Improving Kidney Care: A proposal for renal services at St George's & St Helier hospitals 2021

Engagement report October 2021

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1. Introduction

This report sets out the main findings of the engagement activity which ran between 27 July and 07 September 2021 relating to a clinically-led proposal to improve care for kidney inpatients at St Helier and St George's hospitals. The purpose of this report is to bring together a summary of the key communication and engagement activities, and make recommendations based on feedback for consideration in the Decision Making Business Case.

The proposal was put forward jointly in 2020 by the clinical leads for the respective renal services at Epsom and St Helier University Hospitals NHS Trust and St George's University NHS Foundation Trust.

The proposal and the engagement activity have been undertaken on behalf of the trusts and the wider NHS by a programme team from South West London Clinical Commissioning Group.

The delivery group for the proposal consisted of colleagues from:

- Epsom and St Helier University Hospitals NHS Trust
- Frimley Clinical Commissioning Group
- NHS England & Improvement Specialised Commissioning
- St George's University Hospitals NHS Foundation Trust
- South West London Clinical Commissioning Group
- Surrey Heartlands Clinical Commissioning Group

2. The proposal: summary, context and background

By 2026, St Helier hospital will no longer provide inpatient (overnight) care for kidney patients. This is because in 2020, the NHS got approval to build a brand new £500m specialist emergency care hospital in Sutton.

Six major services will move to the new hospital from Epsom and St Helier. These services include a major emergency department; critical care; emergency surgery; acute medicine; specialist paediatric care and; births.

Under these plans, St Helier's inpatient kidney service would also move to Sutton in 2026. There would be no changes to kidney outpatient services at St Helier or at other hospital clinics or kidney units in Surrey or South West London.

In their response to the 2020 Improving Healthcare Together consultation, renal leaders from St George's and St Helier submitted an alternative proposal for kidney services which said: "...as the newly appointed clinical leaders we are firmly convinced that we could make a further step change in improving the care we offer if we could formally combine forces and locate all our tertiary renal medical

and surgical practice in one new purpose built facility...(and) that the right place for a combined renal service should be at St George's."

Under this new proposal, instead of continuing to have inpatient kidney care at two hospitals, inpatient care would be brought together in a single new £80m unit at St George's Hospital.

A small number of outpatient appointments would also change to the new unit at St George's. This would mean patients who may need extra support and advice, for example after a transplant, would go to St George's. Some outpatient appointments would also move to St Helier, like training for home dialysis.

All other kidney services will remain as they are. This means that 95% of contact with kidney services will stay the same. There will be no changes to existing dialysis services and clinics in local hospitals, units or at home.

The £80m funding for the new kidney unit has been agreed by the NHS.

The proposals also take into account the impact of COVID-19. This is very important as kidney patients are considered vulnerable or extremely vulnerable patients. The new unit would be designed to provide safer services in any future pandemic. Infection control and social distancing are easier to implement in new buildings.

More information on the proposal can be found here <u>https://swlondonccg.nhs.uk/get-involved/have-your-say/improving-kidney-care/</u>

3. Key dates in the development of the proposal

The engagement plan was shared and discussed with a range of stakeholders prior to the launch of engagement. This early engagement with patient representatives, clinicians and stakeholders helped to shape the overall approach and material ahead of launch.

Key engagement included:

- June the St Helier Kidney Patient Association and the St George's Kidney Patient Association
- Tuesday 22nd June 2021– Committees in Common
- Wednesday 23rd June 2021 Community Engagement Steering Group (Membership SWL Healthwatch and Council for Voluntary Services)
- Wednesday 7th July 2021 South West London Governing Body
- Wednesday 7th July 2021 Joint Overview Health & Scrutiny Committee (South West London & Surrey)
- June August 2021 joint NHS communications and Patient & Public Engagement group covering SW London, St Helier and St George's hospitals and the Surrey Heartlands and Frimley clinical commissioning groups.

4. Engagement strategy

We developed an engagement plan which was shared in June 2021 which set out a programme of robust engagement with relevant and interested stakeholders, especially patients and staff. The plan was explicit that we would be honest and open on the impact of the changes, both positive and negative and that we would comply with best practice, work with NHS and other partners to maximise impact and value, and draw on experience of the Improving Healthcare Together consultation of 2019/20.

The plan, and accompanying material, was shaped throughout by engagement with clinicians, expert patients and stakeholders. The plan was shared, scrutinised and agreed with communication and engagement leads across South West London and Surrey and with the Committees in Common and Joint Health Overview & Scrutiny Committee (meetings on 22nd June & 7th July).

Engagement objectives:

Engagement is key to a successful outcome, improving the quality of care and experience for renal patients in South West London.

The overall objective of the plan was to offer all individuals, communities, groups and representatives, who will or may be impacted by the proposals, equal opportunities to engage and share their suggestions, concerns and comments.

We were particularly keen during the engagement to understand:

- the extent to which the new proposals would support better care and experience for patients compared to current arrangements and;
- if the new unit would support recruitment and retention of staff.
- We were also keen to hear views on how a new unit at St. George's may impact travel time for patients and carers.
- Another important aspect was hearing from patients how they thought the design and environment of the new unit at St. George's could best meet their needs, and those of their family and/or carers.

5. Summary of engagement activities and key audiences

The engagement ran from Tuesday 27th July to Tuesday 7th September targeted at three main audiences across SW London and Surrey:

- Those directly affected by the proposals, such as kidney patients and their families and carers and staff working for, or aligned to, kidney services
- those who might be interested by proposals wider NHS staff, community groups and stakeholders
- those with a wider interest the general population with an interest in health.
- To capture patients, staff, families and stakeholders views on the proposals, an engagement questionnaire was shared online and in hard copy format.

Full details of the engagement activities and demographics can be in appendix one and appendix two.

Between 27th July – 7th September we:



Wrote directly to **3,369**

kidney patients to share information about the proposals.



Held 10 independently run focus groups with equalities groups and 14 telephone interviews with those who are digitally excluded.



Held two public listening events on 9th August and 3rd September.



kidney patients via 25 visits to 10 kidney clinics and units.



Drop in sessions for staff at St Helier and St George's hospitals.

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Shared information on social and traditional media including an animation, Vox-pops and images of the proposed new unit.



Worked closely with local kidney patient associations.



Shared updates with key stakeholders and engaged with local groups.



Information available online including updated Q&A.

6. Summary of responses and key themes

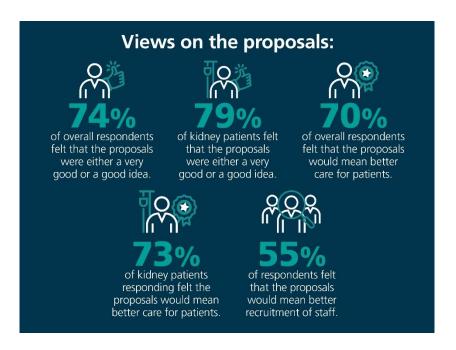
Survey response rate headlines

We received 400 responses to our questionnaire on the improving kidney care proposals:



The following is a summary of responses and feedback from the engagement. The independent research analysis report <u>available here</u> provides a full and detailed breakdown of the engagement activity, responses and findings, and also includes demographic and geographic factors.

Summary of feedback



There were high levels of support overall among patients, even when the impact of travel and transport is considered. Patient representative groups were broadly supportive of the proposals but they would like more detail on how services would change.

Feedback from focus groups and tele-depth interviews with members of the public not currently receiving care is more mixed, although broadly supportive. Staff who responded to the survey were positive in their views of the proposal with 17 of the 18 who responded feeling the proposal is good or very good. Staff feedback from meetings that took place suggest there was support for the proposal and many staff are keen to understand more about the details of the proposal and how they can help to shape future plans.

Geographical responses

Respondents living in South West London were the most positive with 82% saying the proposals were good or very good, followed by Surrey Heartlands (78%) and then Frimley residents (68%).

Support for the proposal

- Almost eight out of ten kidney patients who completed the questionnaire (79%) feel the proposal is either very good or good, and almost three quarters of all respondents to the survey (74%) felt the same
- views on the proposals from those who completed the questionnaire do not significantly differ across demographic groups and those patients most positive about the proposals were those from the South West London CCG area, Croydon patients and patients from ethnic minority backgrounds
- access to centralised and specialist renal care, better patient care and health outcomes and modern up-to-date facilities were the top reasons given for supporting the proposals.

Better care

- Seven in ten respondents who completed the questionnaire feel that the suggested way of delivering kidney care will likely mean better care for patients (70%), and this increases slightly among kidney patients to 73%
- those from ethnic minority backgrounds who completed the questionnaire were even more positive about this with 77% feeling the suggested way of delivering kidney care will likely mean better care for patients.
- around two thirds of respondents who completed the questionnaire, feel the proposed changes to kidney care services would be better for patients compared to now (65%). Around one in six felt services will be worse (16%). Results among kidney patients are slightly more positive with almost seven in ten (69%) feeling the proposed changes will be better for patients.

• common ways mentioned to make visits and stays as comfortable as possible at a new unit include; improving parking, locating the unit more locally, having private rooms or small wards.

Better for staff

- Over half of all respondents who completed the questionnaire feel that the suggested way of delivering kidney care will likely mean better recruitment of staff (55%). Views are slightly more positive among kidney patients with around three in five feeling this will lead to better recruitment of staff (58%). Around a third feel unsure about this across both groups.
- The majority of participants attending the focus groups believed that staff will be attracted to the new unit due to the opportunities to train in renal care and learn from specialists.

Alternative options

- A similar proportion of all respondents who completed the questionnaire either feel there is no better option (44%) or don't know (37%) if there is a better proposal. One in five feel there is a better option (20%). When analysed by different groups of patients, results did not generally differ substantially from the average.
- suggestions for better alternatives included having somewhere with fewer travel related issues, modernising St Helier or having two specialist units.

Travel and transport

- Around three in five respondents who completed the questionnaire feel that their journey will be longer (59%) with a similar result among kidney patients (58%). Most likely to feel their journeys will be longer are those living in Surrey (70%).
- the most common travel and transport concern was around improving parking, followed by improving transport links and having some services more locally based.

Full details of the responses and themes can be found in the independent analysis report.

7. Engagement in action

Before and during this engagement, we adapted our approach and material based on feedback from patient groups, clinicians and NHS colleagues and stakeholders. A mid-point review update was issued to stakeholders and partners to provide oversight and progress, encourage further engagement at local level, and ask for feedback.

At all times, COVID-19 infection control protocols were followed, and specific permission and advice was sought before engaging with kidney patients in local clinics as they are a particularly vulnerable patient

group. These restrictions were also the basis for the decision to make the two listening events 'virtual' rather than face-to-face.

These points below demonstrate the impact of our approach in terms of reach, and also our responsiveness to feedback.

- Good demographic mix across live event and questionnaire responses
- high levels of engagement with primary audience kidney patients
- live events gave plenty of opportunity for discussion and feedback
- we adapted our website following feedback to make it easier to find and navigate
- we included more detail on the Improving Healthcare Together 2019/2020 consultation for context
- updated the Frequently Asked Questions online to reflect feedback from live events and other sources.
- created new content to drive awareness via traditional and social media and stakeholders
- additional outreach work at local level to ensure further opportunities for people to be involved.

8. Recommendations from engagement for consideration by the DMBC

- St George's should proactively explore the option of providing additional and/or dedicated parking spaces for patients using the new kidney unit.
- More detail should be provided on the rationale for choosing St George's as the location for the new unit when both trusts currently have large renal services.
- The design of the new unit should include more single rooms for patients than currently available.
- The continuity of care, and high standard of compassionate care, should be maintained and strengthened through this proposal.
- Opportunities to support more patients to have home dialysis should be actively explored.

An additional area for the trusts to consider, but outside the precise scope of this engagement, are the views of kidney dialysis patients on the current effectiveness of the respective patient transport services. While dialysis will continue to take place as now, patients consistently raised the issue of Patient Transport Service as an issue, and the trusts should consider this feedback when reviewing current operation of this service which is relied on heavily by these patients.

9. Engagement lessons learned

Throughout our engagement on these proposals we have summarised the lessons we have learnt to help take forward in our future engagement work:

- While digital and online channels have a significant and growing role in engagement, there is no substitute for face-to-face meetings
- if the proposal goes forward, local trusts need to reinforce with their local patients that the vast majority of their contact with kidney services will not change location
- writing letters directly to patients appeared effective
- patients and members of the public can find it hard to speak up in public events
- constantly check that language and graphics are easy to understand for all audiences

- test and adapt communication methods e.g. website
- proposals which are clinically-led encourage public confidence
- despite the complexity of the issue, the public and patients need sufficient detail, in sufficient clarity and a multi-layered approach may be helpful here
- constantly check that language and graphics are easy to understand for all audiences and benefits explained as clearly as possible.

Appendix One - Engagement activity and feedback in more detail

a) Those directly affected by the proposals

i. Letters directly to patients

We wrote directly to 3,369 kidney patients registered at St George's Hospital and St Helier Hospital. These patients were identified using criteria defined by the kidney clinicians and assured by each trust's Caldicott Guardian. Letters were addressed to each patient individually and signed by the lead renal clinician from the respective trust. Following receipt of the letter, the team received:

- Five phone calls directly from patients in support of the proposals
- five letters directly from patients three in support of the proposals and two wanting further information or an alternative solution
- three emails directly to <u>swlrenal@swlondon.nhs.uk</u> inbox in support of the proposals, but highlighting concerns over parking costs
- many patients, as mentioned below, referenced the letter during engagement at local clinics.

ii. Engagement at kidney clinics and units

The team ran 25 sessions at dialysis units and outreach clinics to raise awareness of the proposals and speak directly to kidney patients. The team attended each clinic twice, to capture specific established patient groups. Sessions ran from 8am till 8pm to ensure there was an opportunity to speak to those patients receiving dialysis at the morning, afternoon and twilight sessions.

A number of patients reported being familiar with the proposals as they had received the letter in the post mentioned above. There was also a pop-up banner at each clinic, encouraging patients to visit the website to find out more information and to complete the questionnaire online using a QR code to aide access.

Materials were handed out at each session including the questionnaire and freepost envelope for people to complete. In total 613 questionnaires and leaflets were handed to patients and the team had 750 face-to-face conversations. The team also made sure materials were available in an 'easy read' version and in a number of different languages. Following on from the engagement at the clinics, the team received 235 questionnaires directly in the post, including 1 'easy read' version.

Overall, the majority of the conversations were positive and supportive of the proposals. The main questions during this activity related to parking and journey times, continuity of care and the possibility of changes to the location of their regular dialysis sessions. Many patients spoke highly of their experience at their local dialysis clinic and the positive rapport with nurses, consultants and other patients.

Those units further out in Surrey felt a specialist service should be built closer to them. A clearly shared negative experience was of waiting times for patient transport, and many patients wanted this looked at as a priority.

Date	Venue	Key themes Questions asked or raised by individual patients
17/08/20 21	Colliers Wood Dialysis Unit	Overall, people were very positive. At least 90% of those spoken to had received the letter and felt that the proposals were a good idea. Parking came up in discussion a number of times and people were very interested in where the unit would be. People wanted to make sure that the clinics they attend now, remained where they are. Most people were happy to take the survey away and complete at home rather than on the spot - lots of people felt tired and didn't want to have full conversations.
14/08/20 21	Farnborough Dialysis Unit	 Questions asked by kidney patients: Why can't the unit have been considered further down into this end of Surrey? Is there a congestion zone charge now in the STGs area? Will there be any consideration to cover any extra costs that the patient's main carer may face due to the slightly further journey/mileage?
23/08/20 21	Farnborough Dialysis Unit	Theme: Transport – issue around Surrey and is a concern for patients when having to travel further into London.
23/08/20 21	North Wandsworth Dialysis Unit	 It was felt that there were issues at current renal ward at St George's (Champneys) including overcrowding, understaffing and outdated building One patient spoken to supported the proposals but would like improvements at current satellite clinics and nursing quality is variable One patient spoken to asked if multi-storey car park viable? One patient said that dialysis patients feel like they're being forgotten – pumping money into a new clinic when they could improve existing dialysis units Overall: overwhelming support from staff and patients
11/08/20	West Byfleet Dialysis	Parking and distance was raised.
21	Unit	• Q: Has there been any consideration for visitors if an inpatient?
23/08/20 21	Kingston Dialysis Unit	No questions or feedback received
20/08/20	Sutton Dialysis Unit	Questions asked:
21		 Impact on new Sutton hospital? Parking for relatives?

Feedback from 1:1 conversations with patients at dialysis clinics

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iii. Meeting with local kidney patient associations

Before the official launch of the engagement, we established a strong relationship with the respective Kidney Patient Association (KPA) based at each trust. Each KPA kindly helped the communications and engagement team to shape and develop materials, and also gave their opinion on the appropriateness of whether live listening events should be face-to-face or virtual, as both options were viable at the time under Covid-19 social distancing guidelines. The KPAs also endorsed the proposals publicly. During engagement, we shared regular updates via email and had one-to-one conversations with each KPA Chair. Each KPA included information on the proposals on their websites and encouraged their members to share their views by completing the questionnaire.

b) Those who might be interested by proposals

i. Focus groups

Under the Equality Act 2010, we have a duty to consider the potential impact of any potential service change on people with protected characteristics. We have extended this to include those classified as carers and those living in deprived areas. To preserve the objectivity of responses, we commissioned an independent company called ASV to run ten focus groups and 14 telephone interviews covering these populations:

- Older people, aged 65 and over
- young people, aged 16 -24
- people with a disability (including learning disability)
- people from a Black, Asian or minority ethnic background
- people who are pregnant or have had a baby in the last two years
- people living in deprived communities
- carers
- people living in South West London
- people living in Surrey Heartlands
- people living in Frimley
- telephone interviews with those living across the three CCG areas who were digitally excluded.

ASV independently recruited and incentivised participants from across the CCG areas to join the focus groups and telephone interviews. Each session ran for 1.5 hours in the evening via Zoom during 10th August – 19th August 2021.

Each focus group started with participants watching a short animation on the proposals, followed by discussions based on the questionnaire. After sharing information about the proposals, the moderator asked each group the following questions:

- Having listened to the proposals, what are your first impressions of the proposed change?
- Do you think that, based on the examples given, that the proposed changes will make care for kidney patients better, worse, or will it stay?

- Do you think this proposal will see benefits for the staff delivering the services (e.g. doctors/nurses/health care assistants) that are likely to make it easier to recruit people to the team?
- From your personal perspective, and from what we've talked about so far, can you think of any other ways the renal services could be organised?
- If you were to need NHS Renal Services after the proposed move to St George's Hospital in 2025 would this make your journey more or less difficult?
- The proposal is to bring together specialist kidney care services under one roof, from your own viewpoint do you think this will improve or worsen access to services for patients?
- If this new kidney unit at St George's Hospital were to be built, how could the unit and the service be designed to make patients visit or stay as comfortable and stress-free as possible?
- In your opinion and from your own experiences, are there any other solutions or adaptations to the current proposals to make the service better that haven't been considered and should be?

Overall, participants at the focus group felt that having specialist care in one centre was a good idea but identified a number of challenges:

- Parking and transport specifically for those with a disability and participants felt that renal
 patients should have their own parking bays "...underground parking, maybe, if it's a new
 building..."
- investment younger people felt that £80m was a large amount of money to spend on a small service and the money could be spent better elsewhere *"high price potentially for a small change...just my first thoughts..."*
- continuity of care patients might like to see specific clinicians and consultants and if services are disjointed, then this could be an issue. "Some people might like to see specific medics and consultant, which could be an issue.

Feedback from each focus group has been incorporated into the full analysis report.

Dates and details of each focus group

Date & Time	Details
Tuesday August 10 th	GROUP 1:
16:00 - 17:30	All must be ages 65+
Tuesday August 10 th	GROUP 2:
18:00 – 19:30	All must be aged 16 – 24
Thursday August 12	GROUP 3:
16:00 – 17:30	All must have a disability, can include a learning disability
Thursday August 12	GROUP 4:
18:00 – 19:30	All must be from a Black or other minority ethnic background
Tuesday August 17 th	GROUP 5:
16:00 – 17:30	All must be currently pregnant or have given birth in the last 2 years
Tuesday August 17 th	GROUP 6:
18:00 – 19:30	All must live in deprived communities – see excel grid for exact locations
Wednesday August 18 th	GROUP 7:
16:00 – 17:30	All must live in South West London CCG area. Ensure a mix of ages, genders, ethnicities & locations within CCG area
	GROUP 8:
Wednesday August 18 th 18:00 – 19:30	All must be carers for a friend or family member. None to be professional carers. Ensure a mix of ages
	- include some young carers
Thursday August 19 th	GROUP 9:
16:00 – 17:30	All must live in Surrey Heartlands CCG area. Ensure a mix of ages, genders, ethnicities & locations within CCG area
The second second dotte	GROUP 10:
Thursday August 19 th 18:00 – 19:30	All must live in Frimley CCG area. Ensure a mix of ages, genders, ethnicities & locations within CCG area
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ii. Staff engagement

The clinical teams across St George's and St Helier hospitals ran four drop-in sessions for their renal staff and colleagues with an interest. Materials were delivered to each hospital site to aid discussions. Material was also provided to raise awareness through regular staff communication channels. There was broad support for the proposals at each session. However, if the proposal is approved, additional engagement needs to take place with supporting teams such as dieticians and radiology.

The South West London Clinical Commissioning Group also included information about the proposals regularly in their daily update which is circulated to every staff member. The Improving Kidney Care proposals were also discussed at the South West London CCG Team Talk, hosted by Sarah Blow, the Accountable Officer.

iii. Community outreach delivered by CCG engagement teams

Each CCG borough team reached out to local communities and groups with an interest to explain the proposals and seek feedback. Patient & public engagement leads for each borough across South West London, Surrey Heartlands and Frimley CCG approached the following groups identified in the Impact Assessment:

- Long-term-condition support groups e.g. Diabetes UK
- Black and Minority Ethnic groups with a focus on Croydon, Merton & Sutton

- older people's groups e.g. Age UK
- groups that support people with a disability
- groups supporting people with a mental health condition and/or a learning disability and/or autism.
- carers
- groups linked to deprived areas and seldom heard community e.g. Street Watch Merton.

Each borough patient & public engagement team shared regular briefings with their voluntary sector stakeholders and offered to attend their existing meetings or provide additional information. Due to COVID-19 restrictions, opportunities to engage were offered virtually.

Following the Joint Health and Overview Scrutiny Committee meeting in July, councillors shared suggestions of groups to engage with. These suggestions were shared with the relevant local borough team who proactively approached and offered opportunities to engage.

Interest in the proposals and take-up of engagement opportunities varied across each borough. Groups across South West London were keen to find out more and offered their views on the proposals. Many of the groups also included information in their local communications such as weekly newsletters and across their social media channels.

In total, the teams met with 27 key interest groups during 27th July – 7th September.

The response to this community outreach overall was one of broad support for the proposals, with the majority feeling the plan to have specialist services under one roof was a good idea.

Other feedback from this outreach activity included concerns and challenges around travel, particularly for older people or those who are seriously unwell and; if the funding for the Improving Healthcare Together plans would be compromised by this new specialist unit.

Detailed analysis of the feedback from these events can be found in the full analysis report.

iv. Regular updates with stakeholders & governance (including the letters received)

To ensure key stakeholders were kept informed and had an opportunity to share their views, regular updates were sent to the following stakeholder groups across South West London, Surrey Heartlands and Frimley:

- Members of Parliament and Councillors
- Health & Wellbeing Board Chairs
- Overview & Scrutiny Committee Chairs & Deputy Chairs
- Council Chief Executives, Directors of Adult Social Care and Directors of Public Health
- Primary Care Network leads
- Trust staff
- Local Medical Council /GP Federations
- Healthwatch
- Council for Voluntary Services
- Voluntary sector organisations
- CCG governing body members.

In total, four updates were circulated to stakeholders including:

- Invitation to Committees in Common (22nd June)
- launch of engagement following JHOSC decision
- midpoint review and an ask for stakeholders to encourage their peers/constituents to share their views
- close of engagement update and next steps.
- v. Stakeholder responses received

The team received seven emails directly from stakeholders to the <u>swlrenal@swlondon.nhs.uk</u> inbox.

Four responses were directly from Councillors including Merton and Sutton Council. One response received was from the MP for Mitcham & Morden, and one response was from the Leader of Merton Council. The team also received a letter directly from a resident in Merton.

Of the seven emails received, four were not supportive of the proposals. The key themes from the letters and emails related to concerns relating to finances, continuity of care for patients, travel and the future of the St Helier Renal Research Unit building and staff which was funded by patients.

Each letter and/or email was responded to by the programme lead and also shared with the independent analysis team to include in the engagement analysis. Full details can be found in the independent analysis.

The team also received one media enquiry from the *SW Londoner* who asked for further information on the proposals.

c) Those with a wider interest including communications activities

i. Listening events

To enable those with a wider interest to have their say and find out more about the proposals, the team held two listening events on 9th August and 3rd September.

In total, 63 people signed up to both events (31 people for 9th September and 32 people registered for 3rd September).

Both events were an open invite and widely promoted regularly across social media and on CCG websites. Due to ongoing COVID-19 restrictions and concerns around the new Delta variant, and having also sought the advice of the Kidney Patient Associations, each event was held virtually. Participants were asked to sign up via Eventbrite and had an opportunity to ask questions before the meeting.

Questions received via Eventbrite were varied and included:

- Will anything improve kidney health? What will you do to improve kidney health?
- I am very worried about parking. St George's already has a very limited space for staff and patients. There is regular disruption to the public highway on Blackshaw Road with queues for the main car park. How will this be addressed with the limited transport links?
- How can you improve chronic kidney disease?

Each event was independently facilitated by Paul Parsons from The Consultation Institute. The panel for each event was a mixture of clinicians from St George's and St Helier Hospitals and programme staff, and a British Sign Language interpreter was present.

At the start of each event, participants had an opportunity to hear from the panel who set out a short presentation on the proposals. Participants were given an opportunity to ask questions and share feedback. At the end of each event, participants were encouraged to complete the questionnaire.

Comments from each event were wide- ranging and included reference to the following:

- Investment where the money is coming from, if it is sustainable and whether it will affect the Improving Healthcare Together proposals
- continuity of care concerns around separating outpatients and specialist care across sites could mean patients do not always see the same clinician
- travel and transport parking issues at St George's Hospital
- concerns around the future of St Helier Hospital and services for local people.

The reports from both listening events can also be found on our website: https://swlondonccg.nhs.uk/get-involved/have-your-say/improving-kidney-care/listening-events/

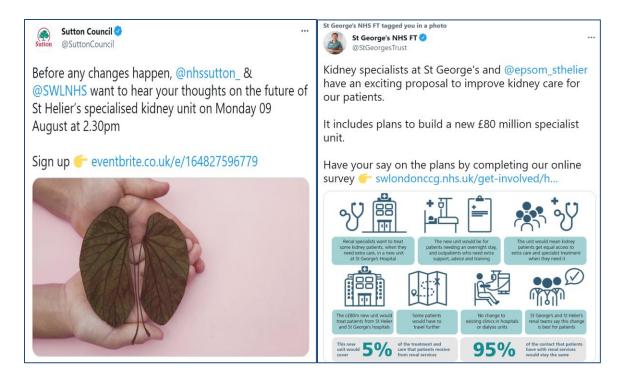
ii. Social media and website

A social media plan was developed by the programme team and shared with communications and engagement colleagues. The host for the Improving Kidney Care social media messages was the @SWLNHS twitter page and Facebook page.

The aim of the social media campaign was to raise awareness of how to access information, have their say and complete the questionnaire.

During pre-engagement and engagement the @SWLNHS twitter and Facebook page shared 44 messages across the channels, including the six boroughs in South West London and Surrey Heartlands.

Social media messages were retweeted, shared and liked by a number of partners' stakeholders including local councillors, Age UK Sutton, Sutton Council and Richmond CVS.



To ensure the content was informative and interesting to local people, the team adapted the content regularly and shared pictures, draft images of the hospital and short films from clinicians.

The best performing tweet was on 20th August with 3056 impressions, four retweets and 16 likes.



The best performing Facebook post was on launch day – 27th July and 4th August which shared details of the listening event on 9th August.

Information on the proposals is hosted on the SWLCCG website. Following feedback from stakeholders that the website was difficult to navigate, the team adapted the site and ensured it was easier to find key documents, event information and the questionnaire.

iii. Materials - ensuring our communications were accessible to all

We worked with a range of stakeholders including renal clinicians and the St George's and St Helier Kidney Patient Associations to co-produce our engagement materials which included:

- An engagement summary leaflet
- an engagement questionnaire (online and hard copy)
- three case studies
- posters
- pull up banners for the dialysis units
- draft images of the proposed kidney unit
- frequently asked questions
- dynamic media and social media content including an animation and vox pops from clinicians.

To ensure we met the needs of people with additional requires we:

- Produced an 'easy read' engagement summary leaflet and engagement questionnaire
- produced an engagement summary leaflet and engagement questionnaire into the three most common other languages across the geographies Tamil, Urdu, Polish and in addition for Frimley, we produced both the summary and questionnaire in Nepalese
- had British Sign Language interpreters at both listening events
- disseminated information on the proposals and signposted people to the documents via multiple channels including
 - Improving Kidney Care website (<u>https://swlondonccg.nhs.uk/get-involved/have-your-say/improving-kidney-care/</u>)
 - o partner websites
 - o stakeholder updates including messages to Voluntary Sector organisations
 - o local media
 - social media (Twitter and Facebook)

Materials were distributed to each dialysis unit, each CCG and the trust sites to aid discussions.

Appendix Two: Demographics

Survey – respondent profile

The online self-selecting survey opened on 27th July and closed on 7th September 2021. The survey received 400 responses. A breakdown of the profile of responses can be found below. Four in five respondents are kidney patients.

Type of respondent	No.	% of all responses	Age	No.	% of all responses
Kidney patient	323	81%	21-44	33	8%
Family or carer	15	4%	45-59	81	20%
Member of the public	33	8%	60-64	45	11%
Member of staff	19	5%	65-74	94	24%
Member of VCS/Faith	4	1%	75-84	72	18%
Other	6	2%	85+	16	5%
Borough (top 5)		270	Ethnicity		
	83	21%	White	225	56%
Croydon			Asian	55	14%
Merton	42	11%	Mixed	3	1%
Sutton	37	9%	Black	46	12%
Wandsworth	23	6%	Other	7	2%
Woking	17	4%	Disability		
Gender			Yes	211	53%
Male	199	50%	Carer		
Female	136	34%	Yes	34	9%

Demographics from other engagement activities

	Target groups	Engagement undertaken	Approx numbers reached
Listening events	 All Older people People with a disability including learning disability and/or autism People with long-term health conditions Political stakeholders and interest groups 	2 events	63 signed up
Clinical pop-ups	• All • Older people	25 visits	750

	 People with a disability including learning disability and/or autism People with long-term health conditions Deprived communities People from ethnic minority populations People with a mental health condition 		
Community outreach – via Patient and Public Engagement Leads	 Long term condition support groups e.g. Diabetes UK Black and Minority Ethnic groups – with a focus on Croydon, Merton & Sutton Older people's groups e.g. Age UK Groups that support people with a disability including physical Groups that support people with a mental health condition and/or a learning disability and/or autism. Carers Groups that are linked to deprived areas and seldom heard community – e.g. Street Watch Merton. 	27 community sessions	
Focus groups	 Older people, aged 65 and over Young people, aged 16 -24 People with a disability (including learning disability) People from a Black, Asian or minority ethnic background People who are pregnant or have had a baby in the last two years People living in deprived communities Carers People living in South West London People living in Surrey Heartlands People living in Frimley Telephone interviews with those living across the three CCG areas who were digitally excluded 	10 groups 14 telephone interviews	89 people 14 people

Demographics from the focus groups and tele depth interviews

One-to-One Interviews

There were a total of 14 one-to-one interviews conducted with people who identified as digitally excluded in line with the NHS Digital definition. The demographic information provided by participants is shown in the tables below.

Sex	Count	%
Female	12	86%
Male	2	14%
Grand Total	14	100%

Age	Count	%
25-34	3	21%
35-44	3	21%
45 -54	1	7%
55-64	1	7%
65-74	5	36%
75-84	1	7%
Grand Total	14	100%

Status	Count	%
Economically Inactive	1	7%
Employed	7	50%
Retired	5	36%
Self Employed	1	7%
Grand Total	14	100%

Ethnicity Count %

Asian Indian	1	7%
Mixed Heritage	1	7%
White British	11	79%
White European	1	7%
Grand Total	14	100%

Disabled?	Count	%
No	14	100%
Grand Total	14	100%

Residence	Count	%
Bracknell	1	7%
Croydon	1	7%
Elmbridge	1	7%
Maidenhead	2	14%
Slough	2	14%
Surrey	2	14%
Wallington	2	14%
Wandsworth	1	7%
Windsor	1	7%
Winkfield	1	7%
Grand Total	14	100%

Focus Groups

In total 89 people took part in the 10 online focus groups. The demographic information they provided is shown in the tables below.

Sex	Count	%
Female	64	72%
Male	25	28%
Grand Total	89	100%

Age	Count	%
18-24	2	2%
25 - 34	32	36%
35-44	18	20%
45 -54	17	19%

55 - 64	9	10%
65 -74	11	12%
Grand Total	89	100%

Status	Count	%
Employed	67	75%
Economically Inactive	1	1%
Not specified	2	2%
Retired	9	10%
Student	8	9%
Unemployed	1	1%
Unemployed due to health	1	1%
Grand Total	89	100%

Ethnicity	Count	%
Asian Chinese	1	1%
Black African	5	6%
Black Afro Caribbean	1	1%
Black British / Caribbean	1	1%
Black British	5	6%
Black British/African	1	1%
Black Caribbean	2	2%
British Asian	2	2%
British Indian	1	1%
Chinese	1	1%
Half Arabic and Half English	1	1%

Indian	3	3%
Mixed Heritage	2	2%
Mixed White and Asian	1	1%
White Asian	1	1%
White British and Indian	1	1%
White British	57	64%
White European	2	2%
White New Zealand	1	1%
Grand Total	89	100%

Disabled?	Count	%
No	78	88%
Yes	11	12%
Grand Total	89	100%

Reported Condition (Disability)

Arthritis - knee and joints

Autism, ADHD

Dyspraxia and Dyslexia

Dyspraxia

EUPD arthritis

Fibromyalgia cervical spondylosis

Heart disease & arthritis

MS

NEAD (Non-epileptic attack disorder)

Spinal ECT

Residence	Count	%
Addiscombe West	1	1%
Ascot	2	2%
Barnes	1	1%
Battersea	1	1%
Bracknell	4	4%
Bramley	1	1%
Broad Green	2	2%
Carshalton	1	1%
Colliers Wood	2	2%
Coulsdon	2	2%
Croydon	6	7%
Egham	1	1%
Guildford	2	2%
Kingston Upon Thames	4	4%
Maidenhead	3	3%
Merton	3	3%
New Addington	3	3%
Old Windsor	1	1%
Reigate and Banstead	1	1%
Richmond	1	1%
Rowledge	1	1%
Runnymede	3	3%
Selsdon	5	6%
Slough	11	12%
Spelthorne	1	1%

Streatham	1	1%
Surrey	3	3%
Sutton	4	4%
Twickenham	2	2%
Waddon	2	2%
Wandsworth	6	7%
Wimbledon	2	2%
Windsor	5	6%
Woking	1	1%
Grand Total	89	100%