

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

The Partnership's response to findings from patient
and public engagement activities in January and
February 2019

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1 Background

Discussions about a partnership between Royal Brompton & Harefield NHS Foundation Trust (RB&HFT) and the partners that make up King's Health Partners (KHP) – Guy's and St Thomas' NHS Foundation Trust (GSTT), King's College Hospital NHS Foundation Trust (KCH) and King's College London (KCL) – started in 2016 in the context of national congenital heart disease standards.

Knowing that NHS England was about to carry out a public consultation about children's congenital heart disease (CHD) services, we realised how much benefit there would be in joining together our services and research. So we began looking at how to work together across adult and child heart and lung specialties.

Following consultation, NHS England said that they were considering no longer commissioning RB&HFT to provide specialist children's CHD services. This was because the hospital could not meet NHS England's national standard that other specialist children's services should be on the same site as children's CHD services. During the consultation, we sent a response to NHS England with a proposal to provide CHD services together, within a larger proposal for a partnership across all adult and child heart and lung specialties across KHP and RB&HFT.

NHS England asked us to carry out more work to explore the proposal further¹. We have since been working to understand how we could best jointly deliver exceptional patient care, research and education

We completed a feasibility study in April 2018², and are now working towards developing a 'strategic case' for November 2019. Before this, NHS England are planning to run a period of public consultation in summer/autumn 2019. The outcome of NHS England's public consultation, and the decision NHS England makes following that consultation, will shape whether, and how, our proposal can go ahead.

We know that to deliver truly effective, high quality services we need our patients, their families and carers, and the wider public to help us shape our proposals. To start this process, we held a series of engagement events, and developed a survey, over January and February 2019.

2 Purpose of this document

This report provides a summary of how the Partnership will use the views and feedback from this engagement programme to help shape its proposals for future heart and lung services.

¹ NHSE Board paper, 30 Nov 2017 – CHD review outcome (Congenital Heart Disease Services for Adults and Children: Future Commissioning Arrangements) <https://www.england.nhs.uk/wp-content/uploads/2017/11/06-pb-30-11-2017-congenital-heart-disease-services.pdf>

² In March 2018, Partners invited patient and public governors and charities allied to partners to an event to discuss the development of the vision for the Partnership. Their views informed the Feasibility Study and particularly highlighted the strong affinity and sense of loyalty patients have towards each partner organisation.

It is written specifically in response to a range of engagement activities, comprising:

- A postal and online survey sent to a sample of 1,276 patients using cardiovascular and respiratory services at all three NHS trusts, with 257 responses (20%).
- Three engagement events – held at Royal Brompton Hospital on 29th January, King’s College Hospital on 30th January, and Guy’s and St Thomas’ on 6th February. Together, over 85 people attended these events (6% response rate and 1:17 recruitment ratio).
- A webinar on 6 February (23 people, including staff)
- Feedback from the Patient Public Reference Group, which met on 22nd January and 21st February.

It is important to acknowledge that this represents the start of a longer and broader engagement process working with patients across the Partnership. We need to reflect on activities to date and discuss how we can ensure the profile of respondents accurately reflects the people who use our services³. Patients also asked a number of questions at the events that we will answer as we develop our plans.

3 Our response to key themes from engagement events

3.1 Current services

What we heard patients and families say

There was overwhelming support for the quality of existing services, with 93% of respondents to our postal and online survey reporting that they thought current services work well or very well. In particular, people were positive about our staff – their expertise, support and care. Key things that patients want to keep about current services include the child-friendly environment (for children’s services), research and current patient involvement in services.

However, we also heard that there are some things that could be improved – including the use of digital records and a greater focus on preventative action. We heard that people’s experiences could be improved, including the quality of food, appointment arrangements and administration.

Overall, we heard strong support for the quality and experience of staff, services and care at our existing hospitals, with concerns around maintaining this, specifically:

- Ensuring King’s College Hospital’s focus on the local population;
- Maintaining Royal Brompton and Harefield’s culture and heritage;
- Maintaining Guy’s and St Thomas’ good quality care – particularly at the Evelina London Children’s Hospital;
- Ensuring staff across all organisations, but particularly Royal Brompton staff, are supported and retained during the period of change.

Our response

It is encouraging that patients and the public feel, on the whole, that existing services provide good care, and we need to ensure we protect this as part of the Partnership. It is also encouraging that some of the

³ For example, we know that parents of children using our services and young people were under-represented at two of three events – people under 16 years represented only 1% of our survey respondent and 16-24year olds only 2%.

areas we are most keen to improve – the focus on IT and digital, and a more population-based approach to healthcare that invests in preventative work – are aligned with the views coming through the engagement events.

There are some areas that we will focus on to address key issues raised here:

- As we move to firming up the locations and layouts for children's and adult services for the Partnership, we will need to consider how the experience patients have in hospital can be improved. This includes thinking about how we can make the best use of our space and the amenities we can provide for patients, including children, young people and their families.
- As our plans for how services will be run in the Partnership model becomes clearer, we need to think through how we can improve operational processes – such as administration and booking. This will probably be linked to our digital programme.
- We are currently exploring how the new Partnership's governance, management and organisation would work, including how patients can contribute to the process. This is important, because it is through this work that we can ensure that the future Partnership works effectively and that it takes the best from the culture and ways of working of each of our organisations.
- We are also beginning to think about the development of a brand for our Partnership. It will be important to maintain the strong cultural identity and heritage of the partner organisations, particularly RB&HFT. This process will include developing values that capture the vision of the Partnership and reflect the positive attributes of each organisation.
- Finally, it will be important to ensure staff are involved in the development of plans and feel supported during the period of change. Retaining the excellent staff across the Partnership is a top priority of all partner organisations.

3.2 Our vision: consolidation of expertise, joined up working and patient-centred care

What we heard patients and families say

So far, during this period of engagement, there has been overwhelmingly positive support for our overall vision. However, there was an acknowledgement that much more detail will be required for patients and their families to fully understand our proposal.

In particular, the benefits of joined up working between services and health and care professionals was recognised – with less duplication, greater opportunities for research and faster access to treatments all being seen as key benefits. There was support for our approach for a patient-centred care model – placing patients (including children and their families) at the heart of planning and delivering services. There was enthusiasm about links with primary care, and the role the Partnership could have in supporting GPs. There was also some discussion about ensuring joined up, integrated care between hospital and out-of-hospital or community services, including supporting paediatricians working in these services as part of a stronger network of care.

Whilst the benefits of bringing together services to improve care and research were highlighted, there was also some concern that the new Partnership could be 'too big, too ambitious'. Specifically, there was a concern around the need to think about continuity of care for patients with lifelong conditions. Participants at the engagement events highlighted the importance of establishing a relationship with their clinical teams, 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.

Our response

It is encouraging that there is support for so many of the fundamental elements of our proposals. This gives us a strong basis to work up more detail in these areas.

There are some areas that we will focus on:

- We will work with our clinical colleagues and other stakeholders to provide more detail about how we will provide continuity of care for our patients with lifelong conditions.
- We will specifically consider how we can support young people moving from children's to adults' services.
- We will describe how our model will balance scale and expertise in specialist services with a desire to make care more local where possible.
- We will engage stakeholders more broadly to understand how the Partnership can work with local hospitals and out-of-hospital services, including community services and primary care, to provide effective support for our patients and their families.

We are committed to sharing information and involving patients in our work. As well as ensuring patients are represented in the Partnership's governance arrangements, we will provide further detailed information on:

- o The numbers of patients who may be affected by the proposals;
- o How patients using services at each partner trust may be affected;
- o Our approach to modelling future demand;
- o Possible financial implications of the proposals, including the costs of new developments, where these are known;
- o Timescales for delivering the proposals.

Finally, while we continue to develop our Partnership plans over the coming months, this should not be at the expense of more immediate term improvements in services – such as in areas such as patient communication, bookings, appointments and waiting times. We continue to work closely with colleagues involved in service improvement and transformation across our partner organisations to make sure our work is aligned.

3.3 Technology and digital

What we heard patients and families say

There has been enthusiasm about the potential for greater use of technology, but recognition that this will not be appropriate for every patient or every situation. It is clear that technology has the potential to reduce trips to hospital, and to ensure better joined up care. It also allows patients, including children, young people and their families, to have more control – with easier access to their medical records and a stronger voice in their care.

However, there was also a significant number of people who felt less 'digitally minded' and there is a recognition that advances in this area must guard against people being digitally excluded.

Our response

It is essential that digital and technology developments lie at the centre of our future models of care and research. Technology has the potential to improve the quality of care – for example through improved

access to care through virtual consultations via the internet; and improved transparency and control – such as through access to electronic patient records. However, we have heard concerns from users and will work to ensure people receive the best care, however they choose to access services.

Over the coming months, we will be developing our digital plan for the Partnership. This will look at the current IT and technology systems used by each partner and explore our joint plans for developing these over the coming years. It will be important to involve patients, families and carers in designing this technology as well as to discuss the implications with our staff.

3.4 Transport and travel

What we heard patients and families say

Transport was a topic that was discussed at many of the events. Parents in particular highlighted the pressures of transport – in terms of cost and lack of parking – which can add to the stress when having an unwell child. For some patients, the new proposed central location was seen as positive, particularly for those travelling from outside London. However, this was not the case for all respondents.

Those who need to use their cars talked about limited parking at all sites, and particularly highlighted the shortage of disabled parking facilities. People were sceptical about the likelihood of 'better facilities elsewhere'. There was concern about the quality of existing patient transport, and questions about whether this would improve under the future proposals.

Patients also raised questions around the provision of on-site patient and carer accommodation, which has not been mentioned in the proposal to date.

Our response

We have heard clearly that transport and access to care is a key concern for patients and families. We anticipate that, under the future model, fewer patients will need to travel to central London for their care – with more one-stop shops based locally and remote consultations via the internet. However, there will still be a need for some patients and their families to travel, and we need to fully understand the implications of the move for people using our services.

We will conduct a detailed travel analysis to support our proposals. This will include mapping how our patients currently travel to each site – both privately and by public and patient transport – and assessing the impact of changes at different times of day and throughout the week. We will use this work to think through how any impacts can best be mitigated, including specifically how the issues of disabled parking capacity could be addressed.

We will try to understand provisions for patient and carer accommodation, specifically for the patients attending the St Thomas' site for heart and lung care, within the wider plans for the development of the St Thomas' estate.

Finally, we will need to hold further discussions with patients and partner organisations to understand the implications of the proposed partnership on patient transport services.

4 Next steps

All partner organisations recognise their legal duty to involve patients and the public in developing the proposals, but they also strongly believe that involving patients and the public will greatly improve the nature of their proposals. This includes including children, young people and their families, and particularly the voices of people whose experiences will be most affected by the Partnership's proposals.

Following review of this report by our Patient Public Reference Group and Partnership Board in February and March, we will reflect on the engagement work to date and put in place plans to engage and involve patients and the public throughout the programme. There are areas that we want to improve to make sure we capture the needs of all the patients we serve. We know that there have been some gaps in engagement to date which we will try to bridge with future efforts, such as ensuring events are at the right time of day with the right facilities for parents of children to attend, and considering how we can better engage young people and patients with complex conditions. We will also produce a Q&A to questions arising from the events and surveys, if they are not addressed in this report.

A further area of importance highlighted by our Patient Public Reference Group is the need to conduct comprehensive staff engagement. Feedback suggests there is a sense that some 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. The Partnership recognises that our staff are the most valuable ambassadors for the Partnership and we will be focused on establishing comprehensive staff communications and engagement across our organisations going forward.

Ongoing patient and public participation will remain fundamental as we develop our Strategic Case and related transformation plans. We want to ensure there will be even greater opportunity to involve patients, their families and carers in evaluating the effectiveness of our proposals from a patient and carer perspective.

Although the Partnership will need to pause engagement activities during NHS England's public consultation, we will work with our Patient Public Reference Group to now develop an engagement plan covering the next phase of activities.

16 March 2019