

Heartnews

Welcome



Sir Neil McKay CB
Chairman of the Joint
Committee of Primary
Care Trusts

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"The four-month public consultation on the future of children's congenital cardiac services came to an end on 1 July and I would like to thank everyone who participated. Nearly 75,000 of you responded to the consultation – making this one of the biggest consultations in the history of the NHS.

Everyone wants the very best possible care for children with congenital heart disease and we are in no doubt that making a decision on the future of services will be difficult. We will be considering all the evidence with great care, including what you told us during consultation, before we make any decisions."

How you shared your views

During consultation thousands of parents, children, clinicians, NHS staff and other people from across the world gave us their views.

31 focus groups took place around the country. These were attended by patients, parents and Black and Minority Ethnic (BAME) community members

petitions were submitted **23**

organisations responded to the consultation **1,121**

national workshops were held for young people **3**

NHS STAFF attended Trust-organised events

OVER 2,000 people attended the 16 consultation events across the country

22,119 people texted a response
Health Impact Assessment (HIA) meetings and phone interviews were arranged

people sent letters **386**

OVER 60 completed consultation response forms were received. The forms were available in 12 languages

51,663

MPs debated some of the issues you raised...

On 23 June 2011 MPs debated some of the issues that had arisen during consultation in Parliament. We have published a response on our website to help address some of the points raised during the debate. For more information please visit: www.specialisedservices.nhs.uk/news/view/55.

Sir Neil McKay CB, Chairman of the Joint Committee of Primary Care Trusts welcomed the debate and had this to say:

"The debate in Parliament is a reminder that whilst people will always defend local services, there is strong support for our case for change and our response to it which aims to ensure the NHS provides the very best possible care for children with congenital heart disease."

Bill Brawn CBE, Immediate Past President of the British Congenital Cardiac Association and Chair of the Safe and Sustainable Standards Working Group

"This summer I have retired as a full time consultant cardiac surgeon and it gives me great pleasure that after several years of pushing for change during my working life, that the NHS has now completed a thorough public consultation on the *Safe and Sustainable* proposals. I support the *Safe and Sustainable* process and I look forward to the NHS making final decisions later in the year. Fewer, larger heart surgery centres leading networks of care is the right way forward for the management of children with congenital heart disease. I was privileged to chair the group which developed the proposed national quality standards and therefore I am acutely aware that getting these standards implemented across the service will improve children's quality of care and ensure these vital services are safe and sustainable for the future."

What happens next?



The responses to the consultation are being analysed by Ipsos MORI - an independent third party. At the end of August Ipsos MORI will publish a report on the consultation responses for the Joint Committee of Primary Care Trusts (the decision-makers). The *Safe and Sustainable* team will also publish in full responses made by organisations, associations and scrutiny committees. As well as the consultation responses the Joint Committee will carefully consider the findings of a number of other pieces of work before any decisions are made, including:

- The parent, patient and BAME focus groups
- The Health Impact Assessment meetings and telephone calls
- The work carried out to test families' travel patterns
- The number of operations each centre performed in 2010/2011
- The information that Trusts have been asked to provide on capacity planning
- The independent panel assessment led by Adrian Pollitt OBE currently looking at the potential impact of the proposals on other services at the Royal Brompton Hospital

Health Overview Scrutiny Committees have until 5 October to submit their final responses to the JCPCT so that they may take into account the report on the outcome of public consultation.

A final decision on services for children with congenital heart disease is expected to be made by the end of 2011. A detailed implementation plan will be developed that is tailored to the final decision, and any changes to children's heart services will be made from 2013 onwards.

Review remains on track despite unprecedented legal action by the Royal Brompton

The Royal Brompton Hospital's unprecedented legal action has failed again to halt the *Safe and Sustainable* process. At a court hearing on 15 July, the judge, Mr Justice Burnett, said that it was 'desirable for the Joint Committee to continue its work of improving paediatric cardiac surgery for the nation'. The Joint Committee of Primary Care Trusts believes that just as it would have been wrong for the hospital to deny people the right to be consulted, it would also have been wrong to halt the process of analysing respondents' views. Mr Justice Burnett encouraged the hospital 'to share evidence about the impact to other services with the independent panel' - evidence which so far has been withheld from the decision makers. Mr Justice Burnett, said that he had concluded "with some hesitation" that the Brompton should be given permission for a full hearing, which will now be in September. *Safe and Sustainable* welcomes the opportunity to present its evidence and will do so robustly. The outcome of the July hearing means that *Safe and Sustainable's* timetable for reaching a decision on the future of children's congenital heart services later this year remains on track.

10 years on from the Bristol inquiry

"This month marks the tenth anniversary of a landmark report published following the public inquiry into the tragic and unnecessary deaths of babies treated at the Bristol Royal Infirmary in the 1990s. In his report at the time Professor Sir Ian Kennedy called for a rationalisation of services but these recommendations fell on deaf ears. Clinicians and many parents agree that change is long overdue. We cannot fall at the last hurdle just because these decisions are difficult. This review is about saving lives. We want to ensure that in future children born with congenital heart disease receive truly world class care."

Dr Patricia Hamilton CBE, Immediate Past President of the Royal College of Paediatrics and Child Health and Chair of the *Safe and Sustainable* Steering Group

BCCA meeting

On 12 July the *Safe and Sustainable* team invited all members of the British Congenital Cardiac Association (BCCA) to meet the *Safe and Sustainable* Steering Group. The purpose of the meeting, which was attended by 50 BCCA members, was to discuss clinical issues arising from the consultation. The Steering Group members do not have any part in the decision-making process but they will advise the decision makers (the Joint Committee of Primary Care Trusts) on significant clinical matters before final decisions are made. BCCA members shared a range of different views on clinical issues including:

- Co-location of specialised children's services
- The role of the Children's Cardiology Centre in the Congenital Heart Network
- The impact of proposed changes on interdependent services including Paediatric Intensive Care Units and retrieval services
- Developing the role of Paediatricians with Expertise in Cardiology across the networks
- Fetal screening pathways and antenatal diagnosis
- Rare and complex procedures
- Neonatal patent ductus arteriosus

The review of services for adults with congenital heart disease

The NHS in England has started the process of reviewing services for adults with congenital heart disease (also known as 'GUCH' services as in 'Grown Ups with Congenital Heart Disease'). These services are currently provided by 21 NHS hospitals in England. A GUCH advisory group has been established made up of GUCH patients and clinicians representing their professional associations and will be chaired by Professor Sir Roger Boyle CBE, the former National Director for Heart Disease and Stroke. The GUCH advisory group held its first meeting in July 2011.

Want to know more?

Visit www.specialisedservices.nhs.uk/info/guch-1 for more information on this review.

Further information

Public consultation has closed but you can still contact the *Safe and Sustainable* team in the following ways:

✉ Write to *Safe and Sustainable*

NHS Specialised Services

2nd floor
Southside
105 Victoria Street
London
SW1E 6QT

☎ Call the review team on 020 7932 3958
@ Email Childheart@nsscg.nhs.uk

Are you on our email list?

Please email nhsspecialisedservices@grayling.com if you would like to receive information about the review.

Keep up to date with the latest information on the review at:
www.specialisedservices.nhs.uk/safeandsustainable

