KING'S HEALTH PARTNERS
An Academic Health Sciences Centre for London
Pioneering better health for all

NHS
Royal Brompton & Harefield
NHS Foundation Trust

Improving heart and lung care for patients: now and in the future

A report on the findings from the patient and public engagement activities in January and February 2019

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(revision April 2019)

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Mutual Gain

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1 EXECUTIVE SUMMARY

King's Health Partners (the Academic Health Sciences Centre comprising Guy's & St Thomas', King's College Hospital and South London & Maudsley NHS Foundation Trusts and King's College London) and Royal Brompton & Harefield NHS Foundation Trust 'are developing proposals to change how they provide care and treatment for patients with heart and lung disease. In some cases, this may change where care and services are provided'. They want to transform the outcomes and experience of patients with cardiovascular and respiratory health conditions by creating an integrated health system – clinical and academic - which touches the lives of more than 15 million people, and helps cardiovascular and respiratory patients on a regional, national and international level.

It is vital that patients, carers, family members and other stakeholders understand the proposals and have a chance to say what they think before the Partnership submits its initial proposals to NHS England. This report outlines the range of engagement activities that have taken place in January and February 2019 to ensure this happens as follows:

- Three engagement events held at the Royal Brompton Hospital on 29th January, King's College Hospital on 30th January and Guy's & St Thomas' on 6th February
- A Webinar on 6th February
- A postal and online survey
- Feedback from the Patient Public Reference Group

This report outlines the methodology used in each of the engagement activities.

1.1 Engagement events

In total the events were attended by 85 people. A summary of the key messages and issues arising from the engagement events is as follows:

- Patients and other participants were appreciative of the opportunity to discuss the Partnership's proposals
- Overall, there was approval for the outline proposal, however, there was also a recognition that much more detail is required to help patients, their families and carers comment in more depth on how the proposals might affect them. This resulted in a degree of anxiety about change and provoked some scepticism because of the lack of detail.
- Participants were willing to reflect on the potential benefits including how the Partnership could strengthen the knowledge and skills of GPs.

- They also could see the disadvantages, for the most part based on the things that do not work currently, such as lack of consistency in, and continuity of, care, the difficulties in making appointments and poor connections with GPs and other local services.
- Parents particularly highlighted the pressures of transport, in particular the cost of transport and parking which adds to the stress, for instance of having an unwell child. There were worries about public transport and, for those unable to use it, concerns about how accessible car parking would be.
- There was enthusiasm about how digital innovation could improve processes but the need to prevent digital exclusion was emphasised.
- The potential benefits of joined-up working for better treatment were recognised.
- The sharing of records was generally welcomed as long as the appropriate safeguards are in place.
- The potential of 'keeping it personal' by focussing on patient choice and patient-centred care, rather than treatment, was supported.
- The importance of continuity of care between individual clinicians and patients was a recurring theme.
- There are still many questions and patients, carers and family members were clear that they want to participate in future discussions about how to answer them.

A number of further questions arose from the discussion at the events. These covered building and development issues, funding, the organisation of the programme, service implications, patient experience, partnership working, implications for staff and the broader context.

The issues, messages and further questions emerging from the Webinar echo those from the engagement events.

1.2 Survey

A total of 257 responses were received to the survey (71 online and 186 completing and returning a paper questionnaire). A summary of the key messages arising from the survey is as follows.

1.2.1 Rounding numbers in the survey

Rounding a number means replacing it with a different number that is approximately equal to the original, but has a shorter, simpler representation; for example, replacing 23.4476 with 23.45. In this report numbers with a value below 0.5 are rounded down to the nearest whole number and those with a value above 0.5 are rounded up. For instance 1.6 becomes 2 and 1.4 becomes 1, because of this values in tables may add up to more or less than 100%.

1.2.2 Views on current care

Is the current service working well?

In response to the question "To what extent do you think the NHS heart/lung care you currently receive is working well?":

- The overwhelming majority of respondents (93%) who provided an answer to this question (including don't know) thought the current service works well (20%) or very well (73%).
- Only 2% of respondents were unsure, stating they 'don't know'.

When considered by care received – including those who would rather not say:

- Recipients of heart and lung care are most likely to state the service works very well (83%);
- Those who received heart care (72%) expressed the same sentiment, closely followed by those who received lung care (71%).

What is particularly good about the current service

- The people
- Medical expertise of the clinical team
- Continuity of care
- Support and reassurance
- Centres of excellence
- Children's care is excellent
- Appointments

What can be improved with the current service

- Regular dialogue
- Inpatient and outpatient food choices
- Digital records / compatible computer systems
- Improved staff attitudes
- More preventative action
- Appointments and administration

What is most important to keep of the current service

- Child friendly environment
- Research
- Involve patients more in their own care
- Safe
- Joined up care
- Improved aftercare
- A more caring attitude for all
- Improved communication

Likelihood to recommend (friends and family)

In response to the question "How likely are you to recommend our NHS heart/lung care to friends and family if they needed similar care or treatment, based on the care you are currently receiving or have recently received?" The responses were as shown in the table below:

	%	No.
Don't Know	1%	3
Extremely unlikely	5%	13
Unlikely	2%	5
Neither likely or unlikely	4%	9
Likely	23%	54
Extremely likely	65%	155
Grand Total	**100%**	**239**

In this case the friends and family score is 81. This score is the result of subtracting the negative responses ('extremely unlikely' and 'unlikely') from the positive responses ('extremely likely' and 'likely').

Reasons for providing this score

Positive Responses (Promoters):

- ✓ Excellent care
- ✓ Complete confidence in the staff

Negative Responses (Detractors):

- × A very small proportion of respondents felt they were *"…fobbed off…"* by staff

- ✓ The hospital is always excellent
- ✓ Excellent clinical staff
- ✓ Service delivery in a centre of excellence

and clinicians in terms of explaining their diagnosis or supporting them with aftercare

- × Lack of attention to aftercare, it's assumed we will work out what we need by ourselves
- × The services are underfunded
- × Frustration with the limitations of services (including referral to service from GPs)

1.2.3 Views on the proposal

- The majority of respondents (69%) who provided an answer thought the proposal would work well sometimes (23%) or would work very well (46%).
- 21% of respondents were unsure and only 6% gave a negative response.

First impressions positive reactions:

- ✓ A wonderful vision
- ✓ Sharing resources to create a centre of excellence
- ✓ Twenty first century technology

First impressions negative reactions

- × The end of a legend (RBH)?
- × Too big
- × Is it overambitious?
- × Patient focus (liking the focus of patient care in the proposal and concerned about the potential to lose this due to the size and scale)

What do you like about the proposal?

- Sensible and cost-effective
- Care at home
- Research and faster access to new treatments
- Reduced duplication
- Good design

What don't you like about the proposal?

- Is this a cost cutting exercise?
- Care at home too soon – concerns that patients may be discharged to care at home before they are ready putting strain on them and their carers
- Cost for patients
- New technology

1.2.4 Anything else?

- Gratitude to NHS staff
- Pastoral care

- Reassurance
- New technology

1.3 Patient Public Reference Groups (PPRG)

Overall, the group emphasised the important value of openness and transparency in preventing unnecessary arousal of concern and suspicion about the proposals in the future.

A summary of the key messages arising from the Patient Public Reference Group is as follows:

- A need for more detailed information about the proposals, including how they affect patients at the different trusts and data relating to demand and capacity planning and financial implications
- Continuity of care, communications and *'getting the basics right'*
- Joined up working – supporting and developing skills in primary and urgent care
- Research and retaining the valuable research partnerships that exist today
- Travel, transport and patient-carer accommodation
- Retaining the reputation and heritage of the Royal Brompton Hospital and the individual trusts involved in the partnership
- Engaging and communicating with staff
- Comments and recommendations on the Partnership's draft response to the findings of the different engagement activities

The PPRG welcomed the opportunity to comment on the engagement report, and recommended the following is addressed in the Partnership's response.

- While acknowledging NHS England's role in bringing information to light as part of its public consultation in summer 2019 – the group would welcome the Partnership's expressed commitment to sharing information about the following in the future:
    - the numbers of patients who are affected
    - *how* patients of each trust will be affected by the proposals
    - the financial implications of the programme, including the cost of the estates expansion
    - demand and capacity modelling
- The need to engage people with multiple complex conditions to ensure the Partnership's transformation programme fully understands and takes account of the needs of such patients in the future design of services
- The response on travel and transport should be strengthened, by making an expressed commitment to addressing the issues that have been highlighted by respondents and the Reference Group

- Acknowledgement of the concerns about retaining the heritage of the Royal Brompton Hospital and how the Partnership will address this in its transformation programme
- To address the matter of patient and carer accommodation, as part of the proposals – it is unclear if this has been considered to date
- To acknowledge the importance of staff engagement and communication in the Partnership

1.4 Appendices

- Appendix One provides the complete reports for the engagement events hosted by each trust.
- Appendix Two provides the full details of the survey findings.
- Appendix Three is a copy of the questionnaire used in the survey.

1.5 Next steps

The findings will be submitted to NHS England to inform the development of its Pre-Consultation Business Case and public consultation that is likely to take place in autumn 2019.

2 INTRODUCTION

King's Health Partners (the Academic Health Sciences Centre comprising Guy's & St Thomas', King's College Hospital and South London & Maudsley NHS Foundation Trusts and King's College London) and Royal Brompton & Harefield NHS Foundation Trust 'are developing proposals to change how they provide care and treatment for patients with heart and lung disease. In some cases, this may change where care and services are provided'. They want to transform the outcomes and experience of patients with cardiovascular and respiratory health conditions by creating an integrated health system – clinical and academic - which touches the lives of more than 15 million people, and helps cardiovascular and respiratory patients on a regional, national and international level.

It is vital that patients, carers, family members and other stakeholders understand the proposals and have a chance to say what they think before the Partnership submits its initial proposals to NHS England. This report outlines the range of engagement activities that taken place in January and February 2019 to ensure this happens as follows:

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- A Webinar on 6th February
- A postal and outline survey
- Feedback from the Patient Public Reference Group

The findings will be submitted to NHS England to inform the development of its Pre-Consultation Business Case and public consultation that is likely to take place in summer 2019.

3 METHODOLOGY

3.1 Sampling for face-to-face events and postal questionnaire

Following circulation of guidance to support consistency, the sampling and recruitment of participants for both the face-to-face events and the postal survey were undertaken by each trust. The aim was to invite a representative cross-section of patients, assuming a recruitment ratio of one in ten, based on the experience of recruiting to previous patient and public engagement activities. The event and survey sample was identified as follows:

- Patients receiving care from cardiovascular and respiratory specialties, with an outpatient attendance or an elective inpatient discharge during July, August and September 2018
- Due to the geographic reach of trusts, particularly Royal Brompton & Harefield, it was recognised that many of those invited might not be able to attend an event, so sample sizes were increased accordingly
- Grouping patients by age and ethnicity, the numbers invited were proportionate to the overall patient population in the sample
- To prevent risk of under-representation, where the numbers in any age and ethnicity groups were lower, the sample was increased as follows:
    - Royal Brompton & Harefield: to achieve at least ten invitations per group
    - Guy's & St Thomas': to achieve 40 per cent BAME representation in the sample

The table below, provides the sample sizes for each trust:

Activity	Royal Brompton & Harefield NHS Foundation Trust	Guy's & St Thomas' NHS Foundation Trust	King's College Hospital NHS Foundation Trust	Total sample size across partnership
Face to face events	567	489	425	1,481
Postal and online survey	606	382	288	1,276

3.2 Public engagement events

Three public engagement events were designed to gather the views of patients, carers, family members and other stakeholders. In total **85** patients, carers and family members attended the events, which took place at:

- Royal Brompton Hospital (29th January)
- The Cicely Saunders Institute, King's College Hospital (30th January)

- The Robens Suite, Guy's and St Thomas' (6th February)

The purpose of each event was to:

- Provide participants with an understanding of the proposal, as set out in the information paper distributed to invitees beforehand and available at the event (https://www.guysandstthomas.nhs.uk/resources/about-us/proposals-to-improve-heart-and-lung-disease-care.pdf)
- Listen to the reactions, experiences, ideas and thoughts of participants that can help the Partnership understand how patients, their families and carers think they may be affected
- Use the findings from the events, and the survey to inform the ongoing development of the Partnership's proposals

At **Royal Brompton Hospital** 26 patients and four carers/family members were present. One mother came with her child, who had received treatment at Royal Brompton, as well as the child's grandmother. A representative from the voluntary and community sector was also present. The experiences of participants covered a range of conditions including chronic asthma, respiratory disease, chronic obstructive pulmonary disease (COPD), idiopathic pulmonary fibrosis (IPF), tracheostomy, congenital heart conditions, and having a child with cystic fibrosis. Some came to support their relatives, others from patient support groups and a hospital governor was also present. A representative from a parent and children's support charity provided useful insights.

At **King's College Hospital** 20 patients and carers/family members brought a breadth of adult experience, primarily from cardiac conditions, including a transplant patient for over 25 years (whose treatment includes a 14-hour operation and a long journey around the M25) and a younger person just beginning treatment for a heart condition. There were others who are active in existing public and patient participation both at King's and in the wider health system, including a public governor at the hospital and a chair of a support group. There were no parents or users of children's service present. Although there were three paediatricians in attendance there was little discussion specifically about children's services.

At **Guy's & St Thomas' Hospital** 35 people attended the event (twenty patients, six parents of child patients and nine carers/family members). In contrast to the earlier events there was a larger number of parents, some of whom also brought their children with them. As well as giving more prominence to children's issues this created a greater sense of fun in the event compared to the previous events, which were in themselves vibrant and very engaging. Overall, there appeared to be greater ethnic diversity, although fewer monitoring

forms were completed than at the previous events. At one table two people had experience of lung cancer treatment and talked positively about the emotional support they had received from the Cancer Centre at Guy's. Among the other perspectives present were a foundation trust governor, a patient and his support worker from a community mental health charity and one participant who was supported to communicate his (or her) views. Diversity monitoring forms were completed by 40 people (20 at Royal Brompton, 11 at King's College and 9 at Guy's & St Thomas'). These are summarised in the following table (note: not all the forms were fully completed, and some respondents ticked more than one option):

Age group	16-24:	25-34	35-44	45-54	55-64	65-74	75-84	85+
	2	*2*	*4*	*4*	*9*	*9*	*9*	*1*
Gender	**Female**				**Male**			
	22				*17*			
Sexual orientation	**Heterosexual or straight**			**Lesbian or gay woman**			**Prefer not to say**	
	36			*1*			*1*	
Religion	**No religion**	**Muslim**	**Christianity**	**Buddhist**	**Hindu**	**Jewish**	**Prefer not to say**	
	6	*3*	*25*	*2*	*2*	*1*	*1*	
Disability, long-term illness or health condition	**Yes**				**No**			
	28				*14*			
	A long-standing illness or health condition				*21*			
	A social communications impairment				*1*			
	A mental health difficulty				*1*			
	A physical impairment or mobility issues				*4*			
	A specific learning disability (e.g. dyslexia, dyspraxia or AD(H)D)				*1*			
	Blind or visual impairment				*1*			
	Deaf or have a hearing impairment				*3*			
	An impairment, health condition or learning difference that is not listed				*3*			
	None				*20*			

Caring responsibilities	Primary carer of a child or children (under 2 years)	*2*
	Primary carer of a child or children (between 2 and 16 years)	*3*
	Primary carer of a disabled child or children	*1*
	Primary carer or assistant for a disabled adult (18 years and over)	*1*
	Primary carer or assistant for an older person or people	*1*
Race or ethnicity	White British	*23*
	Irish	*3*
	Any other White background	*1*
	Indian	*2*
	Pakistani	*1*
	Any other Asian background	*2*
	African	*6*
	Caribbean	*1*
	Any other ethnic group	*1*
Postcodes	Royal Brompton: E18, EN1, HA2, IG6, NW6, NW10, RH8, RM13, SW1A, SW5, SW6, SW11, SW13, TW1, TW1, TW1B, UB4, W3 King's College: BR1, BR2, BR2, DA4, SE5, SE20, SE21, SE22, SE24, SW16, SW16 Guy's & St Thomas': BR3, BR7, SE1, SE1, SE8, SE9, SE13, SE16, SE23	

Each event opened with presentations about the background, the composition of the Partnership, an overview of the proposal and the plans for how to do it, the process and an outline of how it might affect patients and their families, illustrated by two patient stories. The components that would help deliver the plans and next steps were also outlined. These were given by:

- Royal Brompton Hospital: The Chief Executive, Bob Bell, and deputy medical director, Professor Andrew Menzies-Gow
- King's College Hospital: Executive Medical Director, Professor Julia Wendon
- Guy's & St Thomas': Consultant Intensivist & Associate Medical Director, Professor Richard Beale, and Medical Director, Evelina London Children's Healthcare, Dr Sara Hanna

Clare Macdonald, who is leading communications and engagement on this programme for NHS England, was also present at each event to outline NHS England's role and the next stage of the engagement process.

Participants were invited to join small group discussions arranged by service area: Adult Heart, Adult Lung, Children's Heart and Children's Lung. It transpired however that at each event the group debates mostly ranged across the breadth of all services.

The first task was an 'icebreaker' with participants being asked to capture on different coloured 'post-it' notes their reasons for being at the event and their expectations from it. After this, using a feedback grid, participants were asked about their responses to the opening presentation and capture thinking about the overall model of care. These were recorded on 'post-it' notes and added to the grid as strengths, areas for improvement, opportunities and/or challenges. The next part of each event asked participants to draw on their personal and specific experiences or conditions to reflect on five cross-cutting themes:

- Transport and travel
- Joint/shared/partnership working
- Use of digital innovation
- Patient records
- 'Keeping it personal'

Prompt cards with specific questions were provided. As with the earlier discussions, responses tended to cover the breath of the proposal and these were captured on 'post-it' notes, separately coloured for each of the themes.

At the start of each event participants were encouraged to note any specific questions and, before the close, a number of further questions were raised with the whole group. Some were answered immediately by the clinicians and other staff present and, along with a detailed of the discussions at each event, they are captured below in 4.6.

3.3 Webinar

Held on 6th February from 12 noon to 2pm, the Webinar provided an engagement opportunity for patients and the public unable to attend the face-to-face events. There were no registration requirements or individual identification of those taking part. Twenty-two people joined the discussion, four or five of these were patients with the remainder being staff from a range of hospital and community services. Following a similar format as the public events, Professor Richard Beale opened with a presentation and MutualGain then facilitated the debate. Unexpectedly Professor Beale was called away to respond to a

medical emergency, so Andrea Carney (Patient and Public Engagement Lead and Penny Agent (Director of Allied Clinical Sciences) responded to questions from participants.

3.4 Survey

The partners (Royal Brompton & Harefield NHS Foundation Trust and King's Health Partners) provided the opportunity for interested parties to take part in an engagement survey which was available to complete as:

- An online survey
- A hard copy questionnaire returned via Freepost

The survey ran between 9 January and 6 February 2019.

In total 257 responses were received:

- 71 respondents completed the survey online
- 186 respondents provided complete comments through the paper questionnaire

The key demographic characteristics of the respondent sample are shown below (please note answers to these questions were not compulsory and not completed by all 257 respondents):

- 76% are aged between 55 and 84 (based on 218 responses to the question)
- The gender of respondents was, broadly, evenly distributed between male and female (based on 224 responses to the question):
  - 51% Male;
  - 47% Female.
- The majority who provided an answer (including prefer not to say) describe themselves as 'Heterosexual/straight' (88.3% - based on 223 responses to the question).
- The majority who provided an answer (including 'prefer not to say) describe themselves as 'Christian' (60.3% - based on 176 responses to the question).
- The majority who provided an answer (including prefer not to say) reported that they had a disability (70% - based on 223 responses to the question.)
- The majority who provided an answer said they had no caring responsibilities (77.5% - based on 200 responses to the question.)
- Of those respondents who provided a response (including 'prefer not to say) the majority described themselves as White British (70.6% - based on 214 responses to the question.)

A report of the overall analysis of the survey results is provided in Section 6 below.

A detailed breakdown of the demographic characteristics of respondents is provided in Appendix Two. Respondents provided information related to the partner Trust they most often received care from, along with any other hospital that supported their health care needs. The partner Trusts are:

- Royal Brompton & Harefield NHS Foundation Trust:
  - Royal Brompton Hospital
  - Harefield Hospital
- King's College Hospital NHS Foundation Trust:
  - King's College Hospital
  - Variety Children's Hospital
  - Princess Royal University Hospital
- Guy's & St Thomas' NHS Foundation Trust:
  - St Thomas' Hospital
  - Guy's Hospital
  - Evelina London Children's Hospital
  - Evelina London Children's Healthcare

However, on analysis of the data by partner Trust it is clear that no meaningful conclusions can be drawn, except for inference and coincidence. For this reason this information is not included in the report, in our opinion it is likely to be more misleading than enlightening in terms of informing the partners on the engagement exercise outcomes.

3.5 Patient Public Reference Group

Unlike other activities described in this report, this group is facilitated and reported by the Partnership, as opposed to MutualGain.

On 22nd January 2019, the Partnership established a Patient-Public Reference Group, including representatives of charities and support groups for people living with heart and lung conditions, patients and carers.

To ensure the views of patients and the public are adequately reflected, duly considered and influence the work of Royal Brompton & Harefield and King's Health Partners, embracing adults and children's heart and lung services, its objectives are to:

- Receive updates, review and comment upon the development and implementation of the Partnership's engagement plans

- Inform and advise on the Partnership's approach to patient and public engagement (including informing the design of engagement activities and supporting partners to identify and engage key stakeholders)
- Consider the findings of the various patient-public engagement activities and act as critical friends in ensuring the views of patients, their carers and families are taken into account and influence development of the Partnership's clinical academic models
- Provide representation or occasional attendance at other groups within the Partnership's governance structure to contribute to the development of proposals, as required
- Where appropriate, to participate in engagement events and activities, to ensure the group continues to connect with and reflect the voice of wider patient-public stakeholders

The Reference Group will continue to be a key mechanism of engagement for the life of the programme.

4 PUBLIC EVENTS

4.1 Introduction

In this section we provide a summary overview of the outcomes of the three public events

- Royal Brompton Hospital (29th January)
- The Cicely Saunders Institute, King's College Hospital (30th January)
- The Robens Suite, Guy's and St Thomas' (6th February)

Detailed reports for each event are available in Appendix One.

4.2 Events: summary findings

> ***'Would like to input anything useful I can to the integration process. And, since every generation of my family has had serious heart disease, I would like to help build a better future for my sons!'***

A summary of the messages and issues emerging from the engagement events is as follows:

- Patients and other participants were **appreciative of the opportunity to discuss the Partnership's proposals**, drawing on their own experiences (both good and poor). Although most people had been invited by letter or encouraged to attend by staff, there was **some initial uncertainty** about the purpose of the events.
- At the King's College Hospital event there was a strong message from some participants that by embracing the creation of a specialist hub, seeking to strengthen community services, support integration and encourage better self-management, the idea in reality covered more than one proposal which may be unrealistic.
- Overall, there was **approval for the conceptual idea** of the proposal but also recognition that at this stage **much more detail is required**, especially about funding, numbers of patients involved and the design of services and buildings.
- A significant number of participants expressed **anxiety about change**, particularly its impact on their current treatment. There was also some **scepticism** about the motives for the change, based on participants' own experiences and understanding of the wider political and economic context.
- In each of the areas of discussion participants were **willing to reflect on the potential benefits** such as stronger partnerships, specialists working with other parts of the health system and the prospect of more modern facilities.

- They also could see the **disadvantages, for the most part based on the things that do not work currently**, such as **lack of consistency in and continuity of care**, the difficulties in making appointments and poor connections with GPs and other local services. There was considerable criticism of GPs, while appreciating the pressures primary care faces. At the same time there was recognition that **the Partnership could strengthen the knowledge and skills of GP**s in supporting patients with heart and lung conditions.
- Parents particularly highlighted **the pressures of transport** – its high costs and the lack of parking – which add to the stress, for instance of having an unwell child. While the location of Guys' & St Thomas' services will not change under the proposals, there was agreement that the proposed new central location would be better for the Royal Brompton patients, especially for those travelling from outside London, and for anyone currently having to travel to different hospitals to receive care. There were worries however about public transport and, for those unable to use it, concerns about how accessible car parking would be.
- There was enthusiasm about how digital innovation could improve processes but recognition that not everyone is confident about using IT as well as emphasising the need to prevent digital exclusion.
- The potential benefits of joined-up working for better treatment were recognised but there was scepticism about how it would work in practice, particularly strengthening the relationship with GPs.
- The sharing of records between institutions and different parts of the health system and with patients was generally welcomed as long as the appropriate safeguards are in place.
- The potential for 'keeping it personal' by focussing on patient choice and patient-centred care rather than treatment was supported.
- There are still many questions and patients, carers and family members were clear that they want to participate in future discussions about how to answer them.

In addition there were a number of specific messages about each individual trust:

- Many people **talked about Royal Brompton with real affection** and were worried that relationships between patients and clinicians could be lost in a larger partnership.
- Participants were **appreciative of the role of King's College as a local hospital** meeting the needs of its local population and were worried that this element could be lost in a focus on specialist services and within a larger partnership. Some worries

were also expressed about the potential for inequity between services, i.e. a super new specialist centre, existing care at King's College Hospital and the 'home' hospital where there may not be same expertise.

- Many people **talked positively about their experiences at Guy's & St Thomas'** and were therefore keen to ensure good practice continues, develops and is shared more widely.
- Parents praised **provision at the Evelina** and emphasised the need to maintain its quality.

The following paragraphs provide a more detailed description of the debate at all events, based on how the discussions were structured. Some quotes from participants are included. The full report from each event is included in Appendix One.

4.3 Interests and Expectations

4.3.1 What brought you here tonight?

'I'm the parent and carer of a patient who died two years ago but I have developed a real interest in the future of the hospital.'

'Curiosity about how these plans will be implemented and an interest in how my care will be affected.'

The majority of all participants had been invited by letter or encouraged by staff and were motivated to attend because of their own or a family member's experience. They wanted to learn about the detail of the proposals – how it would affect them personally, to learn from the experiences of others, to be able to share with colleagues including community groups they are involved with and, as one said, 'to be aware of what's going on so that I can tell my local doctor in case he doesn't know.'

There was a general desire to gain a better understanding of 'what's going on' and the future impact on their treatment, including as one participant said, 'as a patient and as a healthcare professional' (who had been a GP). One patient was interested in what happens to the service although 'I'd prefer to be treated by Brompton doctors'. At Guy's and St Thomas' the group that focussed on Children's services was particularly interested in the impact on Evelina services and keen to hear the views of other parents.

4.3.2 What do you hope to get out of this event?

'What I want to get out of it? I thought you wanted to get something out of me in the way of ideas!'

The general wish was to find out more about the Partnership. This meant more precise detail about rationale, timescales and how it will be funded, for others it was for reassurance that what is currently good is maintained and, for a smaller number, it was to contribute to a vision for the future. Other areas of interest included staff education and recruitment, family support, the place of end of life care in the proposed plan, the division of responsibilities between the Trusts and how they will co-operate in delivering community integrated services. There was an eagerness to have a voice in discussions and learn about the future possibilities for those patients who live a distance away from the respective hospitals they use and therefore can find them difficult to access.

Although one person commented, 'I don't know but open to hearing what is said', there was an overall desire to find out about the implications for specific services, including:

- 'More information to keep healthy hearts'
- 'What it means for cardiac services'
- An understanding of the future of the lung department, especially for adult outpatients and the relationship with other conditions patients might have, such as cancer
- Improve services for people with asthma
- The implications for the lung division at Guys & St Thomas'
- 'Changes that will make care for my kid easier and better'
- How future technology with remote monitoring and communications could enable local evaluations.

Most people wanted improvements in patient care and appointment services but the maintenance of what is already good, for example a desire that 'the Brompton continues'. There was overwhelming agreement that the opinions of patients need to be heard and taken into consideration for any changes to be successful. As one patient articulated, the hope was to 'get more information and see why it's worth going through the pain of change – things will change for me for the better.' The aspiration of clinicians to understand 'the sorts of questions and ideas everyone has' and 'what patients and parents want from this new Partnership' was welcomed at each of the events

4.4 Overall Model of Care: strengths, areas for improvement, opportunities and challenges

Participants considered:

- What they like about the proposals (strengths) and opportunities
- What they don't like about the proposals (areas for improvement) and challenges

Each of which are discussed in turn below.

4.4.1 What do you like about these proposals?

'In theory this is fantastic, if it comes to pass.'

One person believed the vision to be 'absolutely wonderful – the grandest thing heard for a long time'. There was support for a more holistic approach which would 'treat the patient not the disease' and care being provided closer to home. For some there is evident potential in having a specialist centre but, at the same time, uncertainty about whether the proposal will actually happen or meet the needs of patients. Other positive responses included:

- Excitement about the synergy of four organisations working together
- The idea of a 'purpose-built facility – that's efficient where staff won't have to walk miles down Victorian corridors'
- A better use of money (as it would be more expensive to alter an old building)
- The opportunity to improve training and education for staff, improving research with Imperial and other resources
- Enabling referral to services on the same site resulting in fewer trips to different places
- 'Birth to death service in the one hospital'
- Monitoring at home
- Faster communications and a better relationship with GPs
- The prospect of all the specialists 'under one roof' to facilitate better connections between them
- The concept of multiple specialists working at the same level with less reliance on the triangular structure with the consultant at the top
- Having specialist appointments on the same day - and if coordination was improved it would be 'beneficial to not come to hospital three or more times a week'
- 'By booking them [appointments] all on the same day at one location' would improve the experience of using outpatients
- Support for including mental health expertise with South London and Maudsley being one of the partners

During the Royal Brompton discussions, one participant was particularly pleased that the 'Brompton will not lose its name and not be subsumed'. Another, who had congenital heart disease 80 years ago and was seen by the National Heart Hospital and Royal Brompton, was interested in the continuous monitoring approach. There was enthusiasm about the

prospect of the Westminster Bridge Hospital when available, the future joint development with other hospitals and making specialist care easier to access.

At the King's College Hospital event there were some concerns about the potential inequality between services, i.e. a super new specialist centre, existing care at King's College Hospital and the 'home' hospital where there may not be the same expertise.

At Guy's & St Thomas' there was strong support for the 'excellent idea to have a centralised unit for all patients with specialised services' 'funnelling everything into one centre of excellence' and addressing situations like that for one patient who is 'at the moment, under four different hospitals.' Parents of children being treated were particularly supportive of this idea. Having a cardiothoracic unit 'sounds extremely marvellous' and the idea of a research centre was welcomed. Overall many participants believed that the plans would ensure less travel, time and cost for them.

Patients supported the message that 'this is not about broken services' but an opportunity to use economies of scale to enhance what is already effective. A key challenge remains – how to strengthen consistency of care and ensure ongoing patient feedback to maintain this?

4.4.2 What don't you like about what you have heard today?

'Not enough about the cons. We need more information.'

While there was little sense of overt opposition there were numerous worries about, what one group at the Guy's and St Thomas' event described as, 'the three Cs' of:

- **Communication** between health professionals and their patients
- **Continuity** of care to give patients confidence that their conditions would be treated effectively
- **Capacity** of having adequate staffing and physical space to deliver the proposal's aspirations

At all the events concerns were expressed both about the lack of detail about the proposal itself, the quality and effectiveness of services (even if no change takes place) and the length of time and the challenge of putting in place real partnership. At the Royal Brompton event, one participant felt that 'they are doing it for the money – its valuable land – they want it to develop housing. This site is only 30 years old.' There were many affectionate comments about Royal Brompton and worries that being part of a larger organisation could compromise its reputation. A prediction was made that that there could be future pressure from NHS England to merge, describing it as 'a bureaucrat's dream'.

At the King's College Hospital event there were worries that by embracing the creation of a specialist hub, seeking to strengthen community services, supporting integration and encouraging better self-management, the Partnership seemed to be proposing more than one change which could be unrealistic. For some participants this reinforced the lack of clarity, for instance about any additional burdens and 'where's the money'? How would King's College Hospital's role as a 'local hospital' meeting the needs of the 'local population' be maintained, as there is 'nothing' between the GP and the hospital?

A consistent theme across all events was a clear desire for further explanation about the meaning of working more closely with GPs, the local monitoring and undertaking of tests and how to expect GPs, particularly those outside London, to have the same enthusiasm and commitment for the new plans. Some people concluded that patients may feel lost when they are transferred to their GPs, there would be a loss of patient choice with non-specialist needs not being met and GPs will be uncertain about where to send patients (again especially if they are not based in London). There are already challenges about recruiting staff to community services, placing extra burdens on carers and families, so it is crucial that this proposal does not make the situation worse. There were also some concerns that it would be more difficult to attract top clinicians to local hospitals, as there would be a desire to work at the specialist centre. The gap between 'what exists at the moment in the community at local level and the plan' captured many of the sentiments expressed.

There were other examples of poor practice and scepticism about whether or not the proposal would be able to address them. One participant described how a relative with Down's Syndrome had been poorly treated by doctors when attending the Royal Brompton for a blood test. At Guy's and St Thomas' another parent described how their child was aspirating but it took five weeks to get speech and language support. The reaction to hearing about these kinds of experiences led to calls for training to ensure staff are more aware of and empathetic to different needs. Some clinics feel rushed and 'you have to push to get information, it's not offered' which may not be easy for less confident patients. Concerns were raised about maintaining the relationship with doctors which is currently 'superb' and there was a perception that under the new proposals patients could be dealing with staff who they do not know.

Among some participants there was considerable anxiety about disruption, questions about prioritisation, concern about central demands for reorganisation and maintaining expertise at all levels. These will need to be recognised, as the proposals continue to be developed, to 'prevent chaos', reiterating the importance of clear and ongoing communication.

There were a number of suggestions (both for existing and new services) including reducing waiting times and the number of cancelled appointments. Two table groups at different

events were particularly concerned that NHS patients should be treated the same as private ones who they felt were given greater priority.

The issue of funding arose frequently with concerns about the lack of detail about costs and the sustainability of the project (given the past history of public spending and the pressures on the health service). Together with past experience of poor services, these sentiments also tended to be linked to those participants who were sceptical about the proposals. This meant that there were repeated requests for more information about how this new investment was linked to the ongoing demand for cost savings and efficiency, actual numbers of patients (both private and NHS) and their different locations (acute and primary care and the wider community). There is a need to think about staff, particularly those on the frontline including junior doctors, and ensure that they are involved in discussions about the proposals. There were also concerns about recruitment particularly of international staff, in the context of Brexit. Understanding the lessons from the history of mistakes in other ambitious NHS change projects was also a key message.

4.5 Cross-cutting themes

4.5.1 Transport and travel

'We draw from a large area – travel better for some, less so for others.'

There was a mixture of responses about the transport and travel implications of the proposal. Some people thought public transport access to St Thomas' Hospital at Westminster Bridge is good, although one person described 'getting across the river is a bottleneck of buses'. Patients and families travelling from outside London 'will be pleased to be closer to Waterloo and this is hugely significant'. Those who need to use their cars talked about limited parking at all sites and were sceptical about the likelihood of 'better facilities elsewhere'.

During the Royal Brompton discussions, when one participant asserted that no patients would mind about travelling if the care is good, this was challenged. For some people, getting children, equipment and siblings to the hospital was like a 'military operation' which means that public transport is not an option. This message was also expressed by participants, in the group discussing Children's services (at Guy's & St Thomas'), who agreed that the high costs of parking needs attention as this adds to the stress of bringing a child to the hospital. One parent described 'trying to recoup £1500 for travel and accommodation' and worries that the new emission and existing congestion charges will total £25 per day plus the cost of parking.

In another group, also at the Royal Brompton, the position of Harefield Hospital was raised. A question was asked about why Harefield was not included in the proposal, as 'it requires estate improvement'. Limited public transport made access problematic: 'if local facilities for me (from Staines) are transferred to Harefield – more difficult for transport.'

Although one participant said they would like the hospital to pick up patients there was almost unanimous criticism about existing patient transport, particularly at the Guy's & St Thomas' event.

4.5.2 Joined-up working

'Keep patient choice central – and have choice about where you are treated including out and inpatient.'

'I feel there is often a big divide between my GP and the hospital – how will this be joined-up?'

As with the above discussions, a variety of positive and negative views were expressed. Underpinned by the sharing of records and information, getting joined-up working right could:

- Maintain choice
- Meet individual needs including improving the connection between paediatric and adult conditions
- Share decision-making with families, particularly in the teenage years
- Support networks of practitioners (and bring more patient involvement into these)
- Create easier telephone contact 'to speak to someone that understands your condition rather than having to repeat the explanation to get through from a switchboard system'
- Improve the coordination of appointments so they happen all on one day
- Support for the next steps for joined-up diagnostics: 'I would like to talk to my Doctor when I get my ECG'

Some participants were keen that the new arrangements should provide better continuity of care and speed, bringing about access to patient records for multiple clinicians and services. They wanted this to guarantee holistic and consistent care and address previous poor experiences, perceiving that GPs 'get in the way' or are 'the weakest link'. At the Guy's & St Thomas' event parents endorsed this sentiment, feeling that the proposals could address some of the challenges they experience in primary care. They believed that GPs often appear fearful and over cautious dealing with child cardiac patients and therefore

send them to A&E without attempting treatment. As a result parents spend a lot of unnecessary time in A&E.

For many this emphasised the potential for the proposal to include thinking about how to establish a more direct route for patients to the right team. Establishing cardiac and other training for GPs would help address concerns about the role of primary care in the network surrounding the hospital for lung patients. The option to have some visits closer to, or at home, was positively received but patients would need to feel confident there is training in place to build the skills of the local network. There would also be a need for effective advocacy support so that 'you are able to speak up for yourself' and patients are able to share knowledge about how and what care and services are available.

At Guy's & St Thomas' the connections to other public services were also raised as important areas of consideration, particularly the ongoing impact of austerity cuts. For instance, people without access to IT at home have used local libraries but their future is uncertain, contributing to the risk of digital exclusion for patients and others. The pressures on social care funding to local authorities has also reduced support for community and voluntary support organisations. The consequences for patients who rely on this kind of support to get to the hospital or other appointments should therefore be considered in the proposal.

4.5.3 Use of digital innovation

'I think the ideas are great! More info needed as they progress – remote monitoring, Skype, apps etc.'

At all the events there was enthusiasm about the potential of technology but recognition that it will not be right for every patient or every situation: 'reduces the need for in person appointment' but 'I'm old school and don't do tech. I don't understand how to.' One patient described how a visit to the podiatrist had been enhanced through electronic communication with the GP: 'all clinics should be like that – brilliant'. Another patient has been attending the Royal Brompton for 60 years. It takes five hours to get home which the patient dreads because of fears about their respiratory problem. In this case digital is key, for example access via Skype.

Participants suggested more immediate access to records would allow greater control, accessibility and 'remembering to do things promptly'. As one patient described, there is a 'possible feedback capability to help monitor my condition and feedback to doctor about progress, e.g. following a change to treatment.' For those with long-term conditions there can be greater continuity of care. Other examples of good practice raised included sharing

blood test results and 'more tech could make less need for travel which could give quicker access to consultants'.

There was a significant number of people who felt less 'digitally minded' and therefore training materials could be provided or volunteers to assist them. Although there was recognition of how technology is already in place, for example online appointment booking, there were concerns that the health service did not have a good track record of implementing ambitious new IT systems which could lead to expensive mistakes. This raised worries about the security of records, emergencies 'when everything goes down', confidentiality, hacking, viruses and the ability of patients to opt out if they wish. While admitting that effective IT can be cost effective, there were worries of the danger of digital exclusion if it is the only means of communication, especially for older patients, people with learning difficulties or mental health problems, or those who may not be able afford technology at home. There was also an urgent plea that any technology must be able to be updated – and patients and services kept abreast of this. At the King's College Hospital event there was a strong message about the importance of getting the basics right before embarking on new systems.

One patient reinforced the importance of relationships, 'it is just nice to speak with them (doctors), I don't mind if it is text or call'. The majority of responses seemed to support the comment that 'digital technology and social media are here to stay. The more they are used the better.'

4.5.4 Patient records

'How off putting it is watching them leaf through a thick file looking for the record, not looking at you.'

There was a positive response to the ambition of how digital innovation could join-up patient records, moving away from 'piles of paper', to a single patient record accessible to all clinicians involved in a patient's care. There was support for the idea that records should be accessible for patients (on their phone) with copies for the GP and every team to help prevent delays and deliver the right care. This sharing should also work across different institutions with systems able to 'talk' to each other, transferring new information about any changes to match up to consultant notes. This would address the kind of situation described by one patient who currently gets a copy of letters and tests to take to the GP. The GP can then 'spend 10 minutes looking at the computer for the information when the appointment only lasts 10 minutes'. Although most people appeared happy that information could be shared there were worries about maintaining data protection and

confidentiality and ensuring sufficient resources to build protection from hacking or viruses (reinforcing the messages from the digital innovation discussions).

Support was however tempered by poor past experiences when technology did not work. As in discussions about the other themes, there were concerns about the capacity of GPs, in this instance to maintain accurate information. A number of participants described problems with obtaining their medication at pharmacies because GPs had not updated records following a consultant visit. One person ended up involving PALS because the GP had refused to issue the hospital prescription. These kinds of experiences highlighted the potential for people to feel digitally excluded if patient records and self-care and monitoring all moved on line: 'I know eventually, age wise everyone will be used to it and do it all on line, but it's not for me'. An important reminder therefor came from one participant who stated, 'I would like to hear from patients what they need.'

4.5.5 Keeping it personal

'Clinics that work well are those that know you and predict and manage any difficulties you might have.'

The messages from this theme echo many of the points raised above. Patients talked frequently about the long-standing relationships they have with the doctors and teams at Royal Brompton, King's College and Guy's & St Thomas', emphasising the importance of personal connections through partnerships and communications. They were therefore keen that the proposal must recognise this fully. For instance, the need for a single point of contact was articulated as 'someone you can call or email'. It is important that every patient understands their condition and the latest treatment possibilities and is reassured if repatriated to care locally that this treatment is current. This could include accepting more data from patients, for instance blood pressure monitoring or details of exercise patterns. One patient talked of a hope to see the same clinician occasionally and another was clear they wanted to keep seeing the same consultant after the changes.

Whether interactions are face-to-face or remote, there were worries that some people are 'pushier' than others and that staff need to be sensitive to those who may feel more intimidated. There was a particularly powerful message that 'keeping it personal' in a time of change depends on an ongoing dialogue between patients and professionals that is honest about both the challenges and opportunities.

The general sentiment was that the system needs to direct patients to the right clinical support, but there were various different experiences about how this works. Some clinics work better than others because 'if you feel comfortable asking questions you will be more

confident managing your condition. If you feel rushed – on a conveyor belt it has an impact'. The importance of recognising patients as experts in their own care was highlighted. In addition, and as in the discussions above, several concerns about GPs were raised including that they are overworked, need to be trained, do not provide the right support and communication is poor.

Discussions about involving people in their own care highlighted how, while there was overall support for the concept of person-centred care, there were varied levels of interest in the active role that the patient might take. Encouraging and developing support from charities to patients might be a way of addressing this. The Dimbleby Cancer Centre (at the Cancer Centre at Guy's) was cited as an example of good practice that could help thinking about a broader wellbeing approach. One person shared their positive experience of a charity that has established a choir for people with breathing difficulties. Teaching the members about breathing techniques has 'really, really helped me to manage my condition'. This patient had been able to share the techniques successfully with a friend who had become breathless and was unable to find their inhaler. Building in more of this kind of 'social prescribing' should be a key part of keeping it personal and looking after wellbeing.

Overall there were repeated strong messages about patient choice, continuity of care, fairness in priority given to NHS patients and the need to be holistic and consider the whole patient not the disease. This demands a connected and integrated system to build on the things that work and build greater confidence among patients.

4.6 Further questions

The questions echo issues and messages raised in the discussions described above and are organised below by theme. Although some of these were answered at the events, they are captured verbatim as they may well reoccur during further engagement exercises.

Building and development issues:

- What is on the land at the moment (at St Thomas')?
- Why don't you rebuild on the Royal Brompton Hospital site?
- Will the new site [at St Thomas' Hospital] be big enough to allow for future growth? What is the assessment based on?
- What is the capacity of the new proposal in terms of beds?
- What will the new facilities look like and how will the Partnership involve patients in the design of new buildings?

Funding:

- Does the [NHS] tariff affect our decisions?
- Where is the money coming from and is the government willing to fund this?

- How is the proposal affordable for GPs?

Organisation of the programme:

- What is the timescale for the programme?
- How will NHS England manage/perform the public consultation?
- Will there be further workshops on the proposals?

Service implications:

- Will all respiratory services be in one place?
- Will services for children all be at Evelina?
- Will there be a better link between specialist services and A&E?
- What access will there be to other specialists for non-heart and lung problems?
- Will the South Thames Retrieval service transfer?
- Will the proposal deal with delays and backlogs?
- Is it possible to carry out the integration of heart and lung services without bringing in other care, for example kidney services?
- How will networks work?
- Why change the Children's Hospital?
- Will private patients be able to use this (as I don't think they should)?
- Will proposals improve GP referrals?
- How big is the new team?
- Will the proposals shorten waiting times?

Patient experience:

- In terms of appointments would I remain a patient of Royal Brompton or would I have to change to one of the other partners?
- Will staff rotate/move around to see me/others – in a local hospital?
- Can I ask my doctor at King's to transfer me to the hub if I want?
- Will the use of digital innovation create anxiety for patients, for example when receiving test results, especially if the tests are abnormal?
- As more care is delivered locally in primary care and in local hospitals, is there a danger that doctors may not have sufficient expertise in specialist areas?
- What will be done to improve diagnosis, for example one mother described how her son's condition was not picked up during pregnancy?
- How will the ethos of the Evelina and its special relationship with patients be maintained?

- The Dimbleby Cancer Centre is a good example of holistic care and wellbeing run by the voluntary sector. How will you grow and support further holistic charity support for patient wellbeing?

Partnership working

- What brand will the new service have?
- What do St Thomas' get out of it?
- Will the institutions eventually be merged anyway, if not in the short term?
- If the proposal is to create a centre of excellence, are there plans to link other existing service connections (not mentioned in the presentation), for example Guy's & St Thomas' and Newcastle work together?
- What will the governance arrangements for the Partnership be?
- What will happen to the art at Royal Brompton?

Implications for staff:

- The proposal sounds good but how does all this filter down to junior doctors and other staff on the front line?

Broader context

- What will be the impact of Brexit?
- We may not be able to drive in London eight years, what consequences would this have for the proposal?

4.7 Conclusion

At all events there was a desire to ensure patients continue to be encouraged to participate throughout the patient and public engagement and NHS England consultation processes. These will need to 'pin down' the detail of the numbers of cardiac and lung patients affected, at Royal Brompton, King's College Hospital, Guy's & St Thomas' and in the community, and the costs involved. The differences between the complexity of acute specialist services and delivering in the community need to be acknowledged and articulated, to work out solutions.

'I like the suggestion of consultants going out into the community working with staff in other parts of the system and patients – but this needs to be more than just concepts and nice ideas.'

It will also be important to ensure future workshops are organised at times suitable for different patient groups. Although overall there was a positive and constructive approach from all involved there were patients who wished to emphasise their worries about the quality of care not being maintained and their anxiety about change. As the Partnership

continues to develop its proposals it will be vital to continue to understand and address these worries.

'How do we ensure patients continue to be asked throughout consultation?'

In the future, to ensure that there is healthy debate it would be useful for patients to be provided with specific questions or problems where their input would be valuable. Overall participants recognised that they were not necessarily totally representative of all patients and therefore careful thought needs to be given about how to encourage wider engagement in future patient and public engagement activities, in the material circulated and outreach opportunities for face-to-face discussions.

'How is this going to work over the next 20 years?'

5 WEBINAR

'Makes sense to put services under one roof.'

At the start of the webinar, most participants confirmed they were attending to find out more about the proposals with a clear interest from staff about its implications for their roles. As with the engagement events there seemed to be broad approval for the proposal's potential to address existing service concerns. At the same time there were worries about its scale because 'managing multiple services across multiple locations poses considerable communications and logistics problems'. Similar messages also emerged about the affection for 'the unique patient/clinician atmosphere and values that exists at the Brompton' and worries that this might disappear in a bigger collaboration. One patient, with a pacemaker, described the 'Singing for Breathing' group at Royal Brompton as an 'excellent initiative' and, although having to go to Westminster Bridge would be a minor inconvenience, 'I assume these admirable services will continue.'

The connections with local services were also areas of concern. One person had recently been admitted twice for non-related lung and heart conditions to their local hospital, where medical staff found it difficult to contact Royal Brompton for details of their conditions. There was also the hope that GPs should be involved in the design of the project, particularly its practicalities. One suggestion made was that it would be helpful to have an appointments database accessible to patients to 'check our future appointments without having to bother the switchboard'.

A number of specific questions were raised and are captured verbatim, as with those arising from events, below:

Building and development issues:

- Did Professor Beale say the Royal Brompton will be moving to Westminster Bridge?
- The current Royal Brompton site is vast in comparison to the proposed site at Westminster Bridge, will it be big enough?
- Will there be sufficient space in the new development for the scale of imaging and X ray capacity required?
- As a tertiary centre without an A&E, the Royal Brompton does not face the same bed shortage issues as many other hospital centres. If the Brompton is moved to the Westminster site, will bed capacity be shared with the rest of Guy's & St Thomas'?
- This is a big and exciting project. Some of the problems and challenges will have been experienced by other large and complex organisations. Are you getting external input?

Patient experience

- I use Patient Access, which I find very useful. Would it be possible in the future to link up with this GP service and combine with hospital records as well?
- I am both a heart and lung patient. My biggest concern is that appointments seem be based on availability rather than need due to the pressure on the service. Will it be possible to staff the new development in the way that you envisage?

6 THE SURVEY

6.1 Introduction

This section provides an overview analysis of the survey outcomes of the engagement exercise. The engagement survey was available to complete as:

- An online survey
- A hard copy questionnaire returned via Freepost

The survey ran between 9th January and the 6th February.

In total 257 responses were received:

- 71 respondents completed the survey online
- 186 respondents provided complete comments through the paper questionnaire

The questionnaire considered in turn:

- Views on the current services
- Views on the outline proposal for future heart and lung care
- Anything else that should be considered or that has been missed out in the engagement questions

6.1.1 Rounding numbers in the survey

Rounding a number means replacing it with a different number that is approximately equal to the original, but has a shorter, simpler representation; for example, replacing 23.4476 with 23.45. In this report numbers with a value below 0.5 are rounded down to the nearest whole number and those with a value above 0.5 are rounded up. For instance 1.6 becomes 2 and 1.4 becomes 1, because of this values in tables may add up to more or less than 100%.

6.2 Key demographics

Set out below are the key demographic characteristics of the respondent sample, detailing the self-reported details related to:

- Age
- Gender
- Sexuality
- Religion
- Disability
- Caring responsibilities
- Ethnicity

Each is reported in turn in the remainder of this section.

Please Note: The information was provided on a voluntary basis and not all respondents completed their details, the base quoted in each refers to the number of people who provided answers.

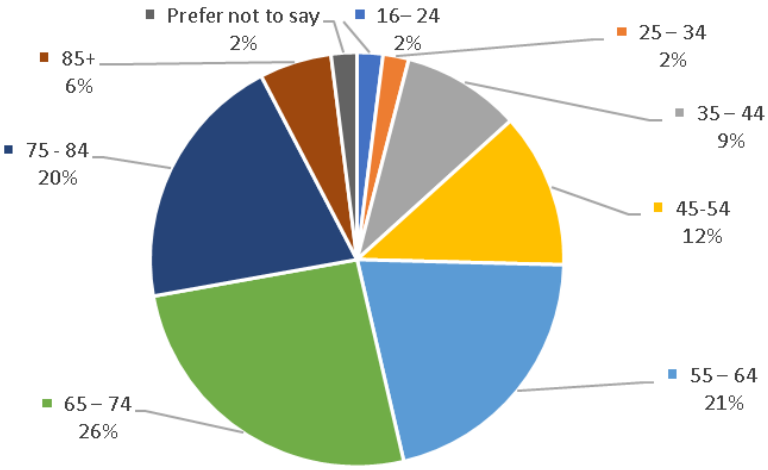
It is also important to note that the response level is low, therefore, when looking at subsamples (cross tabs) the findings are often at the coincidence level and should be treated with caution.

6.2.1 Age

Age distribution shows generally higher response rates from older age groups:

- 67% are aged between 55 and 84

Row Labels	No	%
16– 24	5	(2%)
25 – 34	5	(2%)
35 – 44	23	(9%)
45-54	30	(12%)
55 – 64	52	(21%)
65 – 74	64	(26%)
75 - 84	50	(20%)
85+	14	(6%)
Prefer not to say	5	(2%)
Grand Total	**248**	**100%**



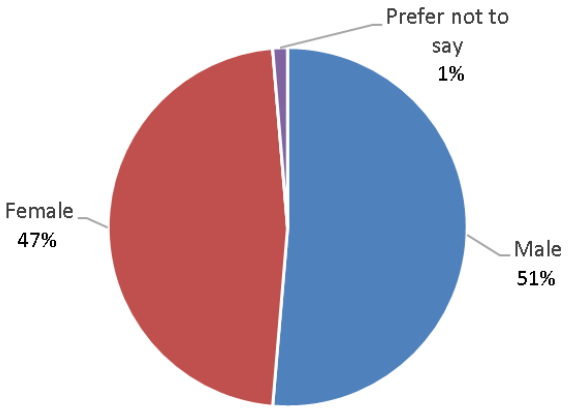
6.2.2 Gender

The gender of respondents was, broadly, evenly distributed between male and female:

- 51% Male
- 47% Female

	No	%
Male	115	(51%)
Female	106	(47%)
Prefer to self-describe	0	(0%)
Prefer not to say	3	(1%)
Total	**224**	**(100%)**

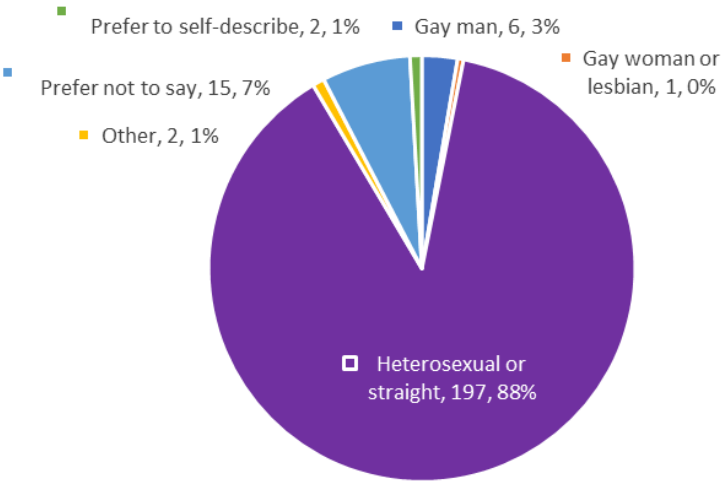
(rounding applied)



6.2.3 Sexuality

The majority who provided an answer (including prefer not to say) describe themselves as 'Heterosexual / straight' (88.3%).

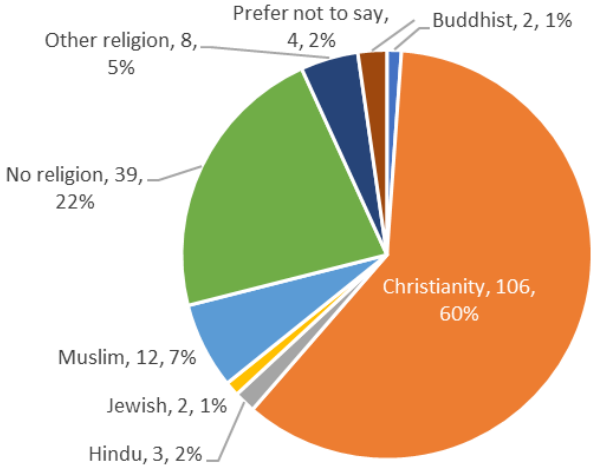
Sexuality	No.	%
Gay man	6	2.7%
Gay woman or lesbian	1	0.4%
Heterosexual or straight	197	88.3%
Other	2	0.9%
Prefer not to say	15	6.7%
Prefer to self-describe	2	0.9%
Grand Total	**223**	**100%**



6.2.4 Religion

The majority who provided an answer (including 'prefer not to say) describe themselves as 'Christian' (60.3%)

Religion	Total
Buddhist	2 (1%)
Christianity	106 (60%)
Hindu	3 (2%)
Jewish	2 (1%)
Muslim	12 (7%)
No religion	39 (22%)
Other religion	8 (5%)
Prefer not to say	4 (2%)
Total	**176 (100%)**



6.2.5 Disability

The majority who provided an answer (including prefer not to say) reported that they had a disability (70%)

Do you have a disability, long-term illness, or health condition	No.	%
Yes	156	70%
No	64	29%
Prefer not to say	3	1%
Grand Total	**223**	**100%**

The full breakdown of reported disabilities are shown in the table below.

Please tell us what your disability is (multiple responses allowed)	No.	%
A long-standing illness or health condition (e.g. cancer, HIV, diabetes, chronic heart disease, or epilepsy)	119	(76%)
An impairment, health condition or learning difference that is not listed above	19	(12%)
A physical impairment or mobility issues (e.g. difficulty using your arms or using a wheelchair or crutches)	25	(16%)
A mental health difficulty (e.g. depression, schizophrenia or anxiety disorder)	12	(8%)
Deaf or have a hearing impairment	8	(5%)
A specific learning difficulty (e.g. dyslexia, dyspraxia or AD(H)D)	7	(4%)
Prefer not to say	2	(1%)
Blind or have a visual impairment uncorrected by glasses Deaf or have a hearing impairment	5	(3%)
Blind or have a visual impairment uncorrected by glasses	1	(0.6%)
A social / communication impairment (e.g. a speech and language impairment or Asperger's syndrome/other autistic spectrum disorder)	1	(0.6%)

Base 156 (number of people declaring they had a disability)

6.2.6 Caring responsibilities

The majority (77%) who provided an answer, including prefer not to say, said they had no caring responsibilities.

Caring responsibilities?	No.	%
None	155	77%
Primary carer of a child or children (between 2 and 18 years)	12	6%
Primary carer or assistant for an older person or people (65 years and over)	10	5%
Prefer not to say	6	3%
Primary carer of a child or children (under 2 years)	4	2%
Primary carer or assistant for a disabled adult (18 years and over)	4	2%
Primary carer of a disabled child or children	3	1.5%
Primary carer of a child or children (between 2 and 18 years)	3	1.5%
Secondary carer (another person carries out main caring role)	2	1%
Primary carer of a child or children (under 2 years)	1	0.5%
Grand Total	**200**	**100%**

6.2.7 Ethnicity

Of those respondents who provided a response the majority described themselves as White British (70.6%)

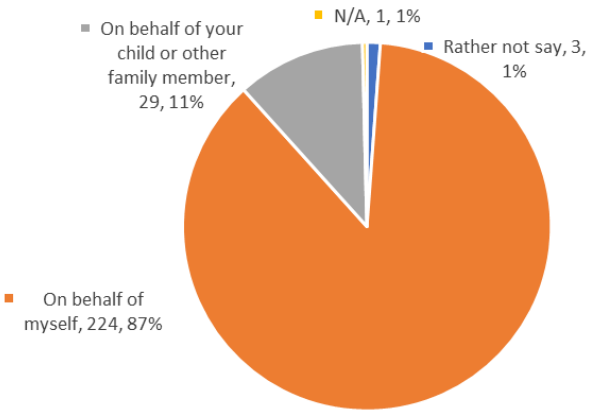
Ethnicity	No.	%
White		
White British	151	70.6%
White Irish	2	0.9%
Any other White background	13	6.1%
Mixed		
White and Black Caribbean	3	1.4%
White and Black African	2	0.9%
White and Asian	1	0.5%
Asian or Asian British		
Indian	5	2.3%
Pakistani	3	1.4%
Bangladeshi	2	0.9%
Any other Asian background	3	1.4%
Black or Black British		
African	9	4.2%
Caribbean	7	3.3%
Any other Black background	3	1.4%
Other Ethnic Groups		
Chinese	2	0.9%
Any other ethnic group	5	2.3%
Prefer not to say	3	1.4%
Grand Total	**214**	**100%**

NB: results are not presented (cross tabulated) by ethnicity due to the small sub sample size which introduces coincidence in the presentation.

6.3 Response basis

The majority who provided an answer – including those who would rather not say - responded on behalf of themselves (87%).

Answering this survey….	No.	%
On behalf of myself	224	87%
On behalf of your child or other family member	29	11%
Rather not say	3	1.2%
N/A	1	0.4%
Grand Total	**257**	**100%**



The majority those who provided an answer on behalf of themselves were responding as a patient of 25 years of age or older (88%).

Responding as…	No	%
… a patient (25 or older)	197	88%
… a parent/carer	18	8%
… a patient (16 - 24)	9	4%
Grand Total	**224**	**100%**

Patients most commonly cited Royal Brompton as the hospital where they received care (134 respondents).

Hospital care received from	No.	
Royal Brompton and Harefield NHS Foundation Trust		
Royal Brompton Hospital, Chelsea	134	(52%)
Harefield Hospital, Harefield near Heathrow	5	(2%)
King's College Hospital NHS Foundation Trust		
King's College Hospital, Denmark Hill	35	(14%)
Variety Children's Hospital, Denmark Hill	1	(0%)
Princess Royal University Hospital, Bromley	19	(7%)
Guy's and St Thomas' NHS Foundation Trust		
St Thomas' Hospital, Westminster	69	(27%)
Guy's Hospital, London Bridge	57	(22%)
Evelina London Children's Hospital, Westminster (St Thomas' Hospital site)	7	(3%)
Rather not say	**2**	(1%)
Grand Total	**329**	

Multiple responses allowed – grand total exceeds total number of respondents
% shown against the base of all respondents (257)

Please note when reading the table on the previous page that this question allowed more than one response and therefore shows all locations care is received, which can be more than one for individuals.

Heart care (on its own) was the most commonly cited form of care (48%) as shown in the table below.

Type of care received	No.	%
Heart care	115	48%
Lung care	80	33%
Heart and lung care	29	12%
Rather not say	18	7%
Grand Total	**242**	**100%**

6.4 Views on current care

6.4.1 Is the current service working well?

In response to the question "To what extent do you think the NHS heart/lung care you currently receive is working well?":

- The overwhelming majority of respondents (93%) who provided an answer to this question thought the current service works well (20%) or very well (73%).
- Only 2% of respondents were unsure, stating they 'don't know'.

	Total
… the service works very well	176 (73%)
… the service works well sometimes	49 (20%)
… the service neither works well nor is it not working well	3 (1%)
… the service tends not to work well.	7 (3%)
… the service does not work well at all	1 (0%)
Don't know	6 (2%)
Total	**242 (100%)**

When considered by care received – including those who would rather not say:

- Recipients of heart and lung care are most likely to state the service works very well (83%);
- Those who received heart care (72%) expressed the same sentiment, closely followed by those who received lung care (71%).

	Heart and lung care	Heart care	Lung care	Rather not say	Total
… the service works very well	24 (83%)	83 (72%)	57 (71%)	12 (67%)	176 (73%)
… the service works well sometimes	4 (14%)	24 (21%)	17 (21%)	4 (22%)	49 (20%)
… the service neither works well nor is it not working well	(0%)	1 (1%)	2 (3%)	(0%)	3 (1%)
… the service tends not to work well.	1 (3%)	4 (3%)	1 (1%)	1 (6%)	7 (3%)
… the service does not work well at all	(0%)	(0%)	1 (1%)	(0%)	1 (0%)
Don't know	(0%)	3 (3%)	2 (3%)	1 (6%)	6 (2%)
Total	**29 (100%)**	**115 (100%)**	**80 (100%)**	**18 (100%)**	**242 (100%)**

When considered by gender there is no significant difference between male and female opinion on what currently works (very well and well sometimes) and what doesn't (tends not to and does not work well at all).

	Male	Female	Prefer not to say	Total
… the service works very well	90 (78%)	76 (74%)	13 (54%)	179
… the service works well sometimes	18 (16%)	19 (18%)	9 (38%)	46
… the service neither works well nor is it not working well	2 (2%)	1 (1%)	0 (0%)	3
… the service tends not to work well.	2 (2%)	3 (3%)	2 (8%)	7
… the service does not work well at all	1 (1%)	0 (0%)	0 (0%)	1
…don't know	2 (2%)	4 (4%)	0 (0%)	6
Total	**115**	**103**	**24**	**242**

	(100%)	**(100%)**	**(100%)**	

Considered by disability, long-term illness, or health condition:

- Respondents who prefer not to say are most likely to feel the service works very well (89%) followed by those who consider themselves in this group (72%) followed closely by those who do not.
- The numbers who consider the service does not work well while small are worth considering going forward to ensure all receive the care they want.

	Do you have a disability, long-term illness, or health condition?			
	Yes	No	Prefer not to say	Grand Total
… the service works very well	103 (72%)	36 (68%)	40 (89%)	179 (74%)
… the service works well sometimes	30 (21%)	13 (25%)	3 (7%)	46 (19%)
… the service will neither work well nor not work well	3 (2%)	(0%)	(0%)	3 (1%)
… the service tends not to work well.	4 (3%)	2 (4%)	1 (2%)	7 (3%)
… the service does not work well at all	(0%)	1 (2%)	(0%)	1 (0%)
Don't know	4 (3%)	1 (2%)	1 (2%)	6 (2%)
Grand Total	**144 (100%)**	**53 (100%)**	**45 (100%)**	**242 (100%)**

6.4.2 What is particularly good about the current service

Respondents were asked to provide 'open' responses to the question "***Is there anything particularly good about the NHS heart/lung care you (or the patient you care for) currently receive?"***

The responses to this question can be grouped into the following broad themes:

- **The people**
  A consistent theme was praise for all the staff at all the partner trusts with mentions for administrative staff such as receptionists, and clinical staff such as consultants. The overarching sentiment is that all staff have time to explain things and are happy to answer any questions with patience and understanding. Summed up as a polite and caring attitude.

  "I appreciate having such high-quality staff looking after me."

- **Medical expertise of the clinical team**
  Aside from the general attitude of all staff, the clinical team come in for particular praise, with a wide spread knowledge of conditions and treatments backed up with access to world class equipment.

  "knowledgeable and extremely helpful with years of experience as is the cardiac ward."

- **Continuity of care**
  An issue of significant importance to respondents was the continuity of care they each received. Of particular importance was establishing a relationship with a consultant, which both provided reassurance and was felt to reduce frustration through not having to repeat their condition and concerns to a new face at every appointment.

  "treated by the same consultant throughout and the familiarity with…case and treatment plan has been amazing."

- **Support and reassurance**
  Respondents value the support they receive both as inpatients, but especially as outpatients. Particular mention was made of having a 'personal nurse' to contact and reports of good email contact with the team.

  "…I can call to speak to nurses specialist if I feel poorly to avoid getting in A&E…"

  "Regular check-ups and action taken when necessary"

- **Centres of excellence**
  Royal Brompton Hospital is singled out for comment by respondents, but there is a general acknowledgment of the world class facilities at all partner Trusts. The main reason for singling out RBH seems to be anecdotal support for the expertise available, as a world leader at the cutting edge of research and technology.

  "Because the Brompton is famous for lungs, it can attract the best junior doctors who want this speciality."

- **Children's care is excellent**
  Whilst a relatively small group within the respondents, parents and carers of young children (5-15) are particularly vocal in their support of the care provided to children. This ranged from discussion of inpatient care to outpatient clinics.

  "children's outpatient clinic is well organised and very efficient. There is very little waiting time in between the various appointments (ECG, echo, cardiologist) within the clinic."

- **Appointments**
  The current approach of the partners to shorten waiting times for appointments was also an area which respondents were keen to see continue. People spoke of little or no delays in appointments, being admitted as required and seeing specialists not available at local hospitals.

  "Appointments are regular and very quick"

6.4.3 What can be improved with the current service

Respondents were then asked to provide 'open' responses to the question ***"Is there anything that could be improved with the NHS heart/lung care you (or the patient you care for) currently receive?"***

The responses to this question can be grouped into the following broad themes:

- **Regular dialogue**
  The desire expressed by respondents was for improvements in the dialogue between patients and clinicians and other staff. The feeling is that currently, once moved to being an outpatient, the levels of support and contact drop off, leaving people anxious about their condition. The feeling was expressed that relatively regular contact during a difficult time would go a long way to reassure people.

  "two-way contact between the patient and lung team member between outpatient appointments"

- **Inpatient and outpatient food choices**
  The standard and variety of catering available to both inpatients and outpatients was felt to be in need of improvement. This was particularly important to patients who

were trying to lead a healthier lifestyle only to be faced with uninspiring and unhealthy food choices.

"Better variety on the menu - including different texture of food i.e. some crunchy food (veg)"

- **Digital records / compatible computer systems**
  A consistent theme was the desire for easily accessible digital patient records.. Frustrations were expressed around having to wait for staff to access paper notes, and the lack of inter-operability between the different trust's and other providers IT systems, resulting in frustration and concerns over delays in treatment.

"digital records"

"Chelsea & West (sic) ***have all my history immediately in front of them, whereas Brompton consultants are thumbing through a pile of scribbled notes, and frequently, they give up searching, and I just tell them my history!"***

- **Improved staff attitudes**
  Recognising that many staff have been praised for their attitudes, respondents still felt there is a need for improvement in staff attitudes. Particularly in the area of involving patients as experts in their own condition and care planning. In short many respondents felt they were ignored.

"The doctors could listen more to what I say."

- **More preventative action**
  Respondents believed a more proactive approach to patients with a recognised condition, to help them manage their illness and prevent any further deterioration, was a very important factor to be considered.

"I think a preventive approach with my heart condition would help…an annual 3D scan to pick up on early signs of problem"

- **Appointments and administration**
  The general administration of appointments was an area respondents felt could be improved. Many felt the systems could realistically adopt standard business practices such as emailing details of appointment to patients, instead of relying on post, recognising that this wouldn't work for all, and perhaps be operated on an opt-in basis.

"Appointment administration seems to be fairly haphazard and needs to be joined-up more efficiently"

"Would happily receive emails instead of letters"

6.4.4 What is most important to keep of the current service

Finally, in relation to current services, respondents were asked to provide 'open' responses to the question "What do you think are the most important things that we need to keep doing to make sure you (or the patient you care for) receive the NHS heart/lung care you need?"

The responses to this question can be grouped into the following broad themes:

- **Child friendly environment**
  Again, for many respondents the welfare of young children was very important. Children were felt to have enough to deal with, without having to endure drab and austere surroundings. The emphasis was upon maintaining an environment that was supportive, fun and welcoming for children.

  "Always having a child friendly environment."

- **Research**
  An overwhelming sentiment is the desire from respondents for all partners to continue to invest in and conduct research to improve patients' lives, now and in the future.

  "Because my daughters condition is a rare electro physiological condition, more research is needed in its treatment."

- **Involve patients more in their own care**
  A recurring theme is the involvement of patients in planning their own care and a call for clinical staff to recognise the benefits they bring in being experts in their own lives and conditions.

  (Continue to) *"...ask questions on how they feel"*

- **Safe**
  A key factor for a majority of respondents is the extent to which the staff and clinicians make them feel safe during difficult and distressing times. The overarching concern is the loss of that feeling of safety and a call for the partners to recognise the importance of maintaining this in any change proposals.

  "Continue to make me feel safe and confident that you know exactly what needs to be done in my case."

- **Joined-up care**

Respondents are concerned that there is a lack of communication and cooperation between different NHS organisations, and any future changes should build in improved joined up working to deliver improved care to all patients.

"Joined up with other NHS department."

- **Improved aftercare**

  While the current aftercare is cited as excellent, respondents believe there is still room for improvement, many feel that there is an assumption that patients understand what is required of them. In many cases this is not true, with people confused and anxious, largely unable to take in basic information.

  "…after operations, to keep in touch with those who are unsure of what to expect and for how long…perhaps explain more what patients can do to improve their own chances of improving their health before and after procedures/operations

- **A more caring attitude for all**

  Respondents desire a move away from a 'one size fits all' approach to more a personalise approach, in which they are able to feel like an individual.

  "A more caring approach, I feel like a number on a long list

- **Improved communication**

  Respondents generally feel that the services would generally benefit from improved internal and patient facing-communications. Respondents reported dissatisfaction with the lack of internal communication between different teams resulting in frustration and poor service delivery. Equally, they felt if there was improved telephone access to consultants this would reduce anxiety and help to avoid future issues/admissions.

  "better telephone access to consultants."

  "Communication with other teams."

6.4.5 Likelihood to recommend (friends and family)

In response to the question "How likely are you to recommend our NHS heart/lung care to friends and family if they needed similar care or treatment, based on the care you are currently receiving or have recently received?" the responses were as shown in the table below.

	%	No.
Don't Know	1%	3
Extremely unlikely	5%	13
Unlikely	2%	5
Neither likely or unlikely	4%	9
Likely	23%	54
Extremely likely	65%	155
Grand Total	**100%**	**239**

In this instance the 'friends and family score is 81. This score is the result of subtracting the negative responses ('extremely unlikely' and 'unlikely') from the positive responses ('extremely likely' and 'likely').

6.4.5.1 Reasons for providing this score

Respondents were asked to provide the reason they had given the score they had, as reported above, "*Please can you tell us the main reason for the answer that you have given?"*

The responses to this question can be grouped into the following broad themes, subdivided into 'promoter' views (providing an 'extremely likely' score) and those of 'detractors' ('Unlikely' and 'Extremely unlikely').

Positive responses:

- ✓ Excellent care
- ✓ Complete confidence in the staff
- ✓ The hospital is always excellent
- ✓ Excellent clinical staff
- ✓ Service delivery in a centre of excellence

Negative responses:

- × A very small proportion of respondents felt they were ***"…fobbed off…"*** by staff and clinicians in terms of explaining their diagnosis or supporting them with aftercare
- × Lack of attention to aftercare, it's assumed we will work out what we need by ourselves
- × The services are underfunded
- × Frustration with the limitations of services (including referral to service from GPs)

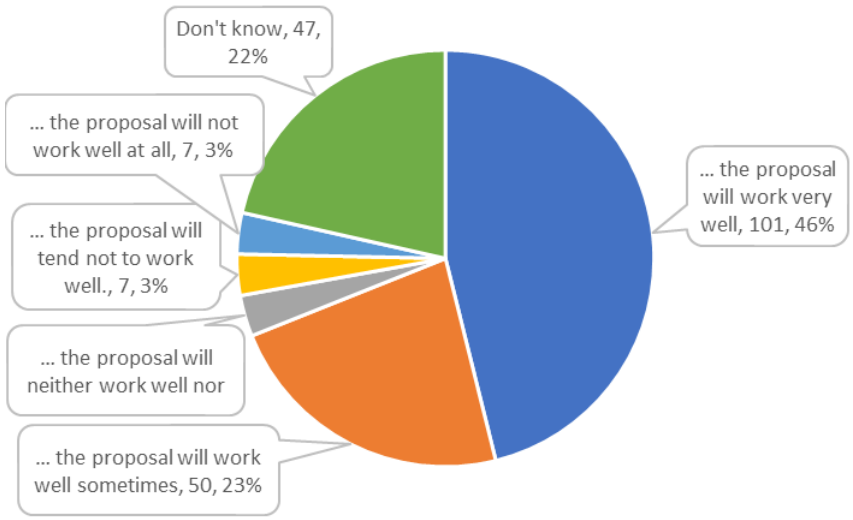
6.5 Views on the proposal

In response to the question "To what extent do you think NHS heart/lung care in our proposal will work well?":

- The majority of respondents who expressed an opinion (69%) thought the proposal would work well sometimes (23%) or would work very well (46%).
- 21% of respondents were unsure and only 6% gave a negative response

As shown in the table and chart below.

	No.	%
… the proposal will work very well	101	46%
… the proposal will work well sometimes	50	23%
… the proposal will neither work well nor not work well	7	3%
… the proposal will tend not to work well.	7	3%
… the proposal will not work well at all	7	3%
Don't know	47	21%
Grand Total	**219**	**100%**



When considered by the type of care received by respondents:

- A majority of patients across all care areas are likely to support the sentiment '…the proposal will work very well…", or '…will work sometimes…'
- Lung care (71%) and Heart care (70%) patients were most likely to support the sentiment; and
- Most heart and lung care patients (59%) were positive but 17% have a negative view. The sample size here is very small but the specific needs of this group are something to monitor going forward.

	Heart and lung care	Heart care	Lung care	Rather not say	Grand Total
… the proposal will work very well	11 (46%)	46 (43%)	35 (50%)	9 (47%)	101 (46%)
… the proposal will work well sometimes	3 (13%)	29 (27%)	15 (21%)	3 (16%)	50 (23%)
… the proposal will not work well nor is it unlikely to not work well	1 (4%)	3 (3%)	3 (4%)	(0%)	7 (3%)
… the proposal will tend not to work well.	3 (13%)	2 (2%)	2 (3%)	(0%)	7 (3%)
… the proposal will not work well at all	1 (4%)	3 (3%)	1 (1%)	2 (11%)	7 (3%)
Don't know	5 (21%)	23 (22%)	14 (20%)	5 (26%)	47 (21%)
Grand Total	**24 (100%)**	**106 (100%)**	**70 (100%)**	**19 (100%)**	**219 (100%)**

- People who **do not** feel they have a disability, long-term illness or condition are the group of respondents most likely to be positive about the proposal (85%) with 59% believing it will work very well and 26% feeling it will work well sometimes.
- People who declare they have a disability, long-term illness or condition are least likely (64%) to report they believe the proposal will work well (22%) or very well (42%), largely because of a much higher level of don't know responses.

	Yes	No	Prefer not to say	Grand Total
… the proposal will work very well	61 (42%)	36 (59%)	4 (29%)	101 (46%)
… the proposal will work well sometimes	31 (22%)	16 (26%)	3 (21%)	50 (23%)
… the proposal will neither work well nor not work well	4 (3%)	1 (2%)	2 (14%)	7 (3%)
… the proposal will not work well at all	5 (3%)	2 (3%)	(0%)	7 (3%)
… the proposal will tend not to work well.	5 (3%)	1 (2%)	1 (7%)	7 (3%)
Don't know	38 (26%)	5 (8%)	4 (29%)	47 (21%)
Grand Total	**144 (100%)**	**61 (100%)**	**14 (100%)**	**219 (100%)**

6.6 First impressions

Respondents were asked to provide 'open' responses to the question "what are your first impressions when you read our proposal?"

The responses to this question can be grouped into the following broad themes:

Positive reactions:

- ✓ **A wonderful vision**
  A recurring theme from the respondents was praise for the vision expressed in the proposal. The feeling was that the proposal set out a vision to modernise service delivery for heart and lung care fit for the twenty-first century, throwing off many of the constraints of the existing estate and operating practices. Working in partnership around care and research were felt to be particularly beneficial.

  "A new purpose-built centre for heart and lung patients would be beneficial for all patients."

- ✓ **Sharing resources to create a centre of excellence**

  The approach of sharing resources, from back office to research, was welcomed and many felt it would deliver significant benefits to patients.

  "An excellent opportunity to pool resources and a large patient cohort, to accelerate congenital heart disease care and research across all ages. This would create the largest centre in the UK - and among the largest few in the world - for congenital heart disease."

- ✓ **Twenty-first century technology**

  The adoption of cutting-edge technology from enabling IT infrastructure to diagnostic and research equipment was a very welcome element of the proposal.

  "The use of technology to improve diagnosis and reduce costs is welcome."

Negative reactions

- ✓ **The end of a legend (RBH)?**

  Some respondents were concerned that the proposals would see the end of Royal Brompton Hospital, which was not at all welcome.

  "Alarm, then sadness at the demise of the RBH."

- ✓ **Too big**

  The proposal is very nice but is it too big to be able to deliver a personalised approach.

  "As a patient will the level of my care be maintained? A very large medical centre could be rather daunting and impersonal, on the other hand having heart and lung specialities in one centre will be more efficient in both time and money. "

- ✓ **Is it overambitious?**

  The scale of the proposal caused some concern with some respondents feeling that this alone made the deliverability of the project questionable.

  "It seems all impressive but with the question mark on its possibility…"

- ✓ **Patient focus**

  Respondents were concerned that the proposal would lead to the loss of one of the attributes most valued in current service, namely the focus on the individual patient and their care needs.

"…worried the proposal will result in loss of focus on patient care…"

"…the proposal seem focused on patient care…"

6.6.1 What do you like about the proposal?

Respondents were asked to provide 'open' responses to the question "what do you like about the proposal for NHS heart/lung care we have developed so far?"

The responses to this question can be grouped into the following broad themes:

- **Sensible and cost-effective**

  The positive benefits of the proposal in terms of efficiency, effectiveness and economy were recognised by many.

  "Economies of scale. More integrated approach (bench to bedside), the prospect and encouragement of new, better and more effective care for patients in the future."

- **Care at home**

  The proposal to deliver more care at home reducing length of stay was seen as a positive benefit.

  "I like the idea of care after the op with follow up near home..."

- **Research and faster access to new treatments**

  The benefits of advanced research facilities and the potential to introduce new treatment faster for patients was also seen as a potential, major, benefit.

  "I like the proposals for more research and keeping up with other countries heart care...."

  "…Faster access to new services, drugs and treatments reduced waiting times…"

- **Reduced duplication**

  The potential for reducing duplication in back office and diagnostic services was also seen as a major benefit of the proposal.

  ".. Less duplication with shared IT and imaging…"

- **Good design**

  The proposals focus on sound design principles and offer the potential to provide a fully functional, accessible facility fit for the twenty first century.

  "…well designed, modern, up to date facility. Easily accessible…"

6.6.2 What don't you like about the proposal?

Respondents were asked to provide 'open' responses to the question "What don't you like about the proposal for NHS heart/lung care we have developed so far?"

The responses to this question can be grouped into the following broad themes:

- **Is this a cost cutting exercise?**
  Can the partners reassure respondents that this is not a cost cutting exercise and actually represents a real investment in the future of services?

  "A small concern that this might be another NHS cutting exercise hidden as an improvement as there have been a lot of those."

- **Care at home (too soon)**
  A significant concern is the potential for patients to be discharged to care at home before they are ready. The partners are urged to consider this issue in developing their proposals.

  "Although less time in hospital is desired by most, I do think people are sent home too quickly and without the support they need."

- **Cost for patients**
  How will the partners consider the financial impact for patients that may result from the implementation of any proposals?

  "appointment…will be harder… (to get) …and more costly to get to appointments.

- **New technology?**
  How will the partners ensure patients who are not familiar with, or afraid of, new technology can benefit equally from the investment in this approach?

  "…Concerns about using new technology e.g. Skype app not all patients have wi-fi at home or know how to use it…plus the dangers of hackers as experienced a few years ago by St Bart's trust…"

6.7 Anything else?

Respondents were asked to provide 'open' responses to the question ***"Do you have any other comments, concerns or suggestions about NHS heart/lung care that you would like to share with us?"***

The responses to this question can be grouped into the following broad themes:

- **Gratitude to NHS staff**

  Overall respondents expressed their gratitude to all the NHS staff at the partner organisation for the care they give and the difference they make in patients' lives.

  "BIG thank you to ALL NHS staff."

  "I get fantastic care at the Royal Brompton"

- **Pastoral care**

  As well as considering the medical care aspects of the proposal, the partners need to ensure the pastoral needs of patients, particularly inpatients, are met. This could include activities and therapies on wards and a constructive approach to entertainment.

  "The pastoral care is as important as the medical care."

- **Reassurance**

  The partners should consider the ways in which they can provide reassurance to patients, their families and carers, that the facilities will provide services that are the equal to or better than existing facilities.

  "Reassurance their tests etc are good… (at the new centre)

- **New technology**

  A consistent concern is the adoption of technology that may be unfamiliar to many or even insecure. The partners should consider how these concerns will be addressed.

  "…The proposal for Skype consultation is a worry as good quality Wi-Fi is hard to obtain in some areas. …"

7 PATIENT-PUBLIC REFERENCE GROUP (PPRG)

The PPRG is convened, facilitated and reported by the Partnership and is independent of MutualGain's activity.

7.1 Comments and recommendations on the findings of the Partnership's patient and public engagement activities

On 21 February 2019 the group met to review the findings of the survey, the three workshops and the webinar that were presented to them in the daft engagement report, before it was approved by the Partnership. The Partnership also invited the group to comment on its draft response to the findings of the engagement report. In particular members were asked to comment on whether they thought anything was missing from the response or if particular findings warranted greater emphasis and consideration by the Partnership

The objectives of the Reference Groups second meeting were to:

- To review the findings of the listening events / workshops, webinar and survey
- To highlight the findings or recurrent themes that the Reference Group believe to be most important for the Partnership to note / consider
- To consider and comment on the Partnership's response

In general the group was unsurprised by views that have been expressed by respondents. The group noted the broad support for the proposals and was reassured to learn there was no overwhelming opposition to the proposals. Members took care to note the following themes, which they believe are particularly important for the Partnership to address going forward.

7.1.1 A need for more detailed information about the proposals, including how they affect patients at the different trusts and data relating to demand and capacity planning and financial implications

While the group acknowledged that the programme is at an early stage, it strongly agreed with respondents that patients, families, carers and members of the public require far more information to be able to understand how the proposals might affect them in the future. It was thought to be particularly difficult for patients of King's College Hospital to understand how the proposals affect the services they use.

The group felt it was very difficult for key stakeholders to be able to understand the scale of the proposals and that there was a need to provide data and information on:

- Who is affected and how many patients will be directly affected?
- What the proposals mean for patients at each trust, in particular addressing gaps in understanding about how King's College Hospital patients are affected
- Capacity planning and reassurance about how the partnership will provide sufficient capacity for the increased inpatient and outpatient activity that would come about as a consequence of the Royal Brompton Hospital services moving to estates on the St Thomas and Evelina London hospital sites
- The financial implications of the proposals, including the capital expenditure that will be required to deliver the expanded healthcare estate that is proposed
- The timescales for delivering the proposals

Members also asked if the Partnership will explore the effect the proposals might have on the capacity of maternity and specialist neo-natal services in the future.

The representative of Muscular Dystrophy UK noted that their members are concerned about the future of the Lane Fox unit, as to date, early information about the proposals does not address this.

Members sought clarity from the Partnership about when the above information would be made available to the group and members of the public. It was acknowledged that NHS England has a key role to play in this in bringing the future public consultation to fruition

The group emphasised the important value of openness and transparency in preventing unnecessary arousal of concern and suspicion about the proposals in the future.

7.1.2 Continuity of care, communications and *'getting the basics right'*

The group acknowledged this was a recurrent themes across all three workshops, which appears to concern patients the most. Members advocated strongly that the Partnership must work closely with patients, their families and carers to ensure that the current quality and continuity of care is not lost as Royal Brompton Services join the services on the St Thomas' and Evelina London hospital sites and the partnership develops further joint working.

There was a shared a concern that a *'bigger team'* might result in the loss of *'patient focused care' and that a 'holistic' approach to care can evaporate when resources are constrained'.* Members emphasised the importance of reassuring and demonstrating to patients this will not be the case.

The group also echoed respondents' views and urged the partnership to *'get the basics right first'*, as part of the transformation process and before any services move. There was a sense that patients have not yet seen an example in other parts of the NHS where this has

been successfully addressed by large scale transformation programmes. When the group spoke of 'getting the basics right' this includes:

- Improving patient administration and communication (written, by telephone and face to face) – the group noted the struggles that some patients have getting through to the right department and person at the right time
- Improving the appointment system and waiting times, both for admissions and appointments
- Ensuring timeliness of patient communication and ease of access to care
- Understanding and addressing the needs of people with complex, multiple healthcare needs who are forced to liaise with multiple specialist teams and can find this particularly challenging and stressful
- Retaining and building on the aspects of care and services that work well – for example, a Cystic Fibrosis patient representative considers communications to be a positive aspect of care presently and that patients would not want to lose the *'familiarity'* brought about by being cared for by a small team.

7.1.3 Joined up working – supporting and developing skills in primary and urgent care

While the group acknowledged the benefits of joined-up working, there is a concern about growing the role of primary and urgent care services in supporting patients with complex heart and lung conditions. Members of the group welcomed the notion of supporting skills development in this part of the healthcare system, but stakeholders will want greater clarification about its role in the network of care that the Partnership's early proposals describe.

7.1.4 Research and retaining the valuable research partnerships that exist today

Again, the group shared the views of both workshop participants and survey respondents in emphasising the important role of research in the Partnership's proposals and sought reassurance that the Partnership would retain and continue to foster its existing relationship with academic institutions. In particular, members were concerned to understand the proposal's implications on the future relationship with Imperial College London, taking into consideration the alternative proposals the delivery of heart and lung services that are being developed by other NHS providers within the North West London area. The group called for a dialogue about research, together with the Partnership and the research and academic partners concerned.

7.1.5 Travel, transport and patient-carer accommodation

The group noted that respondents' views about travel and transport were well made and rightly highlighted in the report. While the group acknowledged that some aspects of the topic are difficult to address in Central London, it is important to tackle early on, as it can have a major impact on how patients, their families and carers access specialist services. In particular, members would like the partnership to:

- Address the cost and practicalities of travel and transport and how expenses are reimbursed to patients and families and this includes:
    - congestion charging and working with TfL to address the significant financial burden
    - the high cost of parking, when patients and families genuinely have no choice but to drive to appointments
    - the limited number and size of disabled parking bays, especially to support people with complex disabilities that requires specialist equipment and transport
- Improve the quality of, and access to, patient transport services provided by the trusts in the future

Coupled with the above, the group felt strongly that 'patient and family accommodation' ought to be considered and planned for in the Partnership's proposals. The matter of accommodation had not been raised by respondents and the group sought information about current and future availability of accommodation for families and carers of child and adult patients.

7.1.6 Retaining the reputation and heritage of the Royal Brompton Hospital and the individual trusts involved in the partnership

The group echoed the views of workshop participants and survey respondents about the importance of retaining and protecting the name and heritage of the Royal Brompton Hospital. There is a worry that the organisation might be lost as the Partnership develops and grows and there is confusion among patient-public stakeholders about the organisational form the Partnership will take in the future. Members sought clarification about how the proposal might affect this going forward and whether there were any proposals for the future branding of the Partnership and services. This is important to patients and staff alike.

7.1.7 Engaging and communicating with staff

Although staff engagement and communication was not highlighted in workshops or in survey responses, the Reference Group wanted to understand how the Partnership will

continue to engage and communicate with staff. Feedback from members' service user networks, suggests there is a sense that staff may not feel as well informed as patients, who are beginning to refer to and ask questions about the Partnership during their hospital appointments. It was noted that staff engagement and communication needs to be addressed.

7.2 Comments and recommendations on the Partnership's draft response to the findings

Taking their discussions into consideration, the group was invited to comment on the Partnership's draft response to the engagement report. The group welcomed the response and the opportunity to comment on it, and recommended the following is addressed in the Partnership's response.

- While acknowledging NHS England's role in bringing information to light as part of its public consultation in summer 2019 – the group would welcome the Partnership's express commitment to sharing information about the following in the future:
    - the numbers of patients who are affected
    - *how* patients of each trust will be affected by the proposals
    - the financial implications of the programme, including the cost of the estates expansion
    - demand and capacity modelling
- The need to engage people with multiple complex conditions to ensure the Partnership's transformation programme fully understands and takes account of the needs of such patients in the future designs services
- The response on travel and transport should be strengthened, by making an express commitment to addressing the issues that have been highlighted by respondents and the Reference Group
- Acknowledgement of the concerns about retaining the heritage of the Royal Brompton Hospital and how the Partnership will address this in its transformation programme
- To address the matter of patient and carer accommodation, as part of the proposals – it is unclear if this has been considered to date
- To acknowledge the importance of staff engagement and communication in the Partnership

8 SUMMARY AND CONCLUSIONS

8.1 Summary

8.1.1 Engagement events

A summary of the key messages and issues arising from the engagement events is as follows:

- Patients and other participants were appreciative of the opportunity to discuss the Partnership's proposals
- Overall there was approval for the conceptual idea of the proposal but also recognition that at this stage much more detail is required. There is anxiety about change and some scepticism.
- Participants were willing to reflect on the potential benefits including how the Partnership could strengthen the knowledge and skills of GPs.
- They also could see the disadvantages, for the most part based on the things that do not work currently.
- Parents particularly highlighted the pressures of transport.
- There was enthusiasm about how digital innovation could improve processes but the need to prevent digital exclusion was emphasised.
- The potential benefits of joined-up working for better treatment were recognised
- The sharing of records was generally welcomed as long as the appropriate safeguards are in place.
- The potential of 'keeping it personal' by focussing on patient choice and patient-centred care rather than treatment was supported.
- There are still many questions and patients, carers and family members were clear that they want to participate in future discussions about how to answer them.

A number of further questions were raised about building and development issues, funding, the organisation of the programme, service implications, patient experience, partnership working, implications for staff and the broader context.

The issues, messages and further questions emerging from the Webinar echo those from the engagement events.

8.1.2 Survey

A summary of the key messages from the survey is set out below.

8.1.2.1 Views on current care

Is the current service working well?

In response to the question "To what extent do you think the NHS heart/lung care you currently receive is working well?":

- The overwhelming majority of respondents who answered the question (93%) thought the current service works well or very well.
- Only 2% of respondents were unsure

When the opinion of current services is considered by the specific service received, while all are well thought of, the higher level of response in the sample from those who received heart care leads to an overall higher satisfaction rate.

What is particularly good about the current service:	What can be improved with the current service:	What is most important to keep of the current service:
▪ The people ▪ Medical expertise of the clinical team ▪ Continuity of care ▪ Support and reassurance ▪ Centres of excellence ▪ Children's care is excellent ▪ Appointments	▪ Regular dialogue ▪ Inpatient and outpatient food choices ▪ Digital records / compatible computer systems ▪ Improved staff attitudes ▪ More preventative action ▪ Appointments and administration	▪ Child friendly environment ▪ Research ▪ Involve patients more in their own care ▪ Safe ▪ Joined up care ▪ Improved aftercare ▪ A more caring attitude for all ▪ Improved communication

Likelihood to recommend (friends and family)

In response to the question "How likely are you to recommend our NHS heart/lung care to friends and family if they needed similar care or treatment, based on the care you are currently receiving or have recently received?" the responses were as shown in the table below.

	%	No.
Don't Know	1%	3
Extremely unlikely	5%	13
Unlikely	2%	5
Neither likely or unlikely	4%	9
Likely	23%	54
Extremely likely	65%	155
Grand Total	**100%**	**239**

In this instance the 'friends and family score is 81. This score is the result of subtracting the negative responses ('extremely unlikely' and 'unlikely') from the positive responses ('extremely likely' and 'likely').

Reasons for providing this score (friends and family)

Positive views (promoters):

- ✓ Excellent care
- ✓ Complete confidence in the staff
- ✓ The hospital is always excellent
- ✓ Excellent clinical staff
- ✓ Service delivery in a centre of excellence

Negative views (detractors):

- × Lack of attention to aftercare, it's assumed we will work out what we need by ourselves
- × The services are underfunded
- × Frustration with the limitations of services (including referral to service from GPs)
- × We feel like we are constantly ***"fobbed off"*** by staff and clinicians (minority opinion)

8.1.2.2 Views on the proposal

The majority of respondents (69%) who provided an answer thought the proposal would work well sometimes (23%) or would work very well (46%).

21% of respondents were unsure and only 6% gave a negative response

First impressions: positive reactions:

- ✓ A wonderful vision
- ✓ Sharing resources to create a centre of excellence
- ✓ Twenty first century technology

First impressions: negative reactions

- × The end of a legend (RBH)?
- × Too big
- × Is it overambitious?
- × Patient focus

What do you like about the proposal?

- Sensible and cost-effective
- Care at home
- Research and faster access to new treatments
- Reduced duplication
- Good design

What don't you like about the proposal?

- Is this a cost cutting exercise?
- Care at home (too soon)
- Cost for patients
- New technology**?**

8.1.2.3 Anything else?

- Gratitude to NHS staff
- Pastoral care
- Reassurance
- New technology

8.1.3 Patient Public Reference Groups (PPRG)

Overall, the group emphasised the important value of openness and transparency in preventing unnecessary arousal of concern and suspicion about the proposals in the future.

A summary of the key messages arising from the Patient Public Reference Group is as follows:

- A need for more detailed information about the proposals, including how they affect patients at the different trusts and data relating to demand and capacity planning and financial implications
- Continuity of care, communications and *'getting the basics right'*
- Joined up working – supporting and developing skills in primary and urgent care
- Research and retaining the valuable research partnerships that exist today
- Travel, transport and patient-carer accommodation
- Retaining the reputation and heritage of the Royal Brompton Hospital and the individual trusts involved in the partnership
- Engaging and communicating with staff
- Comments and recommendations on the Partnership's draft response to the findings of engagement activities

The PPRG welcomed the opportunity to comment on the engagement report, and recommended the following is addressed in the Partnership's response.

- While acknowledging NHS England's role in bringing information to light as part of its public consultation in summer 2019 – the group would welcome the Partnership's express commitment to sharing information about the following in the future:

    - the numbers of patients who are affected
    - *how* patients of each trust will be affected by the proposals
    - the financial implications of the programme, including the cost of the estates expansion
    - demand and capacity modelling
- The need to engage people with multiple complex conditions to ensure the Partnership's transformation programme fully understands and takes account of the needs of such patients in the future designs services
- The response on travel and transport should be strengthened, by making an express commitment to addressing the issues that have been highlighted by respondents and the Reference Group
- Acknowledgement of the concerns about retaining the heritage of the Royal Brompton Hospital and how the Partnership will address this in its transformation programme
- To address the matter of patient and carer accommodation, as part of the proposals – it is unclear if this has been considered to date
- To acknowledge the importance of staff engagement and communication in the Partnership

8.2 Conclusions

8.2.1 Public events

At all events there was a desire to ensure patients continue to be encouraged to participate throughout the patient and public engagement and NHS England consultation processes. These will need to 'pin down' the detail, of the numbers of cardiac and lung patients affected, at Royal Brompton, King's College Hospital, Guy's & St Thomas' and in the community, and the costs involved. The differences between the complexity of acute specialist services and delivering in the community need to be acknowledged and articulated to work out solutions.

'I like the suggestion of consultants going out into the community working with staff in other parts of the system and patients – but this needs to be more than just concepts and nice ideas.'

It will also be important to ensure future workshops are organised at times suitable for different patient groups. Although overall there was a positive and constructive approach from all involved, there were patients who wished to emphasise their worries about the quality of care not being maintained and their anxiety about change. As the Partnership continues to develop its proposals it will be vital to continue to understand and address these worries.

'How do we ensure patients continue to be asked throughout consultation?'

In the future, to ensure that there is healthy debate it would be useful for patients to be provided with specific questions or problems where their input would be valuable. Overall participants recognised that they were not necessarily totally representative of all patients and therefore careful thought needs to be given about how to encourage wider engagement in future patient and public engagement activities, in the material circulated and in outreach opportunities for face-to-face discussions.

'How is this going to work over the next 20 years?'

8.2.2 Survey

The current care was felt to be excellent in terms of the staff, both in terms of general professionalism and the specific and world class expertise of the clinical team. This was underpinned by the continuity of care received and the ability to form a personal relationship with staff. This resulted in an overall feeling of support and reassurance from centres of excellence across the partnership, with a particular emphasis on children's care.

There were, however, areas in which respondents felt the partners could improve. These included a focus on staff, citing a need to improve attitudes and a need to instigate regular dialogue with patients. The perceived inefficiency of the administration systems, in particular appointments, was also an area that was felt to be in need of improvement. Of particular concern was the lack of a unified digital patient record, accessible by all clinicians in all partner organisations, not hampered by incompatible computer systems. Respondents also called for more preventative action to endure their health was more proactively addressed. Finally, there was a call for healthy food for inpatients.

Respondents wanted the partners to continue to provide safe and joined up care in a safe environment, with improved aftercare, while maintaining a child-friendly environment and focusing on providing world-class research.

For the future, respondents urged the partners to support staff to develop a universally caring attitude, supported by improved communications both to patients and between departments, partners and other NHS organisations. There was also a call for improved administrative systems and rehabilitation.

There was no significant opposition to the proposal from survey respondents, however, in line with findings from the events there was an underlying commentary asking for more detail before firm decisions could be made, summed up as "a wonderful vision".

First impressions of the proposal were mixed. Positively, there was a focus on sharing resources among the partners to create a centre of excellence, built around twenty-first century technology and a focus on the patient. On a less positive note, there was concern over the loss of identity of 'brands' with an irreplaceable heritage such as Royal Brompton Hospital, if the Proposal was too big, overambitious and consequently in danger of losing the current, highly valued, focus on the patient.

Respondents were particularly impressed by the sensible and cost-effective approach, offering care at home, reducing duplication and focussing on good design. The focus on research was also felt to be a very positive feature of the proposal that amongst other things would lead to faster access to new treatments.

Respondents were slightly concerned that the entire exercise was motivated by the need to cut costs. There were also concerns over the potential for increased costs for patients in terms of travelling and money from the centralisation of services, the potential for patients to receive care at home before they are ready. Underpinning these was a concern from those who were either nervous or lacked access to the technology in the proposal such as Skype.

9 APPENDIX ONE: INDIVIDUAL PUBLIC EVENT REPORTS

This appendix provides the full reports from the three engagement events.

9.1 Report of the event held at Royal Brompton Hospital, 29th January 2019

The contents of the report are as follows:

1. Background
2. A summary of key issues
3. Introduction
4. Interests and expectations
5. Overall Model of Care: strengths, areas for improvement, opportunities and challenges
6. Cross-cutting themes
7. Further questions
8. Conclusion
9. Appendix: Diversity monitoring

9.1.1 Background

King's Health Partners (the Academic Health Sciences Centre comprising Guy's & St Thomas', King's College Hospital and South London & Maudsley NHS Foundation Trusts and King's College London) and Royal Brompton & Harefield NHS Foundation Trust 'are developing proposals to change how they provide care and treatment for patients with heart and lung disease. In some cases, this may change where care and services are provided'. They want to transform the outcomes and experience of patients with cardiovascular and respiratory health conditions by creating an integrated health system – clinical and academic - which touches the lives of more than 15 million people, and helps cardiovascular and respiratory patients on a regional, national and international level.

It is vital that patients, carers, family members and other stakeholders understand the proposals and have a chance to say what they think before the Partnership submits its initial proposals to NHS England. Three public engagement events were designed to gather these views. This report provides a summary of the discussions that took place at Royal Brompton Hospital on 29th January 2019.

The purpose of the event was to:

- Provide participants with an understanding of the proposal, as set out in the information paper distributed to invitees beforehand and available at the event

(https://www.guysandstthomas.nhs.uk/resources/about-us/proposals-to-improve-heart-and-lung-disease-care.pdf)

- Listen to the reactions, experiences, ideas and thoughts of participants that can help the Partnership understand how patients, their families and carers think they may be affected
- Use the findings from the events, and the survey to inform the ongoing development of the Partnership's proposals

The findings will be submitted to NHS England to inform the development of its Pre-Consultation Business Case and public consultation that is likely to take place in summer 2019.

9.1.2 Summary of key issues

'Want to know what plans are being proposed. To have a voice on anything that is proposed.'

'Patients' opinions to be heard and taken into consideration for any changes to be made.'

- Patients and other participants were appreciative of the opportunity to discuss the Partnership's proposals, drawing on their own experiences (both good and poor).
- Although most people had been invited by letter or encouraged to attend by staff, there was some initial uncertainty about the purpose of the event.
- Overall there was approval for the conceptual idea of the proposal but also a recognition that at this stage much more detail is required. A significant number of participants expressed anxiety about change, particularly its impact on their current treatment. Many people talked about Royal Brompton with real affection and were worried that it could be lost in a larger partnership. There was also some scepticism about the motives for the change.
- In each of the areas of discussion participants were willing to reflect on the potential benefits such as stronger partnerships, specialists working with other parts of the health system and the prospect of more modern facilities.
- They also could see the disadvantages, for the most part based on the things that do not work currently, such as lack of consistency in care, the difficulties in making appointments and poor connections with GPs and other local services.

- There were varied responses to the questions about travel – for some the proposed new location was more central, especially for patients travelling from outside London. There were worries however about public transport and, for those unable to use it, concerns about how adequate parking would be provided.
- There was enthusiasm about how digital innovation could improve processes but recognition that not everyone is confident about using IT as well as emphasising the need to prevent digital exclusion.
- The potential benefits of joined-up working for better treatment were recognised but there was scepticism about how it would work in practice, particularly strengthening the relationship with GPs.
- The sharing of records between institutions and different parts of the health system and with patients was generally welcomed as long as the appropriate safeguards are in place.
- The potential of 'keeping it personal' by focussing on patient choice and patient-centred care rather than treatment was supported.
- For patients there are still many questions but a clear sense that they want to participate in further discussions about how to answer them.

9.1.3 Introduction

Twenty-six patients and four carers/family members as well as clinicians and other staff came together to discuss the Partnership's proposals (see Appendix for the details from the completed diversity monitoring forms). One mother came with her child, who had received treatment at Royal Brompton, as well as the child's grandmother. A representative from the voluntary and community sector was also present. The overall tone of the event was positive about the opportunity to discuss the proposal with both support and scepticism about the proposed changes and how they would affect services. Participants demonstrated genuine inquiry, with patients drawing on both good and poor previous experience to question and challenge the proposal. For a significant number there was considerable anxiety about the concept of change. Patients were keen to share their personal stories that connected across all the themes of the discussion and the breadth of services. It would be worth considering how to capture more of these stories to use in future engagement exercises which will help shape the Partnership's response to NHS England.

The event opened with presentations from Royal Brompton's Chief Executive, Bob Bell, deputy medical director, Professor Andrew Menzies-Gow, and Clare Macdonald, who is leading communications and engagement on this programme for NHS England. These explained the background, the composition of the Partnership, provided an overview of the

proposal and the plans for how to do it, the process and an outline of how it might affect patients and their families, illustrated by two patient stories. The components that would help deliver the plans and next steps were also outlined.

9.1.4 Interests and Expectations

Participants were invited to join small group discussions arranged by service area: Adult Heart, Adult Lung, Children's Heart and Children's Lung. It transpired however that in each group debate mostly ranged across the breadth of all services.

The first task was an 'icebreaker' with participants being asked to capture on different coloured 'post-it' notes their reasons for being at the event and their expectations from it.

9.1.4.1 What brought you here tonight?

'I'm the parent and carer of a patient who died two years ago but I have developed a real interest in the future of the hospital.'

'To support my wife who is a patient.'

'I came as a result of encouragement from staff at Royal Brompton.'

The experiences of patients and carers covered a range of conditions including chronic asthma, respiratory disease, chronic obstructive pulmonary disease (COPD), idiopathic pulmonary fibrosis (IPF), tracheostomy, congenital heart disease, and having a child with cystic fibrosis. Some came to support their relatives, others from patient support groups and a hospital governor was also present. A representative from a parent and children's support charity provided useful insights. One patient was interested in what happens to the service although 'I'd prefer to be treated by Brompton doctors'. A clear message from clinicians was a desire 'to listen', which was welcomed by patients keen that they did and that they should be involved in future events. Most people had been invited by letter or staff. For some, the event invitation was unclear about its purpose which created some initial diffidence about entering into the debate. For example, in one group two participants were under the impression they had been invited to a coronary heart education event.

9.1.4.2 What do you hope to get out of this event?

'I hope to get a) a clear understanding of the project and how it will affect patient care and b) some idea of timescale.'

There was a general wish to find out more about the Partnership as well as 'a greater understanding of the vast NHS organisational structure', seek reassurance that good care would continue, learn about the timescale and direction of the proposal and contribute to the vision. There was an eagerness to have a voice in discussions and learn about the future possibilities for those patients who live a distance away from the hospital and therefore can find it difficult to access.

Specific areas raised were the lung division at Guys & St Thomas', 'changes that will make care for my kid easier and better' and how future technology with remote monitoring and communications could enable local evaluations. Most people wanted improvements in patient care and appointment services but the maintenance of what is already good including a desire that 'the Brompton continues'.

There was overwhelming agreement that the opinions of patients need to be heard and taken into consideration for any changes to be successful. As one patient articulated, the hope was to 'get more information and see why it's worth going through the pain of change – things will change for me for the better.' The aspiration of clinicians to understand 'the sorts of questions and ideas everyone has' and 'what patients and parents want from this new Partnership' was generally welcomed.

9.1.5 Overall Model of Care: strengths, areas for improvement, opportunities and challenges

Using a feedback grid, participants were asked about their responses to the opening presentation and capture thinking about the overall model of care. These were recorded on 'post-it' notes and added to the grid as strengths, areas for improvement, opportunities and/or challenges.

9.1.5.1 What do you like about these proposals?

'Fantastic – I had a heart bypass and pacemaker in 2014 without that I would not be here today. The RBH is a fantastic place with wonderful staff.'

There was a range of positive responses to the proposal including:

- Excitement about the synergy of four organisations working together
- The idea of a 'purpose-built facility – that's efficient where staff won't have to walk miles down Victorian corridors'
- A better use of money (as it would be more expensive to alter an old building)
- The opportunity to improve training and education for staff, improving research with Imperial and other resources

- Enabling referral to services on the same site resulting in fewer trips to different places
- 'Birth to death service in the one hospital'
- Monitoring at home
- Faster communications and a better relationship with GPs

One participant was particularly pleased that the 'Brompton will not lose its name and not be subsumed'. Another, who had congenital heart disease 80 years ago and was seen by the National Heart Hospital and Royal Brompton, was interested in the continuous monitoring approach. There was enthusiasm about the prospect of the Westminster Bridge Hospital when available, the future joint development with other hospitals and making specialist care easier to access.

Patients supported the message that 'this is not about broken services' but an opportunity to use economies of scale to enhance what is already effective. As one person stated the 'range of tests and availability of care feels more complete here in contrast to my experience of other hospitals where care and diagnosis is disjointed'. A key challenge remains – how to strengthen consistency of care and ensure ongoing patient feedback to maintain this?

9.1.5.2 What don't you like about what you have heard today?

'Not enough about the cons. We need more information.'

Concerns were expressed both about the lack of detail about the proposal itself and the quality and effectiveness of services (even if no change takes place). There were worries about the length of time and the challenge of putting in place real partnership. One participant did not 'understand why this site can't be developed – with Crossrail coming it will be easy to get to'. Another that 'they are doing it for the money – it's valuable land – they want it to develop housing. This site is only 30 years old.' There were many affectionate comments about Royal Brompton and worries that being part of a larger organisation could compromise its reputation. A prediction was made that that there could be future pressure to merge from NHS England, describing it as 'a bureaucrat's dream'.

Some people said they would be willing to put up with the existing buildings to remain somewhere smaller as 'bigger is not always better'. They wanted further explanation about the meaning of working more closely with GPs, the local monitoring of ECHOs and other tests and how to expect GPs, for example in Berkshire or other provincial areas, to have the same enthusiasm and commitment for these changes. Others were willing to take a wider

perspective, as one patient commented, 'I live close to RBH and walk here – but have to remember it's a national hospital'.

There were examples of poor practice and scepticism that the proposal would be able to address them. One patient described how a relative with Downs Syndrome had been poorly treated by doctors when attending the hospital for a blood test. This had upset her so much that the test had to be undertaken at home. Another said that Chelsea and Westminster Blood Tests were not shared with Royal Brompton. Doctors do not appear to be aware of visual Lung Function Test results which can help patients see the changes and therefore improve their ability to take better care of themselves. The sentiment in these comments led participants to discuss the need for more training, one example being that staff should have a better awareness of learning disabilities.

Among some participants there was considerable anxiety about disruption, questions about prioritisation, concern about central demands for reorganisation and maintaining expertise at all levels. These will need to be recognised, as the proposals continue to be developed, to 'prevent chaos', reiterating the importance of clear and ongoing communication. One comment encouraged consideration of how 'the positive stories about children's heart services' and what they achieve could be echoed in other areas to build confidence about the positive possibilities of treatment.

9.1.5.3 Cross-cutting themes

The next part of the event asked participants to draw on their personal and specific experiences or conditions to reflect on five cross-cutting themes:

- Transport and travel
- Joint/shared/partnership working
- Use of digital innovation
- Patient records
- 'Keeping it personal'

Prompt cards with specific questions were provided. As with the earlier discussions responses tended to cover the breath of the proposal and these were captured on 'post-it' notes, separately coloured for each of the themes.

9.1.5.4 Transport and travel

'We draw from a large area – travel better for some, less so for others.'

There were considerable differences in opinion about the transport and travel consequences of the proposal. Some people viewed access at St Thomas' Hospital,

Westminster Bridge as good. Patients and families travelling from outside London 'will be pleased to be closer to Waterloo and this is hugely significant'. The possibility of providing a shuttle bus from Waterloo was raised.

At one table there was initially no strong feelings about the subject. However, when one participant asserted that no patients would mind about travelling if the care is good, this was challenged. For some people, getting children, equipment and siblings to the hospital was like a 'military operation' which means that public transport is not an option. Currently there is limited parking at or near Royal Brompton and there was scepticism about the likelihood of 'better facilities elsewhere'. One person described 'getting across the river is a bottleneck of buses' and asked whether car parks would make a difference. There were also concerns about the implications for some people of having to pay the congestion and emission charges. A request was made to ensure an adequate cycle route and access and storage in the new building are provided.

In another group the position of Harefield Hospital was raised. A question was asked about why Harefield was not included in the proposal as 'it requires estate improvement'. Limited public transport made access problematic: 'if local facilities for me (from Staines) are transferred to Harefield – more difficult for transport.'

9.1.5.5 Joined-up working

'Keep patient choice central – and have choice about where you are treated including out and inpatient.'

As with the above discussion, there were a variety of positive and negative views. Underpinned by the sharing of records and information, getting joined-up working right could:

- Maintain choice
- Meet individual needs including improving the connection between paediatric and adult conditions
- Share decision-making with families, particularly in the teenage years
- Support networks of practitioners (and bring more patient involvement into these)
- Create easier telephone contact 'to speak to someone that understands your condition rather than having to repeat the explanation to get through from a switchboard system'
- Improve the coordination of appointments so they happen all on one day

Building on the co-location of tests and facilities in one place, there was also support for the next steps for joined-up diagnostics: 'I would like to talk to my Doctor when I get my ECG'.

There was general recognition of the positive potential of joined-up working but doubts about whether it will work in practice. There will be a need to make sure that every member knows what to do and how to do it with 'firm links to join-up chain'. Some people did not think this would happen as it 'will take 20 years to train people' and getting NHS authority and funding could take '8 to 10 years'. One view was that multi-site working is not generally an advantage for the smooth operational functioning of services.

Some expressed little confidence in their GPs, perceiving they 'get in the way' and do not follow through with hospital prescriptions to save money. Overcoming this lack of confidence will be key – but if achieved will encourage greater patient engagement.

9.1.5.6 Use of digital innovation

'I think the ideas are great! More info needed as they progress – remote monitoring, Skype, apps etc.'

Views ranged from the enthusiastic to the oppositional: 'reduces the need for in person appointment' but 'I'm old school and don't do tech. I don't understand how to.' One patient described a visit to the podiatrist who then communicated electronically with the GP and in turn forwarded the prescription to the chemist where it was easy to collect medication: 'all clinics should be like that – brilliant'. Another patient has been attending the hospital for 60 years. It takes five hours to get home which the patient dreads because of fears about their respiratory problem. In this case digital is key, for example access via Skype.

Participants suggested more immediate access to records would allow greater control, accessibility and 'remembering to do things promptly'. As one patient described, there is a 'possible feedback capability to help monitor my condition and feedback to doctor about progress, e.g. following a change to treatment.' For those with long-term conditions there can be greater continuity of care. Other examples of good practice raised included sharing blood test results and 'more tech could make less need for travel which could give quicker access to consultants'.

There was a significant number of people who felt less 'digitally minded' and therefore training materials could be provided or volunteers to assist them (although some felt that 'some people don't want to learn'). There were concerns about emergencies 'when everything goes down', confidentiality, hacking, viruses and the ability of patients to opt out if they wish. While admitting that effective IT can be cost effective, there were worries of the danger of digital exclusion if it is the only means of communication, especially for older patients. One patient reinforced the importance of relationships, 'it is just nice to speak

with them (doctors), I don't mind if it is text or call'. Nevertheless the majority of responses seemed to support the comment that 'digital technology and social media are here to stay. The more they are used the better.'

9.1.5.7 Patient records

'Better access means that you, the patient, are better informed.'

There was support for the idea that records should be accessible for patients (on their phone) with copies for the GP and every team to help deliver the right care. This sharing should also work across different institutions with systems able to 'talk' to each other, transferring new information about any changes to match up to consultant notes. This would address the situation described by one patient who currently gets a copy of letters and tests to take to the GP. The GP can then 'spend 10 minutes looking at the computer for the information when the appointment only lasts 10 minutes'. There were some concerns about confidentiality, security and that 'there could be too much information' but a general recognition of the advantage in updating records and transferring them quickly to various experts and consultants.

9.1.5.8 Keeping it personal

'There is a very personalised service at the moment at Royal Brompton. Could name and recognise [30] staff. If much bigger, personalised aspect could be diluted.'

The messages from this theme echo many of the points raised above. Patients talked frequently about the long-standing relationships they have with the doctors and teams at Royal Brompton, emphasising the importance of personal connections through partnerships and communications. They were therefore keen that the proposal must recognise this fully. For instance, the need for a single point of contact was articulated as 'someone you can call or email'. It is important that every patient understands their condition and the latest treatment possibilities and is reassured if repatriated to care locally that this treatment is current. This could include accepting more data from patients, for instance blood pressure monitoring or details of exercise patterns. One patient talked of a hope to see the same clinician occasionally: 'now I see someone different every time! However, it's more important that each one is thoroughly conversant with my needs'. On the other hand another participant was clear they wanted to keep seeing the same consultant after the changes.

Whether interactions are face-to-face or remote, there were worries that some people are 'pushier' than others and that staff need to be sensitive to those who may feel more intimidated. One participant believed that 'ethos is personal not in the bricks and mortar and so the positive ethos will transfer to the new hospital, but ethos is fragile in the modern age'. There was a particularly powerful message that 'keeping it personal' in a time of change depends on an ongoing dialogue between patients and professionals that is honest about both the challenges and opportunities.

9.1.6 Further questions

At the start of the event participants were encouraged to note any specific questions and, before the close, a number of further questions were raised with the whole group. Some were answered immediately by the clinicians and other staff present. They are worth noting nevertheless as they echo many of the themes from the discussions described above and may well reoccur during further engagement exercises (note that these are captured verbatim):

- What is on the land at the moment (at St Thomas')?
- What do St Thomas' get out of it?
- What is the timescale for the programme?
- Why don't you rebuild this site [Royal Brompton Hospital]?
- Will the new site [at St Thomas' Hospital] be big enough to allow for future growth? What is the assessment based on?
- Will there be more beds in the new hospital?
- What will happen to the art at Royal Brompton?
- Will all respiratory services be in one place?
- Will services for children all be at Evelina?
- Will the institutions eventually be merged anyway, if not in the short term?
- Will there be a better link between specialist services and A&E?
- What access will there be to other specialists for non-heart and lung problems?
- Does the [NHS] tariff affect our decisions?
- How will NHS England manage/perform the public consultation?
- In terms of appointments would I remain a patient of Royal Brompton or would I have to change to one of the other partners?
- Will staff rotate/move around to see me/others – in a local hospital?

9.1.7 Conclusion

At the end of the table discussions there was positive feedback about the 'excellent' event but a desire to ensure patients continue to be encouraged to participate throughout the patient and public engagement and NHS England consultation process. It will also be important to ensure future workshops are organised at times suitable for different patient groups. Although overall there was a positive and constructive approach from all involved there were a small group of patients who wished to emphasise their worries about the quality of care not being maintained and their anxiety about change. As the partnership continues to develop its proposals it will be vital to continue to understand and address these worries.

'How do we ensure patients continue to be asked throughout consultation?'

9.1.8 Diversity Monitoring

Twenty diversity monitoring forms were completed, and these are summarised below:

Age group	16-24:	25-34	35-44	45-54	55-64	65-74	75-84
	1	*1*	*3*	*3*	*3*	*5*	*4*
Gender	Female				Male		
	13				*7*		
Sexual orientation	Heterosexual or straight						
	19						
Religion	No religion	Muslim	Christianity		Buddhist	Hindu	Jewish
	3	*1*	*13*		*1*	*1*	*1*
Disability, long-term illness or health condition	Yes				No		
	15				*3*		
	A long-standing illness or health condition	A physical impairment or mobility issues	A specific learning disability (e.g. dyslexia, dyspraxia or AD(H)D)		Deaf or have a hearing impairment	An impairment, health condition or learning difference that is not listed	
	13	*3*	*1*		*1*	*1*	
Caring responsibilities	None	Primary carer of a child or children (under 2 years)	Primary carer of a child or children (between 2 and 16 years)		Primary carer of a disabled child or children	Primary carer or assistant for a disabled adult (18	

					years and over)
	11	*2*	*2*	*1*	*1*
Race or ethnicity	White British	Irish	Any other White background	Any other Asian background	African
	10	*1*	*2*	*1*	*5*
Postcodes	E18, EN1, HA2, IG6, NW6, NW10, RH8, RM13, SW1A, SW5, SW6, SW11, SW13, TW1, TW1, TW1B, UB4, W3				

9.2 Report of the engagement event held at the Cicely Saunders Institute, King's College Hospital, 30th January 2019

The contents of the report are as follows:

1. Background
2. A summary of key issues
3. Introduction
4. Interests and expectations
5. Overall Model of Care: strengths, areas for improvement, opportunities and challenges
6. Cross-cutting themes
7. Further questions
8. Conclusion
9. Appendix: Diversity monitoring

9.2.1 Background

King's Health Partners (the Academic Health Sciences Centre comprising Guy's & St Thomas', King's College Hospital and South London & Maudsley NHS Foundation Trusts and King's College London) and Royal Brompton & Harefield NHS Foundation Trust 'are developing proposals to change how they provide care and treatment for patients with heart and lung disease. In some cases, this may change where care and services are provided'. They want to transform the outcomes and experience of patients with cardiovascular and respiratory health conditions by creating an integrated health system – clinical and academic - which touches the lives of more than 15 million people, and helps cardiovascular and respiratory patients on a regional, national and international level.

It is vital that patients, carers, family members and other stakeholders understand the proposals and have a chance to say what they think before the Partnership submits its initial proposals to NHS England. Three public engagement events were designed to gather these views. This report provides a summary of the discussions that took place at the second event at King's College Hospital on 30 January 2019.

The purpose of the event was to:

- Provide participants with an understanding of the proposal, as set out in the information paper distributed to invitees beforehand and available at the event (https://www.guysandstthomas.nhs.uk/resources/about-us/proposals-to-improve-heart-and-lung-disease-care.pdf)
- Listen to the reactions, experiences, ideas and thoughts of participants that can help the Partnership understand how patients, their families and carers think they may be affected
- Use the findings from the events, and the survey to inform the ongoing development of the Partnership's proposals

The findings will be submitted to NHS England to inform the development of its Pre-Consultation Business Case and public consultation that is likely to take place in summer 2019.

9.2.2 Summary of key issues

'Would like to input anything useful I can to the integration process. And, since every generation of my family has had serious heart disease, I would like to help build a better future for my sons!'

- Patients and other participants were appreciative of the opportunity to discuss the Partnership's proposals, drawing on their own experiences (both good and poor).
- Although most people had been invited by letter or encouraged to attend by staff, there was some initial uncertainty about the purpose of the event.
- Overall there was approval for the conceptual idea of the proposal but also recognition that at this stage much more detail is required, especially about resources and numbers of patients involved. There was a strong message from some participants that by embracing the creation of a specialist hub, seeking to strengthen community services, support integration and encourage better self-management the idea in reality covered more than one proposal which may be unrealistic. A significant number of participants expressed anxiety about change, particularly its

impact on their current treatment. There was also some scepticism about the motives for the change.

- Many people talked about the role of King's College Hospital as a local hospital meeting the needs of its local population with real affection and were worried that this element could be lost in a focus on specialist services and within a larger partnership.
- Some worries were expressed about the potential for inequity between services, i.e. a super new specialist centre, existing care at King's College Hospital and the quality of care at the 'home' hospital where there may not be same expertise.
- In each of the areas of discussion participants were willing to reflect on the potential benefits such as stronger partnerships, specialists working with other parts of the health system and the prospect of more modern facilities.
- They could also see the disadvantages, for the most part based on the things that do not work currently, such as lack of consistency in care, the difficulties in making appointments and poor connections with GPs and other local services.
- There were varied responses to the questions about travel – for some the proposed new location was more central, especially for patients travelling from outside London. There were worries however about public transport and, for those unable to use it, concerns about how parking would be provided.
- There was enthusiasm about how digital innovation could improve processes but recognition that not everyone is confident about using IT as well as emphasising the need to prevent digital exclusion.
- The potential benefits of joined-up working for better treatment were recognised but there was scepticism about how it would work in practice, particularly strengthening the relationship with GPs.
- The sharing of records between institutions and different parts of the health system and with patients was generally welcomed as long as the appropriate safeguards are in place.
- The potential of 'keeping it personal' by focusing on patient choice and patient-centred care rather than treatment was supported.
- For patients there are still many questions but a clear sense that they want to participate in further discussions about how to answer them.

9.2.3 Introduction

Twenty patients and carers/family members as well as clinicians and other staff came together to discuss the Partnership's proposals (see Appendix for the details from the completed diversity monitoring forms). There was a breadth of adult experience, primarily

from cardiac patients, including a transplant patient for over 25 years (whose treatment includes a 14-hour operation and a long journey around the M25) and a younger person just beginning treatment for a heart condition. There were no parents or users of children's service present (although there three paediatricians in attendance). This meant there was little discussion specifically about children's services. There was a range of feelings from apprehension about change to excitement at the possibility of new and improved services, but the atmosphere was largely co-operative and positive. A clear message was conveyed that the needs of existing patients must continue to be met whatever the outcome of the plans. Participants seemed to appreciate that the clinicians present were able to answer many questions raised during the individual table discussions.

The event opened with presentations from the Executive Medical Director, Professor Julia Wendon, and Clare Macdonald who is leading communications and engagement on this programme for NHS England. These explained the background, the composition of the Partnership, provided an overview of the proposal and the plans for how to do it, the process and an outline of how it might affect patients and their families, illustrated by two patient stories. The components that would help deliver the plans and next steps were also outlined.

9.2.4 Interests and Expectations

Participants were invited to join small group discussions arranged by service area: Adult Heart, Adult Lung, Children's Heart and Children's Lung. It transpired however that in each group debate mostly ranged across the breadth of all services.

The first task was an 'icebreaker' with participants being asked to capture on different coloured 'post-it' notes their reasons for being at the event and their expectations from it.

9.2.4.1 What brought you here tonight?

'To find out details of any improvements - information on options that might be available.'

'For contacts and belong to a community group – share concerns – feel secure about health and learn about future risks related to heart problems.'

'To meet other people with the same health problems as me and learn.'

The majority of participants had come to learn about the detail of the proposals – how it would affect them personally, to learn from the experiences of others, to be able to share with colleagues including community groups they are involved with and, as one said, 'to be aware of what's going on so that I can tell my local doctor in case he doesn't know.' Most

people had been invited as a patient either by letter or encouraged by staff although a significant number were uncertain about the purpose of the event. There were others who are active in existing public and patient participation both at King's and in the wider health system, including a public governor at the hospital and a chair of a support group.

9.2.4.2 What do you hope to get out of this event?

'I would like to know what has been happening in the past and how things are going [to work] in the future.'

Generally participants wanted to leave the event with more information and a greater understanding of the Partnership. For some this meant more precise detail about timescales and costs, for others it was for reassurance that what is currently good is maintained and, for a smaller number, it was to contribute to a vision for the future. Other areas of interest included staff education and recruitment, family support, the place of end of life care in the proposed plan, the rationale for the proposal, how it will be funded, the division of responsibilities between the Trusts and how they will co-operate in delivering community integrated services.

9.2.5 Overall Model of Care: strengths, areas for improvement, opportunities and challenges

Using a feedback grid, participants were asked about their responses to the opening presentation and capture thinking about the overall model of care. These were recorded on 'post-it' notes and added to the grid as strengths, areas for improvement, opportunities and/or challenges.

9.2.5.1 What do you like about these proposals?

'In theory this is fantastic, if it comes to pass.'
'Fabulous potential – specialist centre!'
'Quality of services has to be changed and maintained'

There were many positive responses. One person believed the vision to be 'absolutely wonderful – the grandest thing heard for a long time'. Another said it was a 'great idea', particularly as it would reduce travel for patients, especially for those required to fast before their appointments and can therefore end up driving while tired. An older patient saw the super hub as having benefits for 'someone of my age'. There was support for a more holistic approach which would 'treat the patient not the disease' and care being provided closer to home. For some there is evident potential in having a specialist centre

but, at the same time, uncertainty about whether the proposal will actually happen or meet the needs of patients. The quality of services will have to be changed and maintained to become more consistent although there were some concerns about the potential inequity between services, i.e. a super new specialist centre, existing care at King's College Hospital and the quality of care at the 'home' hospital where there may not be the same expertise.

For instance, during the last year one patient had never seen the same doctor or nurse more than once and therefore expressed the hope that the new proposal would ensure better continuity of care.

There was a strong message from one group that using more digital technologies will be helpful for people living alone, especially those with no family support network to assist with travel and appointments.

9.2.5.2 What don't you like about what you have heard today?

'Don't siphon off the resources to the 'ivory tower'

Although there were few comments that were overtly opposed to the proposal there was considerable uncertainty about its exact nature. By embracing the creation of a specialist hub, seeking to strengthen community services, supporting integration and encouraging better self-management, the Partnership seemed to be proposing more than one change which could be unrealistic. For some participants this reinforced the lack of clarity, for instance about any additional burdens and 'where's the money'? How would King's College Hospital's role as a 'local hospital' meeting the needs of the 'local population' be maintained, as there is 'nothing' between the GP and the hospital? There were concerns that some patients may feel lost when they are transferred to their GPs, there would be a loss of patient choice with non-specialist needs not being met and GPs will be uncertain about where to send patients (especially if they are not based in London). There are already challenges about recruiting staff to community services placing extra burdens on carers and families, so it is crucial that this proposal does not make the situation worse. There were also some concerns that it would be more difficult to attract top clinicians to local hospitals, as there would be a desire to work at the specialist centre.

There were a number of suggestions (both for existing and new services) including reducing waiting times and the number of cancelled appointments. One table group was particularly concerned that NHS patients should be treated the same as private ones who they felt were given greater priority.

'Site in Chelsea is worth a fortune; how can we make savings as well?'

The issue of funding arose frequently with concerns about the lack of detail about costs and the sustainability of the project (given the past history of public spending), for instance one participant's perception was that the NHS is on its knees at the moment so 'I can't see this [the proposal] happening' and another that the 'NHS is overworked and understaffed.' Together with past experience of poor services, these sentiments also tended to be linked to those participants who were sceptical about the proposals. This meant that there were repeated requests for more information about resources, actual numbers of patients (both private and NHS) and in different locations (acute and primary care and the wider community). There is a need to think about staff, particularly those on the frontline including junior doctors, and ensure that they are involved in discussions about the proposals. Although there is no plan for mergers in the proposals, a concern was expressed that it would also be crucial to learn from previous restructures of services and organisations both in the health service and elsewhere.

'Things like bringing together accounting practices and building a more inclusive culture will be a struggle.'

9.2.6 Cross-cutting themes

The next part of the event asked participants to draw on their personal and specific experiences or condition to reflect on five cross-cutting themes:

- Transport and travel
- Joint/shared/partnership working
- Use of digital innovation
- Patient records
- 'Keeping it personal'

Prompt cards with specific questions were provided. As with the earlier discussions responses tended to cover the breath of the proposal and these were captured on 'post-it' notes, separately coloured for each of the themes.

9.2.6.1 Transport and travel

'Look forward to transport becoming easier.'

There was a mixture of responses, based on individual experiences. For example patients travelling from Kent see Westminster Bridge as a more convenient and central location. On the other hand others felt that it would be difficult to drive to Westminster and were concerned about whether there would be adequate parking facilities.

9.2.6.2 Joined-up working

'Ensure effective linkage between the hub and local hospital with helplines for staff, parents and families.'

Some participants were keen that the new arrangements should provide better continuity of care and speed, bringing access to information for multiple clinicians and services. They wanted this to guarantee holistic and consistent care. There were examples of previous poor experiences which need to be improved. One patient described how seeing a new clinician meant a change in medication and only being provided with a 2 week-supply. When they visited their GP for a repeat script the information about the change had not been sent through and the pharmacist was unable to provide an emergency supply, as there were no records. This meant they were left with no medication. Another described that in one year they have seen three consultants and different registrars and cardiac nurses which meant having to explain their history time and again.

On the other hand, another participant talked about how the Local Care Record seemed to work effectively in GP practices but less well at King's College Hospital. Although there was support for the idea of getting patients home sooner this could also result in an increased burden for carers who may not know where to seek advice.

The training of staff would be key, as would the building of trust across the care pathways to ensure families are reassured that teams are familiar with the needs of patients. One suggestion was to have a clinical nurse specialist to support a journey through the system as well as pathway coordinators. There would be a need for effective advocacy support so that 'you are able to speak up for yourself' and patients are able to share knowledge about how and what care and services are available.

9.2.6.3 Use of digital innovation

'Full support for digital – patients see it as the way forward' but 'IT is unrealistic for certain people.'

There were mixed messages about the use of technology. Some participants see it as the way forward, both for themselves and 'the next generation of heart patients'. They expressed willingness to use their personal phones for appointments, consultations and results and were comfortable with Skype, WhatsApp, Facetime, etc. At the same time it was recognised that not everyone would be so comfortable, especially older people who may need support to use any new system. Although there was recognition of how technology is already in place, for example online appointment booking, there were concerns that the health service did not have a good track record of implementing ambitious new IT systems

which could lead to expensive mistakes and raised worries about the security of records. There was a strong message therefore about the importance of getting the basics right before embarking on new systems.

Some people felt that new technology could help patients to talk to each other and share experiences which they saw as beneficial. At the same time these developments should be additional to patients meeting casually in waiting rooms and other settings, which can also be a source of mutual support. It would also be important for patients to have a choice about the kind of technology that helps them.

9.2.6.4 Patient records

'For me it has to work for the patients first. Any collaboration has to make patients' lives better.'

Effective record keeping is required and a decrease in delays to support patients and consultants across the different settings. Most people appeared happy that information could be shared but there were worries about maintaining data protection and ensuring sufficient resources to build protection from hacking or viruses. As one participant stated, 'I would like to hear from patients what they need.'

9.2.6.5 Keeping it personal

'I like King's and don't want to change.'

'Currently I have a lot of trust in my consultant.'

Overall there were strong messages about patient choice, continuity of care, fairness in priority given to NHS patients and the need to be holistic and consider the whole patient not the disease. Linked to the issues raised above, this demands a connected and integrated system to build on the things that work and build greater confidence among patients who may 'not feel qualified to make decisions regarding our care.'

9.2.7 Further questions

At the start of the event participants were encouraged to note any specific questions and, before the close, a number of further questions were raised with the whole group. Some were answered immediately by the clinicians and other staff present. They are worth noting nevertheless as they echo many of the themes from the discussions described above and may well reoccur during further engagement (note that these are captured verbatim):

- The proposal sounds good but how does all this filter down to junior doctors and other staff on the front line?
- Where is the money coming from?
- Will the use of digital innovation create anxiety for patients, for example when receiving test results, especially if the tests are abnormal?
- As more care is delivered locally in primary care and in local hospitals, is there a danger that doctors may not have sufficient expertise in specialist areas?
- Can I ask my doctor at King's to transfer me to the hub if I want?
- What is the capacity of the new proposal in terms of beds?
- Will the proposal deal with delays and backlogs?
- Is it possible to carry out the integration of heart and lung services without bringing in other care, for example kidney services?
- What will be the impact of Brexit?
- Is the government ready to fund this?

9.2.8 Conclusion

At the end of the table discussions there were similar concluding points made about the need to 'pin down the detail' including an understanding, in any future workshops, of the numbers of cardiac and lung patients affected, at King's College Hospital, Guy's & St Thomas' and in the community, and the costs involved. The differences between the complexity of acute specialist services and delivering in the community need to be acknowledged and articulated to work out solutions. Unsurprisingly there was a yearning [overly emotive?] for reassurance.

'How is this going to work over the next 20 years?'

9.2.9 Diversity Monitoring

Eleven diversity monitoring forms were completed, and these are summarised below:

Age group	25-34	55-64		65-74	75-84
	1	*4*		*4*	*2*
Gender	Female			Male	
	5			*5*	
Sexual orientation	Heterosexual or straight			Gay woman or lesbian	
	9			*1*	
Religion	No religion	Muslim	Christianity	Hindu	Prefer not to say

	3	*1*	*5*	*1*	*1*
Disability, long-term illness or health condition	Yes			No	
	8			*2*	
	A long-standing illness or health condition	A mental health difficulty	A physical impairment or mobility issues	Deaf or have a hearing impairment	An impairment, health condition or learning difference that is not listed
	5	*1*	*1*	*1*	*1*
Caring responsibilities	None:		Primary carer or assistant for an older person or people		
	5		*1*		
Race or ethnicity	White British	Irish		Indian	African
	6	*2*		*1*	*1*
Postcodes	BR1, BR2, BR2, DA4, SE5, SE20, SE21, SE22, SE24, SW16, SW16				

9.3 Report of the event held in the Robens Suite, Guy's and St Thomas', 6th February 2019

The contents of the report are as follows:

1. Background
2. A summary of key issues
3. Introduction
4. Interests and expectations
5. Overall Model of Care: strengths, areas for improvement, opportunities and challenges
6. Cross-cutting themes
7. Further questions
8. Conclusion
9. Appendix: Diversity monitoring

9.3.1 Background

King's Health Partners (the Academic Health Sciences Centre comprising Guy's & St Thomas', King's College Hospital and South London & Maudsley NHS Foundation Trusts and King's College London) and Royal Brompton & Harefield NHS Foundation Trust 'are

developing proposals to change how they provide care and treatment for patients with heart and lung disease. In some cases, this may change where care and services are provided'. They want to transform the outcomes and experience of patients with cardiovascular and respiratory health conditions by creating an integrated health system – clinical and academic - which touches the lives of more than 15 million people, and helps cardiovascular and respiratory patients on a regional, national and international level.

It is vital that patients, carers, family members and other stakeholders understand the proposals and have a chance to say what they think before the Partnership submits its initial proposals to NHS England. Three public engagement events were designed to gather these views. This report provides a summary of the discussions that took place at the third of these, held in the Robens Suite at Guy's & St Thomas' Hospital on 6 February 2019.

The purpose of the event was to:

- Provide participants with an understanding of the proposal, as set out in the information paper distributed to invitees beforehand and available at the event (https://www.guysandstthomas.nhs.uk/resources/about-us/proposals-to-improve-heart-and-lung-disease-care.pdf)
- Listen to the reactions, experiences, ideas and thoughts of participants that can help the Partnership understand how patients, their families and carers think they may be affected
- Use the findings from the events, and the survey to inform the ongoing development of the Partnership's proposals

The findings will be submitted to NHS England to inform the development of its Pre-Consultation Business Case and public consultation that is likely to take place in summer 2019.

9.3.2 Summary of key issues

> ***'My son has been treated since he was born at Guy's and Evelina. He will remain under hospital all his life, so I care what happens.'***
>
> ***'Have an understanding of the future of the lung department – especially for outpatient adults and especially when related to their other illness e.g. cancer.'***

- Patients and other participants were appreciative of the opportunity to discuss the Partnership's proposals, drawing on their own experiences (both good and poor).

- Most people had been invited by letter or encouraged to attend by staff. There seemed a clearer understanding about the purpose of the discussion than at the previous events.
- Overall there was approval for the conceptual idea of the proposal but also recognition that much more detail is required, particularly about funding and design of both services and buildings. For many participants there is residual scepticism about the changes, based on their own experiences and understanding of the wider political and economic context.
- Many people talked positively about their experiences at Guy's, St Thomas' and the Evelina, and were therefore keen to ensure good practice continues, develops and is shared more widely.
- A larger number of parents, some with their children, attended which resulted in more discussion about Children's Services than at the earlier events. There was praise for provision at the Evelina and the need to maintain its quality.
- In each of the areas of discussion participants were willing to reflect on the potential benefits such as stronger partnerships, specialists working with other parts of the health system and the prospect of more modern facilities.
- They also could see the disadvantages, for the most part based on the things that do not work currently, such as lack of consistency in care and the difficulties in making appointments and poor connections with other local services. Throughout the discussions there was considerable criticism of GPs, while appreciating the pressures primary care faces. At the same time there was recognition that the Partnership could strengthen the knowledge and skills of GPs in supporting patients with heart and lung conditions.
- Parents particularly highlighted the pressures of transport – its high costs and the lack of parking – which add to the stress of having an unwell child. While the location of Guys' & St Thomas' services will not change under the proposals, there was agreement that the proposed new central location would be better for the Royal Brompton patients, especially for those travelling from outside London, and for anyone currently having to travel to different hospitals to receive care. As at the previous events, there were worries however about public transport and, for those unable to use it, concerns about how accessible car parking would be provided.
- There was considerable enthusiasm about how digital innovation could improve processes but recognition that not everyone is confident about using IT as well as emphasising the need to prevent digital exclusion.
- The potential benefits of joined-up working for better treatment were recognised but there was scepticism about how it would work in practice, particularly

strengthening the relationship with GPs. The need for connections to other public and voluntary and community sector services was highlighted but recognition that this may be challenging given their funding is less secure than that of the NHS.

- The sharing of records between institutions and different parts of the health system and with patients was generally welcomed as long as the appropriate safeguards are in place.
- The potential of 'keeping it personal' by focussing on patient choice and patient-centred care rather than treatment was supported. Embracing a broader wellbeing agenda, for example working with charities, would strengthen this area of work.
- For patients there are still many questions but a clear sense that they want to participate in further discussions about how to answer them in a structured and constructive fashion.

9.3.3 Introduction

Twenty patients, six parents of child patients and nine carers/family members as well as clinicians and other staff came together to discuss the Partnership's proposals (see Appendix for the details from the completed diversity monitoring forms). In contrast to the other two engagement events there was a larger number of parents, some of whom also brought their children with them. As well as giving more prominence to children's issues this created a vibrant atmosphere injecting a greater sense of fun in the event. Overall there appeared to be greater ethnic diversity, although fewer monitoring forms were completed than at the previous events. At one table two people had experience of lung cancer treatment and talked positively about the emotional support they had received from the Cancer Centre at Guy's. Among the other perspectives present were a foundation trust governor, a patient and his support worker from a community mental health charity and one non-verbal participant who required one-to-one support to make his contribution.

Although, as with the earlier events, there was a range of feelings from apprehension about change to excitement at the possibility of new and improved services, the atmosphere was largely co-operative and positive. A clear message was conveyed however that the needs of existing patients must continue to be met whatever the outcome of the plans. Participants seemed to appreciate that the clinicians present were able to answer many questions raised during the individual table discussions.

The event opened with presentations from the lead clinicians, Professor Richard Beale, Consultant Intensivist & Associate Medical Director, and Dr Sara Hanna, Medical Director, Evelina London Children's Healthcare, and Clare Macdonald, who is leading communications and engagement on this programme for NHS England. These explained the background, the

composition of the Partnership, provided an overview of the proposal and the plans for how to do it, the process and an outline of how it might affect patients and their families, illustrated by two patient stories. The components that would help deliver the plans and next steps were also outlined.

9.3.4 Interests and Expectations

Participants were invited to join small group discussions arranged by service area: Adult Heart, Adult Lung, Children's Heart and Children's Lung. There was more focus on the perspective of parents and children at the table discussing Children's Heart and Lung, but the other groups mostly ranged across the breadth of all services.

The first task was an 'icebreaker' with participants being asked to capture on different coloured 'post-it' notes their reasons for being at the event and their expectations from it.

9.3.4.1 What brought you here tonight?

'Curiosity about how these plans will be implemented and an interest in how my care will be affected.'

'Quite curious to get an insight into new research, the treatment being done and the league of success.'

The majority of participants had been invited by letter and were motivated to attend because of their own or a family member's experience, several specifically mentioning heart surgery. They wanted a better understanding of 'what's going on' and the future impact on their treatment, including as one participant said, 'as patient and as a healthcare professional' (who had been a GP). The group that focussed on Children's services was particularly interested in the impact on Evelina services and keen to hear the views of other parents. Interestingly the word 'curiosity' was used several times as was the desire to contribute and help, as one person described being 'the eyes and ears' of other colleagues unable to be present.

9.3.4.2 What do you hope to get out of this event?

'What I want to get out of it? I thought you wanted to get something out of me in the way of ideas!'

Although one person said, 'I don't know but open to hearing what is said', there was an overall desire to find out more about the implications for specific services, including:

- 'More information to keep healthy hearts'

- The implications for cardiac services
- An understanding of the future of the lung department, especially for adult outpatients and the relationship with other conditions patients might have, such as cancer
- Improve services for people with asthma

One participant highlighted an interest in prevention and a desire to see more of it in the proposal 'so it is like having a mammogram before the person has to go to A&E.' Several participants wanted to hear how new technology ('the modernity of nowadays' was one description) could create better care options. On one table there was focus on the aspiration that empathy should form a strong strand in the proposal. The hope for 'reassurance that the process will be in the best interests of my care and care of other patients' was also a common theme.

9.3.5 Overall Model of Care: strengths, areas for improvement, opportunities and challenges

Using a feedback grid, participants were asked about their responses to the opening presentation to capture their thinking about the overall model of care. These were recorded on 'post-it' notes and added to the grid as strengths, areas for improvement, opportunities and/or challenges.

9.3.5.1 What do you like about these proposals?

'Quite comfortable with all the proposals. Will improve patient care a hell of a lot.'

There was strong support for the 'excellent idea to have a centralised unit for all patients with specialised services' 'funnelling everything into one centre of excellence' and addressing situations like that for one patient who is 'at the moment, under four different hospitals.' Parents of children being treated were particularly supportive of this idea. Having a cardiothoracic unit 'sounds extremely marvellous' and the idea of a research centre was welcomed. Overall many participants believed that the plans would ensure less travel, time and cost for them.

Other elements that met with approval included:

- The prospect of all the specialists 'under one roof' to facilitate better connections between them
- The concept of multiple specialists working at the same level with less reliance on the triangular structure with the consultant at the top

- Having specialist appointments on the same day - and if coordination was improved it would be 'beneficial to not come to hospital three or more times a week'
- 'By booking them [appointments] all on the same day at one location' would improve the experience of using outpatients

One participant liked the idea of the network surrounding the centre as it would 'filter expertise and increase possibilities of being treated at home.' There was also support for including mental health expertise with South London and Maudsley being one of the partners. Overall therefore there was a great deal of support for the ambitions of the Partnership – as an entity itself – but also the concept of partnership working and its potential positive impact on day-to-day experiences and cementing the relationships to create this. Unsurprisingly this enthusiasm was tempered by worries about funding and the length of time the plans will take to be realised.

9.3.5.2 What don't you like about what you have heard today?

'How will it translate in practice?'

'I have a direct experience of a central service, cancer that was good, but what if you have more than one condition – how do we connect them all better?'

There was little sense of opposition to the ideas outlined but worries about what one group described as 'the three Cs' of:

- **Communication** between health professionals and their patients
- **Continuity** of care to give patients confidence that their conditions would be treated effectively
- **Capacity** of having adequate staffing and physical space to deliver the proposal's aspirations

There is a need for more connection across services, for instance to address heart problems caused by cancer treatment, to improve the poor current links and create holistic care. As well as the specific treatments this should be 'all about the people – like seeing the same person and building a relationship.' Examples of different situations were provided such as the parent who described how their son was aspirating but it took five weeks to get speech and language support. On the other hand neurology and cardiology were highlighted as already working well together already, good practice that could be built on in other service areas.

The gap between 'what exists at the moment in the community at local level and the plan' captured some of the worries. A suggestion was made that having a GP centre attached to

the new hospital, where patients could go first, would aid the overall continuity of care. There were complaints about GPs 'not being up to scratch'. Although Guys and St Thomas' provide full reports to the GP at the moment it often does not get to them, perhaps because they are 'under pressure'. One patient said they did not trust their GP because they had been 'given a different description in the past to what was prescribed by hospital.' For several participants there was a sense that the proposals might increase expectations of GPs in respect to patients' heart or lung care. As the proposal will increase GP responsibility this could cause anxiety for patients.

Concerns were raised about maintaining the relationship with doctors which is currently 'superb'. There was a perception that under the new proposals patients could be dealing with staff who they do not know. More detail about how this would work would therefore be needed. One patient, being treated under three hospitals currently, felt quite happy with this situation and questioned whether a one-stop shop would be as thorough in the delivery of care.

There were several requests to 'improve empathy as well as expertise'. Some clinics feel rushed and 'you have to push to get information, it's not offered' which may not be easy for less confident patients. There was a suggestion that consultants and nurses should have simulated training (including the use of a mask that reduces oxygen flow similar to the experience of struggling to breathe), as 'this would really help them to understand what it feels like'. This kind of initiative could build an emotional empathy between staff and patients, an area of support particularly important for the families of children being treated.

Other concerns included *'who will the network be and how will they be trained?'*

There were many questions about funding and how this new investment linked to the ongoing demand for cost savings and efficiency, the extent of investment needed in IT and recruitment particularly of international staff, in the context of Brexit. One group was worried about the improvement of equipment and its maintenance, highlighting the need for accuracy about monitoring heart rates. Understanding the lessons from the history of mistakes in other ambitious NHS change projects was also a key message.

9.3.6 Cross-cutting themes

The next part of the event asked participants to draw on their personal and specific experiences or condition to reflect on five cross-cutting themes:

- Transport and travel
- Joint/shared/partnership working
- Use of digital innovation

- Patient records
- 'Keeping it personal'

Prompt cards with specific questions were provided. As with the earlier discussions responses tended to cover the breath of the proposal and these were captured on 'post-it' notes, separately coloured for each of the themes.

9.3.6.1 Transport and travel

'Travel is quite a nightmare' – patient transport is dreadful.'

Participants in the group discussing Children's services were all agreed that the high costs of parking needs attention as this adds to the stress of bringing a child to the hospital. One parent described 'trying to recoup £1500 for travel and accommodation' although also acknowledged that the team had been flexible by booking appointments to help reduce this level of cost. The new emission and existing congestion charges will total £25 per day plus the cost of parking. There was plea therefore for concessions to be introduced for parents having to drive their children to the hospital. The plans for more specialists in the community were welcomed: 'it is stressful travelling from Kent, so I want treatment in my local hospital'.

For others the new development on the St Thomas' site would be a 'superb location', especially as it is easier 'travelling to central London than to the hospital in Kent.' Nevertheless there were a number of existing travel challenges. Some patients have been advised to use their cars because public transport has a detrimental effect on their condition. One described how, having contracted pneumonia after travelling by train, they need to be able to drive and therefore it is 'fortunate that the new site will be central'. This does of course mean the need for adequate parking facilities as currently 'I wait a long time for a parking space'. Support for the new location was endorsed by another patient.

One group, the majority of who lived nearby, did not have any travel or transport concerns. One person did not 'mind travelling to different hospitals as have a good relationship with the staff'. Another felt that having one-to-one appointments meant 'coming out is exercise for us'. Although one participant said they would like the hospital to pick up patients there was almost unanimous criticism about existing patient transport.

9.3.6.2 Joined-up working

'I feel there is often a big divide between my GP and the hospital – how will this be joined-up?'

Most the participants in the Children's group felt that the proposals could address some of the challenges they experience in primary care. There was a sense that GPs often appear fearful and over cautious dealing with child cardiac patients and send them to A&E without attempting treatment when parents express concerns. As a result parents spend a lot of unnecessary time in A&E. The new proposal therefore needs to include thinking about to establish a more direct route for patients to the right team. Establishing GP cardiac training also needs to be developed.

Similar concerns were raised about the role of primary care in the network surrounding the hospital for lung patients. Some participants described GPs as 'the weakest link' and the struggle to get appointments which could lead to a deterioration of their condition. This kind of situation led to one person simply going direct to their specialist.

The option to have some visits closer to, or at home, was positively received (as explained in the proposal outline document they had been sent) but patients would need to feel confident there is training to build the skills of the local network. Sharing of expertise was seen as key: 'the lung nurse, she really knows the condition and the continuity helps' but 'who will be part of the network locally, will it be a GP or a nurse with training?'

The connections to other public services were also raised as important areas of consideration, particularly the ongoing impact of austerity cuts. For instance, people without access to IT at home have used local libraries but their future is uncertain. The pressures on social care funding to local authorities have also reduced support for community and voluntary support organisations. The consequences for patients who rely on this kind of support to get to the hospital or other appointments should therefore be considered in the proposal.

9.3.6.3 Use of digital innovation

'We should be able to access our letters, history, records etc. – you can't always remember the dates of things.'

'Would like technology because wouldn't have to travel and it will be less cost.'

Echoing the discussions at the two earlier engagement events there was enthusiasm about the potential of technology but recognition that it will not be right for every patient or every situation. Electronic records are crucial and can enable easier patient access to a summary record of key dates and milestones, treatments, etc. but 'Skype is not good if a physical examination is needed'. Not all services use digital records and some still use paper systems, but they must work together, nevertheless. In addition centres do not use the same technology or systems although when (or if) they are joined-up this will be beneficial.

Patients in the Children's group supported the use of wearable devices and smart technology to support self-management of care and liked the control they provide especially in emergencies. They agreed that data should be accessible to specialist teams, consultant and GPs as well as the choice to access it themselves. Although one patient 'felt it was a bit Big Brother', all others liked the idea of home monitoring and use of remote sensors to gather healthcare data.

Guy's & St Thomas' is already using apps for appointments and many people are already booking online. There was a challenge to the stereotype as 'older people do use technology – iPhones and laptops – in 20 years when this is done everyone will be using it'.

One patient, connected to the hospital via a special phone and sensor on the heart, described it as 'great.' On one occasion, an alarm was set off and they had a phone call asking whether they needed an ambulance. As part of a research project, regular conference calls are held, and the doctors can access and review the patient's readings from the sensor: 'it's really good – I couldn't walk 50 yards before I had this.' The idea of virtual clinics was positively received, and the suggestion made that if a patient is seen three times a year, two appointments could be online and one in person. At the moment, 'centres don't use the same technology or systems. When this is joined up it will be better.'
It remains the situation that a lot of people may not feel at ease with technology. For some groups, for example, people with learning difficulties or mental health problems, or those who may not be able afford technology at home, this needs to be recognised. The possibility of providing training should therefore be explored. There was also an urgent plea that any technology must be able to be updated – and patients and services kept abreast of this.

9.3.6.4 Patient records

'It would be easier, working as one team, looking at one record.'

'How off putting it is watching them leaf through a thick file looking for the record, not looking at you.'

There was a positive response to the ambition of how digital innovation could join-up patient records, moving away from 'piles of paper', accessible to all treating clinicians, as long as safeguards about confidentiality were maintained. Patients were aware of their ability to opt in and out of permission about which professional could view their records but recognised this could impact on clinicians getting 'the whole picture'. One person explained that a note about potential heart problems strengthened a preventative approach. Another

talked about the difference between younger and older doctors, highlighting 'a young doctor who was very thorough and even phoned on Saturday to check on me'.

This support was however tempered by poor experiences in the past. One person had been incorrectly discharged from lung care at Lewisham Hospital due to a mistake on a record. Another shared the experience of having a penicillin allergy incorrectly noted which resulted in an infection so 'if within one hospital they can't get it right, how will that work across many?' There were concerns about the capacity of GPs to maintain accurate information. A number of participants described problems with obtaining their medication at pharmacies because GPs had not updated records following a consultant visit. One person ended up involving PALS because the GP had refused to issue the hospital prescription.

Although some people had signed up to access records through a portal, in practice it had not worked. Current access by clinicians to recent test results on records needed to improve. Three people spoke about having examinations at one hospital then within a month having the same at another as results were not recorded and shared. One lung patient, also on dialysis, did not have the password and had difficulty contacting anyone to help them obtain it. This emphasised the potential for people to feel digitally excluded if patient records and self-care and monitoring all moved on line: 'I know eventually, age wise everyone will be used to it and do it all on line, but it's not for me'.

9.3.6.5 Keeping it personal

'Clinics that work well are those that know you and predict and manage any difficulties you might have.'

The general sentiment was that the system needs to direct patients to the right clinical support, but there were various different experiences about how this works. Outreach at the Royal Marsden was described as good, which meant that there was no need to use A&E. One patient felt 'lucky to live in London as it seems easier to be joined up in care here than if you lived out in a county'. Some clinics work better than others because 'if you feel comfortable asking questions you will be more confident managing your condition. If you feel rushed – on a conveyor belt it has an impact'.

Another experience offered an example of what happens when clinicians do not work together and share care. The patient was booked for a procedure but this it could not take place as the clinicians had not read or understood that the patient could not lie flat, due to their condition. It was felt that this incident also highlighted the importance of recognising patients as experts in their own care. In addition, and as in the discussions above, several

concerns about GPs were raised including that they are overworked, need to be trained, do not provide the right support and communication is poor.

Discussions about involving people in their own care highlighted how, while there was overall support for the concept of person-centred care, there were varied levels of interest in the active role that the patient might take including:

- 'The onus is moving on you to manage more of your own care, but we are all different, not everyone can.'
- 'I like to go and read up, but some people would not want to.'
- 'Some might not be confident to ask questions of a doctor.'

It was suggested that encouraging and developing support from charities to patients might be a way of addressing this. The Dimbleby Cancer Centre (at the Cancer Centre at Guy's) was cited as an example of good practice that could help thinking about a broader wellbeing approach (see further questions below). One person shared their positive experience of a charity that has established a choir for people with breathing difficulties. Teaching the members about breathing techniques has 'really, really helped me to manage my condition'. This patient had been able to share the techniques successfully with a friend who had become breathless and was unable to find their inhaler. Building in more of this kind of 'social prescribing' should be a key part of keeping it personal and looking after wellbeing.

9.3.7 Further questions

At the start of the event participants were encouraged to note any specific questions and, before the close, a number of these were raised with the whole group. Some were answered immediately by the clinicians and other staff present. They are worth noting nevertheless as they echo many of the themes from the discussions described above and may well reoccur during further engagement (note that these are captured verbatim):

- What brand will the new service have?
- Will the South Thames Retrieval service transfer?
- If the proposal is to create a centre of excellence, are there plans to link other existing service connections (not mentioned in the presentation), for example Guy's & St Thomas' and Newcastle work together?
- What will be done to improve diagnosis, for example one mother described how her son's condition was not picked up during pregnancy?
- How will the ethos of the Evelina and its special relationship with patients be maintained?

- The Dimbleby Cancer Centre is a good example of holistic care and wellbeing run by the voluntary sector. How will you grow and support further holistic charity support for patient wellbeing?
- Will there be further workshops on the proposals?
- We may not be able to drive in London eight years, what consequences would this have for the proposal?
- Why change the Children's Hospital?
- What will the new facilities look like and how will the Partnership involve patients in the design of new buildings?
- Will private patients be able to use this (as I don't think they should)?
- Will proposals improve GP referrals?
- How big is the new team?
- Will the proposals shorten waiting times?
- How is the proposal affordable for GPs?
- How will networks work?
- What will the governance arrangements for the Partnership be?

9.3.8 Conclusion

At the end of the event therefore participants still had many questions to explore. There was a strong sense of engagement and an eagerness for patients to be part of future debate. The overall consensus was that patients need more concrete detail particularly about the affordability of the proposals, staffing, the design and shape of care and services as well as new and/or improved buildings.

'I like the suggestion of consultants going out into the community working with staff in other parts of the system and patients – but this needs to be more than just concepts and nice ideas.'

To ensure that there was healthy debate it would be useful for patients to be provided with options to consider or specific questions or problems where their input would be valuable. Participants recognised that they were not necessarily totally representative of all patients and therefore careful thought needs to be given about how to encourage wider engagement in future patient and public engagement activities in the material circulated and outreach opportunities for face-to-face discussions.

9.3.9 Appendix: Diversity Monitoring

Nine diversity monitoring forms were completed, and these are summarised below:

Age group	16-24	35-44	45-54	65-74	75-84	85+
	1	*1*	*1*	*2*	*3*	*1*
Gender	Female			Male		
	4			*5*		
Sexual orientation	Heterosexual or straight			Prefer not to say		
	8			*1*		
Religion	Muslim		Christianity		Buddhist	
	1		*7*		*1*	
Disability, long-term illness or health condition	Yes			No		
	5			*9*		
	A long-standing illness or health condition	A social communications impairment	Blind or having a visual impairment	Deaf or have a hearing impairment	An impairment, health condition or learning difference that is not listed	
	3	*1*	*1*	*1*	*2*	
Caring responsibilities	None:		Primary carer of a child or children (between 2 and 18 years)			
	4		*1*			
Race or ethnicity	White British	Irish	Indian	Pakistani	Any other Asian background	Caribbean	Any other ethnic group
	4	*1*	*1*	*1*	*1*	*1*	*1*
Postcodes	BR3, BR7, SE1, SE1, SE8, SE9, SE13, SE16, SE23						

10 APPENDIX TWO: DETAILED SURVEY RESULTS

10.1 Rounding numbers in the survey

Rounding a number means replacing it with a different number that is approximately equal to the original, but has a shorter, simpler representation; for example, replacing 23.4476 with 23.45. In this report numbers with a value below 0.5 are rounded down to the nearest whole number and those with a value above 0.5 are rounded up. For instance 1.6 becomes 2 and 1.4 becomes 1, because of this values in tables may add up to more or less than 100%.

10.2 Response basis

Answering this survey….	No.	%
Rather not say	3	1.2%
On behalf of myself	224	87%
On behalf of your child or other family member	29	11%
N/A	1	0.4%
Grand Total	**257**	**100%**

Responding as…	No	%
… a patient (25 or older)	207	82%
… a parent/carer	28	11%
… a patient (16 - 24)	9	4%
… Foundation Trust member	4	2%
... rather not say	1	0.4%
Don't Know	1	0.4%
my daughter she’s 14 years old	1	0.4%
Grand Total	**253**	**100%**

Hospital care received from	No.	%
Royal Brompton and Harefield NHS Foundation Trust		
Royal Brompton Hospital, Chelsea	134	41%
Harefield Hospital, Harefield near Heathrow	5	2%
King’s College Hospital NHS Foundation Trust		
King’s College Hospital, Denmark Hill	35	11%
Variety Children’s Hospital, Denmark Hill	1	0%
Princess Royal University Hospital, Bromley	19	6%

Guy's and St Thomas' NHS Foundation Trust		
St Thomas' Hospital, Westminster	69	21%
Guy's Hospital, London Bridge	57	17%
Evelina London Children's Hospital, Westminster (St Thomas' Hospital site)	7	2%
Rather not say	**2**	**1%**
Grand Total	**329**	**100%**

Type of care received	No.	%
Heart and lung care	29	12%
Heart care	115	48%
Lung care	80	33%
Rather not say	18	7%
Grand Total	**237**	**100%**

10.3 Views on the current service

To what extent do you think the NHS heart/lung care you currently receive is working well?	No.	%
… the service does not work well at all	1	0.4%
… the service neither works well nor is it not working well	3	1.2%
… the service tends not to work well.	7	2.9%
… the service works very well	179	74.0%
… the service works well sometimes	46	19.0%
Don't know	6	2.5%
Grand Total	**242**	**100%**

How likely are you to recommend our NHS heart/lung care to friends and family if they needed similar care or treatment, based on the care you are currently receiving or have recently received?	No.	%
Don't Know (0)	3	1%
Extremely unlikely (1)	13	5%
Unlikely (2)	5	2%
Neither likely nor unlikely (3)	9	4%
Likely (4)	54	23%
Extremely likely (5)	155	65%
Grand Total	**239**	**100%**

10.4 Views on our proposal

To what extent do you think NHS heart/lung care in our proposal will work well?	No.	%
… the proposal will not work well at all	7	3%
… the proposal will not work well nor is it unlikely to not work well	7	3%
… the proposal will tend not to work well.	7	3%
… the proposal will work very well	101	46%
… the proposal will work well sometimes	50	23%
Don't know	47	21%
Grand Total	**219**	**100%**

10.5 Diversity Monitoring

Row Labels	No	%
16– 24	5	2%
25 – 34	5	2%
35 – 44	23	9%
45-54	30	12%
55 – 64	52	21%
65 – 74	64	26%
75 - 84	50	20%
85+	14	6%
Prefer not to say	5	2%
Grand Total	**248**	**100%**

Gender	No.	%
Male	115	51%
Female	106	47%
Prefer to self-describe	0	0%
Prefer not to say	3	1%
Total	**224**	**100%**

Sexuality	No.	%
Gay man	6	2.7%
Gay woman or lesbian	1	0.4%
Heterosexual or straight	197	88.3%
Other	2	0.9%
Prefer not to say	15	6.7%
Prefer to self-describe	2	0.9%
Grand Total	**223**	**100%**

Religion	No.	%
Buddhist	2	1%
Christianity	106	60%
Hindu	3	2%
Jewish	2	1%
Muslim	12	7%
No religion	39	22%
Other religion	8	5%
Prefer not to say	4	2%
Total	**176**	**100%**

Do you have a disability, long-term illness, or health condition	No.	%
No	64	28.70%
Prefer not to say	3	1.35%
Yes	156	69.96%
Grand Total	**223**	**100%**

Please tell us what your disability is (multiple responses allowed)	No.
Prefer not to say	2
Deaf or have a hearing impairment	8
Blind or have a visual impairment uncorrected by glasses Deaf or have a hearing impairment	5
Blind or have a visual impairment uncorrected by glasses	1
An impairment, health condition or learning difference that is not listed above	19
A specific learning difficulty (e.g. dyslexia, dyspraxia or AD(H)D)	7
A social / communication impairment (e.g. a speech and language impairment or Asperger's syndrome/other autistic spectrum disorder)	1
A physical impairment or mobility issues (e.g. difficulty using your arms or using a wheelchair or crutches)	25
A mental health difficulty (e.g. depression, schizophrenia or anxiety disorder)	12
A long-standing illness or health condition (e.g. cancer, HIV, diabetes, chronic heart disease, or epilepsy)	119

Caring responsibilities?	No.	%
None	155	77.50%
Prefer not to say	6	3.00%
Primary carer of a child or children (between 2 and 18 years)	12	6.00%
Primary carer of a child or children (between 2 and 18 years)	3	1.50%
Primary carer of a child or children (under 2 years)	4	2.00%
Primary carer of a child or children (under 2 years)	1	0.50%
Primary carer of a disabled child or children	3	1.50%
Primary carer or assistant for a disabled adult (18 years and over)	4	2.00%
Primary carer or assistant for an older person or people (65 years and over)	10	5.00%
Secondary carer (another person carries out main caring role)	2	1.00%
Grand Total	**200**	**100%**

Ethnicity	No.	%
White British	151	70.6%
Any other White background	13	6.1%
African	9	4.2%
Caribbean	7	3.3%
Any other ethnic group	5	2.3%
Indian	5	2.3%
Any other Asian background	3	1.4%
Any other Black background	3	1.4%
Pakistani	3	1.4%
Prefer not to say	3	1.4%
White and Black Caribbean	3	1.4%
Bangladeshi	2	0.9%
Chinese	2	0.9%
White and Black African	2	0.9%
White Irish	2	0.9%
White and Asian	1	0.5%
Grand Total	**214**	**100%**

RESPONDENT POSTCODE (FIRST CHARACTERS)	No.	%
AL1	1	0.49%
AL5	1	0.49%
BR1	3	1.46%
BR2	2	0.98%
BR3	2	0.98%
BR4	1	0.49%
BR6	4	1.95%
BR7	2	0.98%
CB6	1	0.49%
CM1	1	0.49%
CM7	1	0.49%
CO4	1	0.49%
CO5	2	0.98%
CR0	1	0.49%

RESPONDENT POSTCODE (FIRST CHARACTERS)	No.	%
CR2	2	0.98%
CR3	1	0.49%
CR7	1	0.49%
CT10	1	0.49%
CT11	1	0.49%
CT15	1	0.49%
CT2	1	0.49%
CT20	1	0.49%
CT21	1	0.49%
CT4	1	0.49%
CT5	2	0.98%
CT8	1	0.49%
CT9	1	0.49%
D910	1	0.49%
DA1	1	0.49%
DA15	2	0.98%
DA17	2	0.98%
DA18	1	0.49%
DA3	1	0.49%
DA4	1	0.49%
DA5	3	1.46%
DA7	1	0.49%
DA74	1	0.49%
DA8	1	0.49%
DN3	1	0.49%
E1	1	0.49%
E8	1	0.49%
EN5	1	0.49%
EN8	1	0.49%
GU11	1	0.49%
GU3	1	0.49%
HA1	1	0.49%
HA12	1	0.49%
HA4	1	0.49%
HA5	3	1.46%

RESPONDENT POSTCODE (FIRST CHARACTERS)	No.	%
HP3	1	0.49%
HP4	1	0.49%
HR2	1	0.49%
IP14	1	0.49%
KT10	1	0.49%
KT14	1	0.49%
KT17	1	0.49%
KT20	2	0.98%
KT21	1	0.49%
KT5	1	0.49%
KT6	1	0.49%
LU2	1	0.49%
LU4	1	0.49%
M21	1	0.49%
ME16	1	0.49%
ME17	1	0.49%
ME18	1	0.49%
ME3	3	1.46%
ME7	1	0.49%
MK16	1	0.49%
MK4	1	0.49%
N11	1	0.49%
N12	1	0.49%
NE2	1	0.49%
NP20	1	0.49%
NR28	1	0.49%
NR6	1	0.49%
NW10	2	0.98%
NW6	1	0.49%
OX13	1	0.49%
OX28	1	0.49%
P02	1	0.49%
PR9	1	0.49%
RG45	1	0.49%
RH1	1	0.49%

RESPONDENT POSTCODE (FIRST CHARACTERS)	No.	%
RH10	1	0.49%
RH12	1	0.49%
RH13	1	0.49%
RH18	1	0.49%
RH19	1	0.49%
RH8	1	0.49%
RM16	1	0.49%
RM3	1	0.49%
SE1	3	1.46%
SE13	1	0.49%
SE16	1	0.49%
SE17	1	0.49%
SE18	2	0.98%
SE19	1	0.49%
SE2	2	0.98%
SE20	2	0.98%
SE21	2	0.98%
SE23	2	0.98%
SE24	1	0.49%
SE25	1	0.49%
SE26	2	0.98%
SE27	3	1.46%
SE3	1	0.49%
SE6	2	0.98%
SE8	1	0.49%
SE9	2	0.98%
SL6	1	0.49%
SM1	1	0.49%
SM3	1	0.49%
SO18	1	0.49%
SP7	1	0.49%
SW	1	0.49%
SW1	3	1.46%
SW11	4	1.95%
SW12	2	0.98%

RESPONDENT POSTCODE (FIRST CHARACTERS)	No.	%
SW15	1	0.49%
SW16	1	0.49%
SW18	3	1.46%
SW19	2	0.98%
SW1P	1	0.49%
SW2	2	0.98%
SW3	2	0.98%
SW6	1	0.49%
SW8	2	0.98%
SY15	1	0.49%
SY4	1	0.49%
TN1	1	0.49%
TN14	1	0.49%
TN15	1	0.49%
TN16	1	0.49%
TN17	1	0.49%
TN2	1	0.49%
TN21	1	0.49%
TN26	1	0.49%
TQ13	1	0.49%
TW1	2	0.98%
TW10	2	0.98%
TW14	2	0.98%
TW2	2	0.98%
TW3	1	0.49%
TW5	2	0.98%
UB5	1	0.49%
UB6	1	0.49%
W11	1	0.49%
W13	1	0.49%
W14	2	0.98%
W3	1	0.49%
W5	1	0.49%
W6	1	0.49%
W8	1	0.49%

RESPONDENT POSTCODE (FIRST CHARACTERS)	No.	%
Grand Total	205	100%

11 APPENDIX THREE: SURVEY QUESTIONNAIRE

Introduction

Thank you for taking time to take part in this survey, which is being conducted by Royal Brompton & Harefield NHS Foundation Trust and King's Health Partners (King's College London and Guy's and St Thomas', King's College Hospital and South London and Maudsley NHS Foundation Trusts) to help us develop proposals for the way heart and lung services are provided for you and your family now and in the future.

We are keen to understand what you think about the heart and lung care that you and your family receive now and what you think about the proposals we have developed so far. The results of this survey will be independently analysed, and a report produced in February 2019.

About the NHS trusts involved in this work

Royal Brompton & Harefield NHS Foundation Trust is the largest specialist heart and lung centre in the UK and among the largest in Europe. We work from two main sites – Royal Brompton Hospital in Chelsea, West London, and Harefield Hospital, near Uxbridge

King's Health Partners Academic Health Sciences Centre (AHSC) is a pioneering collaboration between King's College London and Guy's and St Thomas', King's College Hospital and South London and Maudsley NHS Foundation Trusts. We work together to make sure that the lessons from research are used more swiftly, to provide better and more joined up physical and mental health care for people.

Who should complete the survey?

This survey is for adults, children and young people who receive heart and lung care at any of the hospitals listed above. Carers or parents of a patient can also complete the survey on their own or together with the patient. If you are the parent or carer of a young patient, please encourage and help them to complete the survey too.

Completing the survey

Before you complete this survey, please read the information paper that was sent to you with this survey (if you received this by post). If you are completing this survey online (e.g. on your mobile phone, tablet or computer) you can download a copy of the information paper at www.rbht.nhs.uk/about-us/kings-health-partners-collaboration

Please return your completed paper survey to us by no later than **6 February 2019** using the freepost address:

FREEPOST LON15753

Patient and Public Involvement, RBH – KHP Engagement
King's College Hospital
Executive Nursing
Denmark Hill
London SE5 9RS

Alternatively you can complete it online at https://goo.gl/fMTAor

Or, scanned hard copy responses can be emailed to surveys@asv-online.co.uk

A BIT ABOUT YOU

Q1. To help us understand your response better, please can you tell us if you are answering this survey …

(Please select only one)

… on behalf of myself	☐	Please go to Q2
… on behalf of your child or other family member	☐	
… on behalf of my organisation (please specify in the box below)	☐	Please go to Q3
...rather not say	☐	

Q2. You told us you were responding on behalf of yourself, could you just tell us if you are responding as…

(Please select only one)

… a parent/carer	☐
… a patient (16-24)	☐
… a patient (25 or older)	☐
… Foundation Trust member	☐
…Foundation Trust governor	☐
… other (please specify in the box below)	☐
...rather not say	☐

Q3. Could you tell us which hospital you, or the person you care for, receives care from?

(Please tick all that apply)

Royal Brompton Hospital, Chelsea ☐

Harefield Hospital, Harefield near Heathrow ☐

St Thomas' Hospital, Westminster ☐

Evelina London Children's Hospital, Westminster (St Thomas' Hospital site) ☐

King's College Hospital, Denmark Hill ☐

Variety Children's Hospital, Denmark Hill ☐

Princess Royal University Hospital ☐

Other (please specify in the box below) ☐

☐

Rather not say ☐

Q4. What type of care do you receive?

(Please select only one)

Heart care ☐

Lung care ☐

Heart and lung care ☐

Other (please specify in the box below) ☐

☐

Rather not say ☐

SECTION 1: VIEWS ON SERVICES

Q5. To what extent do you think the NHS heart/lung care you currently receive is working well?

I think….

… the service does not work well at all	… the service tends not to work well.	… the service neither works well nor not works well	… the service works well sometimes	… the service works very well	Don't Know
☐	☐	☐	☐	☐	☐

Q6. Is there anything particularly good about the NHS heart/lung care you currently receive?

(Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

Q7. Is there anything that could be improved with the NHS heart/lung care you currently receive?

(Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

Q8. What do you think are the most important things that we need to keep doing to make sure you (or the patient you care for) receive the NHS heart/lung care you need? (Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

Q9. What are the most important things we should change to improve our NHS heart/lung care in the future? (Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

Q10. How likely are you to recommend our NHS heart/lung care to friends and family if they needed similar care or treatment, based on the care you are currently receiving or have recently received?

Extremely likely	Likely	Neither likely nor unlikely	Unlikely	Extremely unlikely	Don't Know
☐	☐	☐	☐	☐	☐

Q11. Please can you tell us the main reason for the answer that you have given?

(Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

SECTION 2: VIEWS ON OUR PROPOSAL

Before you complete this section, please take some time to read the information document that describes the partnership's vision and the proposal we have developed so far. If you have received this survey by post, a copy of the information paper should have been sent to you. Otherwise, you will find a copy at www.rbht.nhs.uk/about-us/kings-health-partners-collaboration

What are your first impressions when you read our proposal?

(Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

Q12. What do you like about the proposal for NHS heart/lung care we have developed so far?

(Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

Q13. What don't you like about the proposal for NHS heart/lung care we have developed so far?

(Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

Q14. To what extent do you think NHS heart/lung care in our proposal will work well?

I think….

… the proposal will not work well at all	… the proposal will tend not to work well.	… the proposal will neither work well nor not work well	… the proposal will work well sometimes	… the proposal will work very well	Don't Know
☐	☐	☐	☐	☐	☐

SECTION 4: ANYTHING ELSE?

Q16. Do you have any other comments, concerns or suggestions about NHS heart/lung care that you would like to share with us?

(Please write your answer in the box below – use an additional sheet if there is not enough room for your answer)

SECTION 5: DIVERSITY MONITORING

More About You

The information you give us helps us to understand if patients from across our diverse communities have different experiences. We use this information to help us to plan our services to best meet the needs of everyone.

It would help us to understand your answers better if we knew a little bit about you. These questions are optional, but we hope you will complete them.

The information is collected anonymously and cannot be used to identify you personally.

Q16. How old are you?

5 - 9	❑	55 – 64	❑
10 - 15	❑	65 – 74	❑
16– 24	❑	75 - 84	❑
25 – 34	❑	85+	❑
35 – 44	❑	Prefer not to say	❑
45 - 54	❑		

Q17. What is your gender?

Male	Female	Prefer to self-describe……	Prefer not to say
❑	❑	❑	❑

Q18. Which of the following terms best describes your sexual orientation? (Please select only one)

Heterosexual or straight	❑	Prefer not to say	❑
Gay man	❑	Prefer to self-describe	❑
Gay woman or lesbian	❑	Other	❑
Bisexual	❑		

Q19. What do you consider your religion to be? (Please select only one)

No religion	❑	Muslim	❑
Christianity	❑	Sikh	❑
Buddhist	❑	Prefer not to say	❑
Hindu	❑	Other religion	❑

Jewish	❑

Q20. Do you have a disability, long-term illness, or health condition?

Yes	No	Prefer not to say
❑ (Go to Q21)	❑ (Go to Q22)	❑ (Go to Q22)

Q21. Please can you tell us what your disability, long-term illness or health condition relates to? (Please tick all that apply)

A long-standing illness or health condition (e.g. cancer, HIV, diabetes, chronic heart disease, or epilepsy)	❑
A mental health difficulty (e.g. depression, schizophrenia or anxiety disorder)	❑
A physical impairment or mobility issues (e.g. difficulty using your arms or using a wheelchair or crutches)	❑
A social / communication impairment (e.g. a speech and language impairment or Asperger's syndrome/other autistic spectrum disorder)	❑
A specific learning difficulty (e.g. dyslexia, dyspraxia or AD(H)D)	❑
Blind or have a visual impairment uncorrected by glasses	❑
Deaf or have a hearing impairment	❑
An impairment, health condition or learning difference that is not listed above	❑
Prefer not to say	❑

Q22. Do you have any caring responsibilities? (Please tick all that apply)

None	❑
Primary carer of a child or children (under 2 years)	❑
Primary carer of a child or children (between 2 and 18 years)	❑
Primary carer of a disabled child or children	❑
Primary carer or assistant for a disabled adult (18 years and over)	❑
Primary carer or assistant for an older person or people (65 years and over)	❑
Secondary carer (another person carries out main caring role)	❑
Prefer not to say	❑

Q23. Which race, or ethnicity best describes you? (Please select one box only)

White

British	❑
Irish	❑
Any other White background	❑

Mixed

White and Black Caribbean	❑
White and Black African	❑
White and Asian	❑
Any other mixed background	❑

Asian or Asian British

Indian	❑
Pakistani	❑
Bangladeshi	❑
Any other Asian background	❑

Black or Black British

Caribbean	❑
African	❑
Any other Black background	❑

Other Ethnic Groups

Chinese	❑
Any other ethnic group	❑
Prefer not to say	❑

Q24. What is the first half of your postcode? (For example SE11, E2, or N22)

Thank you completing this survey and for taking the time to contribute to the formulation of our proposal

If you would like to be kept informed about our work, you can use our web form at www.rbht.nhs.uk/about-us/kings-health-partners-collaboration

This survey is being conducted on behalf of Royal Brompton & Harefield NHS Foundation Trust and King's Health Partners (an Academic Health Sciences Centre (AHSC) which is a collaboration between King's College London and Guy's and St Thomas', King's College Hospital and South London and Maudsley NHS Foundation Trusts).

This survey is one of the ways you can share your views about our proposal for **Improving care for patients with heart and lung disease: now and in the future.** You can share your views on our proposal until midnight **6 February 2019**. There are different ways you can get involved to ensure your views are heard. For more details, please visit www.rbht.nhs.uk/about-us/kings-health-partners-collaboration

Data Protection

Thank you for taking the time to complete our survey. The information you have provided will be treated confidentially. The comments that we have received will not be attributed to any individuals. This information is also used by the Foundation Trust to help us monitor the effectiveness of our equality policies and to help comply with legal requirements.

The information you have provided will be treated in accordance with the Data Protection Act 2018 and other laws such as the Health and Social Care Act 2012. (www.legislation.gov.uk/ukpga/1998/29/contents and www.legislation.gov.uk/ukpga/2012/7/contents/enacted)

Thank you for sharing your opinions the analysis report will be available in February 2019 at: www.rbht.nhs.uk/about-us/kings-health-partners-collaboration