- If you educate people and word gets out there, it would improve a person's life substantially.
- There needs to be consistency in creating a single network, nationally.
- The difference between pre-emptive and not is just time, you still need the same amount of care. It's important to incentivise the pathway.
- FL recommends that the programme look out for and respond to the renal tariff proposals (for transplant) when NHSI bring them out late 2017/early 2018. Consultation is due in the next few months.
- The other point made was specific to the implications of health inequality driven by the significant lengths of time BAME patients wait on dialysis for transplantation compared to their white counterparts. This is a profound and far reaching reality in renal management and at the very least there should be a pathway to optimise care for patients whatever their ethnicity who are required to dialyse for long periods of time.

## Patient feedback on the proposed interventions

### **Intervention 10: Introduce collective purchasing (i.e. join up procurement) across South London hospitals where beneficial to do so.**

- Patients felt this was very important. The view of most people was that the NHS is poor at this, and it is a “no brainer” and we should already be doing it.
- Sometimes collective purchasing is great but it depends who does the negotiating. They could end up buying something that’s really rubbish.
- Many patients felt it was important that the quality of what was being purchased was well considered and that items are not only selected because they are cheaper, if they are worse quality. One patient said there is a big difference between the quality of dialysis machines.
- “We are constantly informed through the media that NHS does not have enough money, cuts and reductions in services etc. So why are opportunities for collective purchasing which must be cost effective not already in place?”
- "Get on with it!" Collective purchasing doesn't have to mean everyone buys the same thing. For example take dialysis machines. Collate purchasing requirements (including preferred manufacturers and numbers from each Trust) centrally. Negotiate framework agreements with centrally committed volumes to secure value for money. Allow for volume variation to incentivate manufacturers to encourage Trusts to switch to their technologies. There is so much that could be done to reduce costs here. Start with the largest areas of external expenditure. Begin by aiming for all Trusts to pay less than the current lowest price amongst the Trusts for any given item. Work on consolidation of suppliers (where appropriate) as a second step. Never be dependent for critical items on just one or two companies e.g. like PD. You will need to increase resource and skills levels within procurement.
- Big services contracts appear to vary in value between ESTH and SGH. This can't be right. How much information sharing is taking place between Trusts?
- Finally any changes that affect patients must be explained. Changing medication or machine will make some patients worried. Side-effects should be explained. An example of this is the use of cetirizine vs heparin as a line lock. The former causes sudden but temporary tingling and numbness in the lips. If not forewarned it can be worrying. Changing immuno-suppressant would be a big deal for any transplant patient if they were stable with no side effects. And please stop buying poor quality tourniquets and blood pressure cuffs.

## Patient feedback on the proposed interventions

### **Intervention 11: Increase nephrology input into District General Hospitals.**

- If you have dialysis in a District General Hospital then you do currently have less access to getting a transplant, although this is not a major problem in London.
- One patient shared his experience – his partner had experienced many delays in getting treatment.
- One patient, who lives near Guildford, queried why Frimley Park was chosen as dialysis centre. Out of the three hospitals in the area, Frimley is at one end of Surrey which means most people have to travel further for their dialysis. PA responded that the decision was made taking into consideration service provision for an area larger than Surrey and that Frimley is the most suitable location when considering the broader area.
- One individual agreed it would be sensible to use the specialist clinical staff from the renal units to travel to the District General Hospitals to perform clinics. However this individual said it is important that enough specialist skills are kept at specialist centres so that the level of expertise overall is not reduced/ diluted. It is important not to spread your experienced staff too thinly.

## Additional patient feedback (aside from the proposed interventions)

### **Incentivisation**

There was recognition that the current system doesn't incentivise the right behaviours, and that we need to ensure that measurement is right. For example, to ensure good shared information and good quality of peer support across organisations.

There was a clear desire for a win-win, and to ensure that any new system well considers incentivisation and does not create new unintended and negative consequences.

### **Where home dialysis patients are taken by ambulance**

One patient expressed that there needs to be improvement across the system in their knowledge of renal patients. For example, he does home dialysis but when he has problems they do not take him to a kidney unit initially (which he believes they should do). Instead the ambulance takes him to a dialysis unit and then the next day he gets moved to the kidney unit. He flags this is a waste of NHS money as well as a waste of beds and patient time. Following this point there was discussion around whether the ambulance crew know where they should be taking home dialysis patients who experience problems, and whether there is an IT system which flags that this patient is home dialysis and so already has dialysis equipment available and needs additional input.

### **Intensive Care Units use of fistulas**

There was the comment that often if a renal patient ends up in Intensive Care then the staff will put a line in rather than use the fistula that is fitted. There was the query about why this was and whether this could change.

### **Prevention**

One of the groups felt that prevention should be more of a key priority and that all the interventions that link to prevention need to be prioritised.

## Additional patient feedback (aside from the proposed interventions)

### **Helpful feedback from a Kidney Patient Association:**

Where the change affects patients directly the criteria I have seen many patients apply (including myself) include:

- Does it benefit me? Will the clinical outcomes improve?
- Will it affect travel and wait times (lead-time for appointment & in the waiting room) for treatment?
- How will it change my relationships with fellow patients and staff and will it impact on any relatives and carers? For better or worse?
- Is the emotional investment in the change worth the return?
- Generally the chronic nature of CKD (the mental fortitude required to combat it) as well as the age and "factory-like" process of a dialysis facility leads to a very conservative approach to change by most patients who become very dependent on relationships (point 3) and develop an "us against the world" attitude.

As I mentioned prior to the meeting, there is a lot of scepticism amongst staff and patients about change within the NHS. Much of this centres about the organisations ability to deliver the planned benefits. So as in any change once the change is clearly defined, implementation is crucial and my experience so far is that the NHS fails badly here.

The main reasons I have observed are:

- Failure to manage the change process leading to time and cost overruns
- Not enough attention is given to bring those who will have to operate in the new environment in at the beginning and have them drive that change through. They are too busy with operational challenges. I haven't seen evidence of change management training for management/clinical leaders (it may be there - but not evident in the actions during change).
- Insufficient money spent to achieve the desired outcome (doing things on the cheap)
- An inability to release operational staff (including clinicians) from their day jobs to implement change. So change becomes hostage to operation crises and takes far longer than commercial organisations. Projects that take 6 weeks in business have taken a year or more in the hospital. For example peer support got held up by the bureaucracy of criminal record checks but overtaken by the closure the hospital wing where renal was based.
- The time take to implement change leads to the issues. The problems don't stand still and what you are trying to fix at the beginning may no longer be the issue at the end.

## Additional patient feedback (aside from the proposed interventions)

Most successful NHS change seems to happen through continuous (process) improvement and some invention rather than transformation.

- So more modest change should be attempted first.
- Staff exchanges (secondments) might help imbed sharing and standardisation.
- Identify and empower change leaders. Have project budgets based on the business cases.
- Please test a new set up before closing the old one (e.g. for vascular services)
- Be prepared to have clinicians time freed to be part of the change team.
- It is better to not bother with the change if you can't fund and resource it properly.
- Predict the risk of unintended consequences. We discussed how virtual clinics might reduce fees to the hospital, thus undermining the funding model for the consultants and departments based in large physical buildings. (Comparison - High Street to Internet retailer, High Street Bank to Internet Banking)
- Change the measurement systems to reflect the new reality after the change.
- Finally the ill-defined interventions require more definition and consultation.
- For the better defined ones, involve patients through the design and implementation process soon. Involve patients beyond the KPA's. You can avoid some of the worst patient issues that way.



## Next steps for the renal workstream



## Next steps for the renal workstream

Patients were given the opportunity to share additional feedback with the programme team within the two weeks following the workshop either in writing or by telephone, and some individuals took the opportunity to do so.

The feedback collected from renal patient representatives who attended this workshop helps to inform the programme of what matters to patients and the feedback collected will be taken on board within the next steps of the programme. For example, we will consider which interventions patients viewed as higher priorities and we will need to consider and address any questions/concerns that were raised by attendees about the interventions.

Overall, patients at the workshop felt that all the interventions, as they were described/ at their current level of detail, had benefits. Notably some interventions are more detailed than others at this stage, and patients often seemed keen to be given additional details. Patient opinions about the interventions will continue to be sought when proposals are more detailed.

The Programme's Steering group is in the process of considering the specifics of how the interventions would best be implemented across south London. For example, which posts would be required to support the delivery, where they posts would sit in the system and the governance structure. We plan to have a confirmed delivery approach by August 2017 and aim to undertake further planning in order to start implementing interventions as soon as possible.



## Appendices

## Appendix 1: Example invite letter send to current renal patients at Epsom & St Helier, Guy's & St Thomas', King's College and St George's Hospitals

Silvia Novo  
Programme Officer  
South London Programme  
NHS England

[s.novo@nhs.net](mailto:s.novo@nhs.net)

01138 253737

Dear .....

**Re: Renal patient workshop on Monday 26 June, 5 - 7pm (please arrive at 4.45pm)**

NHE England and King's College Hospital NHS Foundation Trust would like to invite you to attend a renal patient workshop on Monday 26<sup>th</sup> June at Skipton House in Elephant and Castle (map attached).

NHS England is working with NHS trusts to improve a number of specialised services in south London, including renal services. In February 2017, we held a workshop with clinicians (mainly doctors and nurses) from renal services across south London to develop ideas and proposals to improve services.

As a current user of specialised renal services, we are keen to hear your views on the different proposals. We have invited a small number of patients who currently use renal services, as well as members of Kidney Patient Associations. A doctor from King's College Hospital NHS Foundation Trust, Epsom & St Helier, St. George's University Hospitals NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust will also be attending the workshop. Please be assured that we are not expecting you to have an expert knowledge of renal services – we simply want to hear the opinions that you hold.

We will be happy to reimburse any travel costs in line with NHS England's Patient and Public Voice (PPV) Expenses Policy, and light refreshments will be provided.

We will provide an agenda and further information about how you can contribute to the workshop in the coming weeks. For now, we hope the following information is helpful, should you choose to attend.

- We will send a document to you about a week before the workshop that explains the programme's objectives and proposals to improve renal services. Of course, we aim to present this information in a 'patient friendly' manner, which avoids jargon. To get the best from the workshop, we suggest you set aside about 1-1.5 hours to read the information beforehand.
- During the workshop, you will be very welcome to ask questions about the different ways we propose to improve renal services
- We are also keen to hear your views about whether or not the proposals are sensible, when considering the objectives of the programme

- We encourage you to use your own knowledge and experiences of being a renal patient to provide any ideas to improve the proposals further
- It is also a chance to highlight any concerns you and other patients might have about the proposals
- Once the proposals have been discussed, you will have the opportunity to provide any additional views or feedback about our plans
- This is a one-off event and you will not be required to attend any future sessions in relation to this programme. We might invite you to a follow-up event, but if we do then you will not need to come if you do not want to.

The views of patients are important to us – your views and experiences will help us to improve renal services, so that we can continue to provide high quality care that meets the needs of our patients. Patients are often able to bring a different perspective to those of NHS staff, and it would be really helpful to hear this sort of feedback in relation to each of the proposed improvements.

If you would like to attend this workshop then please contact Silvia Novo, Programme Officer for the South London Programme, via e-mail to [s.novo@nhs.net](mailto:s.novo@nhs.net) or on 01138 253737 and she will send further information to you. It is important that you register planned attendance with Silvia in advance of the meeting. Please do not hesitate to contact Silvia should you have any further queries in relation to this invite.

Thank you in advance for your assistance and we do hope to see you on 26<sup>th</sup> June. Please arrive at 4.45pm to allow time to sign in and get to the meeting room.

Yours sincerely,

South London Programme Team

Enc.: Map and directions to Skipton House

## Appendix 2: List of Kidney Patient Associations (KPAs) invited to the event

Guy's & St Thomas' KPA

King's KPA

St George's KPA

St Helier & Surrey KPA

Kent KPA

South East KPA