Annex G: Joint Consultation response from Royal Brompton and Harefield NHS Foundation Trust and King's Health Partners

Congenital Heart Disease Consultation Joint Response - a vision for congenital heart disease care in the 2020s

Introduction

We welcome the opportunity, through this consultation, to provide a further proposal for consideration that we believe would add significant value for patients, commissioners, services and clinicians, in seizing a unique opportunity to build a transformational Congenital Heart Disease (CHD) service from ante-natal diagnosis to adulthood as part of a world leading cardiovascular and respiratory collaboration. Building on our separate organisational responses to the earlier sections of the consultation, this document has been developed jointly by RBH and GSTT (on behalf of KHP), to set out a vision that we would like to further develop in partnership with commissioners.

Summary

RBH and KHP (GSTT, KCH and KCL) have agreed to begin a full assessment of the potential for a strategic partnership that will deliver an international benchmark cardiovascular and respiratory health system, comprising a clinical delivery network and global centre of excellence for care, discovery and translational medicine based at the Westminster Bridge Campus, in a newly created specialist heart and lung centre.
This strategic partnership would deliver a new model healthcare system for a large population with heart and lung diseases that will provide significant benefit for patients, taxpayers and UK plc.
It will:

- offer unrivalled opportunity to standardise care and improve quality in a sustainable model, for a large population.
- be of a scale to compete with the largest centres in the world, and to allow sufficient critical mass to develop sub-specialisation in rarer conditions.
- further strengthen research teams, and be an extremely valuable clinical resource to attract investment and collaboration from Medical Technology and Bio Tech industrial partners.
- have a particular focus on development of innovative methods of healthcare delivery, particularly to help patients living with long term heart & lung conditions.
- have an absolute commitment to recruit, train and develop the multidisciplinary workforce required to support the high quality, safe care of patients with Heart and lung diseases now and into the future in a sustainable manner.

If successful, we believe this venture would make a significant contribution to the UK's life science strategy post EU exit.

In addition to the considerable benefits already set out, our broader vision also allows us to propose a model for Congenital Heart Disease (CHD) services that brings together the existing RBH and GSTT services to deliver a joint, world class, service for all CHD patients from ante-natal to adulthood. This model is set out in this document.

We believe that our proposed model for CHD services would have wide-ranging benefits to patients through improved equity of access to specialist care, world class outcomes in a sustainable model and a leading research and education offering for the next generation of staff and therapies. Our proposed model would allow all standards to be met once co-location is achieved. This model will also deliver a sustainable solution for a broader range of services beyond CHD, and allow a planned transition approach in the context of a broader future vision.

The range of benefits we set out for our proposed CHD model can also serve as an indication of the scale of opportunity across our areas of collaboration in cardiovascular, respiratory and critical care service, research and education.

We are committed to working in partnership with patients and families, and commissioners, to co-design services. We know that our ambitious plans will not be delivered without the leadership and skills of wider system partners and we are keen to work closely with NHS England in delivery of these benefits. We would also seek to begin to deliver the benefits of a joint service ahead of any physical movement of services and have set out a range of actions that could take this forward.

Benefits for Congenital Heart Disease Services – alignment with Congenital Heart Disease Standards

Some of the potential benefits of the joint service are described below with reference to the different sections of the CHD standards document.

A. Network

We will work together as a single service, in partnership with other leading centres in regional networks, to deliver a service that provides world leading care, outcomes, research and education across foetal, neonatal, children's and adult services – caring for patients throughout their lives – and to play a leading part in a nationally sustainable system for patients with congenital heart disease. This will build on both services' existing networks of care with other providers, with over 9,000 paediatric out-patient visits at 30 locations in London, home counties, and south east.

B. Staffing and skills

The new joint GSTT/RBH CHD service, in partnership with KHP, will have a major focus on training and developing the multidisciplinary workforce that is required for the future service. New models of care, new technologies and development of personalised medical care will require a highly skilled multidisciplinary workforce. A sustainable model, through the above, will attract the best talent for all disciplines, and will scale to deliver the training and education solutions required to grow our own workforce and to support the workforce of the wider network (e.g. nursing and practitioner courses). This will be a significant contribution to the workforce strategy for the UK's future post EU exit.

Children and families of patients will increasingly require personalised care, risk assessments and advice based on genotype as well as detailed phenotype. Alongside CHD there will be increasing numbers of patients of all ages identified to have inherited cardiac conditions, or to carry genes that may predispose them to increased future risk. RBH has already signalled its intent to join with the other KHP partners in the South London Genomic Medical Centre bid.

Remote monitoring is increasingly possible and useful, and we will focus on ensuring this capability is developed across our networks. The increased scale of the new service will allow development of

sub-specialist excellence, which will provide opportunities to offer national scale services for the most complex cases.

C. Facilities

The intention is to develop state of the art facilities for patients of all ages requiring specialist heart and lung treatments on the Westminster Bridge campus, as part of a vibrant broader health campus.

D. Interdependencies

The bringing together of the various teams provides an ideal platform to deliver high-quality paediatric and adult sub-specialised surgery. The large population and the complementary skills will enable to new teams to consolidate expertise in areas such as Ebstein surgery, complex paediatric electrophysiology and hybrid technologies. Scale and critical mass of expertise will also be very attractive to industry and will be a natural launch pad for new devices and innovation. There are numerous other sub-specialist areas of ACHD care that have the potential to be significantly strengthened in the proposed new model. These include pulmonary hypertension, advanced heart failure & transplantation and access to non-cardiac intervention in high risk patients. In addition, the co-location of services for inherited and acquired cardiac disease will allow patients with CHD to benefit from advances in these areas. Young patients with rare acquired cardiac diseases, such as Kawasaki Disease, should also benefit from the scale to allow sub-specialty development.
Co-location of paediatric services in a children's hospital on the same site as adult CHD services, and co-located with key related services (e.g. maternity, foetal) – will bring the best of all linkages in an integrated offering providing equity of access to services.

E. Training and education

Our combined service will deliver benefits in training and education through combined scale, for example in collaborating to produce a practitioner curriculum that could be rolled out nationally and deliver a sustainable solution for these key staff, and in providing critical mass to deliver leading training programmes and rotations for all staff groups in a resource constrained environment. There is a "good fit" between the units is in terms of teaching and training. The Evelina/GSTT has embraced national training programmes and the RBH team international training. The joint team would have the ability to be leaders in this field with the ability to develop a whole new range of educational opportunities for the rest of the UK and further afield.

F. Organisation, governance and audit

Our vision is to bring our services together as a single congenital heart disease service. This will provide benefits in standardisation of protocols, not only for the specialist centre but for the wider networks we will serve. The development of standard protocols, pathways, joint leadership and governance processes will be a priority to implement ahead of April 2019.

G. Research

The CHD service at the RBH, in collaboration with Imperial College, has the largest output of ACHD research in the world. Bringing together the whole spectrum of congenital heart disease care in an environment where there is a plethora of non-cardiac specialists provides both the optimal environment and the academic legacy to develop a comprehensive research strategy tailored to the changing challenges of the specialty. Life-long multi-system clinical research is becoming increasingly important as the complexity of congenital care increases. The major challenges to the field, such as

the long-term holistic management of the Hypoplastic Left Heart (HLHS) patients will be ideally provided for in this environment.

KHP, in partnership with KCL, has an international reputation in cardiovascular research, and has just established the new KCL Academic Institute for Children. In the field of CHD and inherited cardiac conditions, the scale of the new service would be able to attract the best talent and develop sub-specialties. We believe this large specialist clinical service collaborating with two great universities in London would be extremely attractive to commercial and research partners, offering opportunities for partnerships and sustainable models of funding innovation.

H. Communication with patients

We are committed to working in partnership with patients and families to co-design services. Services will be designed alongside patients in order to ensure their needs are at the centre of all we do.

I. Transition

A comprehensive transition programme is key to successful life-long care for congenital heart disease patients. There already exist good working relationships between the transition teams at Evelina, GSTT and RBH with the use of shared documentation. The nurse-led model of transition clinics is highly successful. Transition services could easily be strengthened for more patients through the increased scale of service. In addition, the GSTT team brings a track record in delivering high quality psychological services to this population. Scale also provides improved opportunities in transition (e.g. dedicated environment, training and education), and will allow us to improve services at this often critical time in patients' lives.

J. Pregnancy and conception

In each sub-specialist area of ACHD care the two units bring complementary strengths. One example of this would be a coming together of the two High-Risk Pregnancy services. Both are highly successful and well-thought off units. However a bringing together of the RBH obstetric academic output and the same-site working model of GSTT raises the delivery of care to a higher level - creating a unit that could potentially be world-leading. For example the new unit would be one of the few units in the country/world able to provide onsite comprehensive obstetric care to a high-risk pregnant pulmonary hypertension patient. At present in London no unit has the ideal model of care for these patients combining a designated PH centre, a high-risk cardiac obstetric team, an onsite neonatal unit and onsite maternity care.

K. Foetal

Our proposed model will be a service from ante-natal through to adulthood on an acute campus with all interdependent services. We will work through our networks to deliver high quality pathways for all patients who are referred by local centres, as both our services currently do. We will work in partnership with the broader, world leading, services in KHP.

L. Palliative care and bereavement

Our proposed model will bring together the strengths of our existing services and link closely with the high quality psychological support offered at scale within KHP.

M. Dental

Our proposed model will offer improved access to leading specialist dental services within KHP.

Benefits to non-CHD specialist heart and lung services

Our proposed model will allow a sustainable approach to transition of all CHD services, and related and interdependent services (including pulmonary hypertension, paediatric respiratory, PICU and others), as these came together in our broader vision for a world leading cardiovascular and respiratory health system.

Timeline

It is our intention that in our proposed model the accommodation of CHD services on the Westminster Bridge Campus will be achieved in the new buildings of Evelina London for children, and our joint centre for adults.

If our future vision is accepted, we commit to working in partnership with NHSE, patient groups, and others to further develop our services ahead of physical co-location, to begin to deliver the benefits of a joint service. Early priorities signalled by our clinicians to begin exploration for implementation ahead of April 2019 include:

- ensuring all staff are inducted across all sites and thus able to work where needed to provide care for patients.
- designing and developing cross-site cover and eventually joint rotas to provide the best possible sustainable care.
- launching and delivering our joint training offer for practitioners, nurses and medical staff.
- developing standardised joint protocols and pathways to improve consistency, outcomes and sustainability across the network.
- improving our network coherence and partnership with local referring centres, and delivering outreach education and support as one service.
- implementing seamless research protocols to allow all trials to be delivered wherever a patient is seen.
- developing and implementing pathways to see existing patients where their needs are best met (we anticipate this to be small numbers initially driven by patient need and choice and informed by clinical decision making).

In the context of our broader vision, and if supported by commissioners, it would be possible to move services as soon as capacity is available. For paediatric services this should be by 2021/22 when further capital development at the Evelina London is completed, a joint CHD service for patients of all ages is in place, and the new specialist heart and lung centre is being developed alongside our collaboration to create what would be a world leading heart and lung institute. This will allow managed transition of both the CHD service and related services at the RBH site, ensuring sustainability of high quality care at all times, while still delivering the broader range of benefits anticipated in our proposal. We would then expect the adult services to move to the new specialist heart and lung centre at the Westminster Bridge Campus by mid to late 2020s as this is completed. The timing of moves would of course be subject to planning considerations.