FAQs on the public consultation into the proposed changes to children's congenital heart services in England

The recommendations

Who agreed the recommendations for public consultation?

The recommendations for change were agreed by a joint committee of Primary Care Trusts (JCPCT) which comprises the Chair of each of the 10 Specialised Commissioning Groups in England (or the nominated PCT representative) and the Director of National Specialised Commissioning; it is chaired by the Chief Executive of the East of England Strategic Health Authority – Sir Neil McKay. The establishment of a JCPCT ensures that each region and each PCT in England is represented on the decision-making body.

Why just two centres in London?

The *Safe and Sustainable* consultation on the future of children's congenital heart services proposes that there should be two rather than three Specialist Surgical Centres in London. The forecast activity levels for London and its catchment area (currently around 1,250 paediatric procedures per year) mean that two centres would be well placed to meet the proposed ideal number of 500 procedures a year. This could only happen with three London centres if patients were diverted from neighbouring catchment areas into London. The JCPCT recommends that this would significantly, and unjustifiably, increase travel times and impact on access for patients outside of London, South East and East of England.

Based on the considerable evidence available members of the Joint Committee of Primary Care Trusts expressed a preference that children's heart surgery should be carried out at the Evelina Children's Hospital and Great Ormond Street Hospital. People taking part in the consultation will be free to say that they want three London

centres and to express a preference for the Royal Brompton Hospital as a Specialist Surgical Centre if they prefer only two centres.

Why just two centres in the north?

Northern England (defined as Newcastle, Liverpool and Leeds centres) needs 2 centres as there are not enough patients to ensure all 3 achieve the 400 procedure minimum. These 2 should either be Liverpool and Newcastle or Liverpool and Leeds as Newcastle and Leeds cannot achieve the 400 minimum each while maintaining strong networks and access times.

Why does Southampton only appear in one option when it was ranked so highly by Sir Ian Kennedy's assessment panel?

Although the Southampton centre scored highly in Sir Ian Kennedy's assessment it remains unclear whether the Southampton centre can generate enough referrals to meet the proposed minimum level of 400 child heart operations a year. This figure was developed and endorsed by the professional associations and is considered by the clinical experts to be one of the core standards for improving care in the future.

Why does the Bristol centre appear in all of the options?

Based on the assumption that patients will travel to their nearest centre and a consideration of existing clinical networks, the initial findings of the JCPCT's analysis suggest that the Bristol and Southampton centres are not both viable in the same configuration options. This is due to the fact there are too few patients in South Central England, South West England and South Wales to ensure both centres carry out the minimum 400 procedures, without making potentially unreasonable changes to catchment areas for the populations of London, South East England and the Midlands. Bristol has been included in all options because an ambulance would not be able to retrieve children from the South West Cornwall and South Wales in an emergency within the time-limits recommended by the Paediatric Intensive Care Society if the Bristol centre no longer carried out surgery as it is over three hours to Southampton or Birmingham.

So why does Option B include both Southampton and Bristol?

It is possible that since our analysis the Southampton centre may be able to demonstrate that it can perform 400 child heart operations each year due to a proposed collaboration with the John Radcliffe Hospital. During consultation we will test how patient flows in South Central England could change following the suspension of the service at the John Radcliffe Hospital in 2010 and what impact, if any, this would have on the numbers for the Bristol service. The validated activity data for the 2010/11 year will be available to us in June 2011. Separately, we will also test whether the postcodes that we have included in the Southampton network make option B viable.

Why doesn't the John Radcliffe Hospital in Oxford appear in any of the recommendations?

The JCPCT has recommended that the Oxford Centre should be discounted from all options on the basis that it is not viable to assume that this centre could meet the quality standards in the future and because retention of the centre would not improve access arrangements.

Can you explain briefly how you see services actually working if we have fewer centres offering surgery to children with congenital heart defects?

The JCPCT proposes that services would be provided through networks called congenital heart networks. These would be clinically led. These networks would be led by the specialist surgical centre which would be able to perform specialist interventional and surgical procedures. Although many children will need surgery the number of children needing surgery more than once in their life is low. Therefore, the new networks would bring cardiology care closer to home through district children's cardiology services. The role of paediatricians with expertise in cardiology and children's cardiology specialist nurses would be strengthened to ensure seamless and consistent local care.

When considering patient flows, might parents prefer to follow the surgeon they already know, regardless of what your patient flow analysis says?

This is an important point and, given the importance of patient choice, one of the factors that we are very keen to test out during the consultation period. We already have professional data on 'patient flows' – including forecasts - which have informed the recommended options. However, as part of the consultation process, we seek the views of patients, parents, staff and local commissioners to gather their views.

I have heard that the NHS in Wales is planning its own child heart surgery service in Cardiff. Does this mean that your assumptions about activity levels at Bristol are wrong?

The NHS in Wales has confirmed that it has no plans to develop a child heart surgery service. The centre in Cardiff stopped performing heart surgery for children in 1998 because it recognised that it was not performing a sufficient number of surgical procedures to be sustainable.

Is your process robust?

Details about the process we have used are set out in the Pre-Consultation Business Case. The *Safe and Sustainable* review has been led by clinicians and the chosen options were arrived at after an extremely thorough process. On 27 January 2011, just before the JCPCT agreed recommendations for consultation on 16 February, the process that we have followed to identify potential options was presented to the expert steering group which endorsed the process. We have set out a significant amount of information about the way in which the Joint Committee of Primary Care Trusts reached its recommendations. Safe and Sustainable has itself been subject to external scrutiny by both the National Clinical Advisory Team and the Office of Government Commerce Gateway programme and the review team has been commended for the robustness of the process.

The clinical evidence

What is the clinical evidence for concentrating centres/ having fewer centres?

A recommendation for the concentration of medical and nursing expertise in smaller centres of excellence providing children's congenital cardiac services was made as far back as 2001 in the report of the public inquiry into paediatric cardiac surgical services at the Bristol Royal Infirmary. Subsequent working groups and reports have endorsed the recommendation, including the Royal College of Surgeons in 2007 and then in 2010 by the expert group of clinicians that has advised the *Safe and Sustainable* review and the independent National Clinical Advisory Team. The evidence base for ensuring a critical mass of surgical procedures per surgical unit is drawn from other examples in surgery which show that the more frequently a surgeon is performing a particular procedure, the better the outcomes in both morbidity and mortality.

The *Safe and Sustainable* review team asked the Public Health Resource Unit to carry out an independent review of the available literature around the relationship between volume and outcome in paediatric cardiac surgery. Two particular studies from that review are worth highlighting. The first was published in 2008 and was significant in that it was based on a study of a large number of operations of more than 55,000 over a period of 17 years. This study concluded that large volume hospitals performed more complex operations and achieved superior results. A further study based on over 32,000 patients found that for more difficult surgical procedures smaller surgical units performed significantly worse.

What are the risks that come with smaller centres?

- <u>24 hours a day seven days a week</u>
  Smaller centres with two or three surgeons are unable to operate safe surgical rotas which guarantee care at all times of the day or night when a child needs it.
- <u>Cancellations</u>
  Some centres need to cancel planned surgery which can cause considerable distress and upheaval for families. Without enough surgeons at each centre

planned operations are more likely to be cancelled especially if an emergency arises.

- Attracting and retaining the best staff

  At smaller centres it is harder for surgical teams to see enough children with a variety of conditions to maintain their skills so that they can give children the very best care and attract other excellent staff.

- Isolation

  Staff working in small centres that do not work in collaboration with other centres risk being isolated from their peers in larger busier centres. This can mean smaller centres might not use the latest techniques for children's care.

- Suspensions in service

  Centres rely heavily on their staff. Sudden changes in staffing could destabilise a small centre meaning that surgery and cardiology services have to be suspended for a period of time.

- Strain on surgeons

  If a centre only has two surgeons it can place a significant strain on them especially when urgent care is required. Imagine the strain on surgeons who may have performed operations all day and then get called out at night. It is not sensible for a surgeon who is over-tired to carry out complex surgery.

What is the clinical evidence for four cardiac surgeons per centre?

The proposed *Safe and Sustainable* standards, endorsed by the relevant professional associations, recommend that children's congenital heart surgery units are staffed by a minimum of 4 consultant congenital cardiac surgeons. In 2003 the report of the Paediatric and Congenital Cardiac Services Review Group recommended a minimum of three surgeons in each surgical centre, based on professional consensus. However, in 2007 the Royal College of Surgeons of England recommended 'four or five surgeons' in each centre based on the need to concentrate expertise in the interests of quality.

The minimum of 4 surgeons per team can be supported by looking at the job plans and available sessions of the surgeons. At all times there should be a surgeon available to be in theatre; a surgeon on-call for emergencies; a surgeon available for outpatient clinics; and a surgeon available to undertake ward rounds. In addition,

given the average of 40 weeks at work per year (the remaining time being spent on annual leave, study leave or conducting research), there may only ever be 3 of the surgeons at work, available to cover all of the above positions at any one time.

Who is actually supporting this review?

Many organisations and individuals support the rationale for change. Professional associations, surgeons, cardiologists, paediatricians, nurses and other clinicians have urged the NHS for many years to centralise children's heart surgery in fewer, larger centres. Parent groups and the leading national heart charity also publicly support the fact that there needs to be change.

Examples of supporting organisations:

- British Heart Foundation
- Children's Heart Federation
- Little Hearts Matter
- British Congenital Cardiac Association
- Academy of Royal Colleges
- Royal College of Paediatrics and Child Health
- Royal College of Surgeons
- Royal College of Nursing
- Society for Cardiothoracic Surgery in Great Britain and Ireland
- Specialised Healthcare Alliance
- Paediatric Intensive Care Society

Taking part in the consultation

What are you actually consulting on?

We would like people's views on the following areas:

- Standards of care: higher standards of care provided consistently across the country
- Congenital heart networks: surgical centres lead a congenital heart network

- Better monitoring: improved system for analysis and reporting of mortality and morbidity data
- Surgical centres: for the number and location of hospitals that provide children's heart surgical services in the future

Haven't decisions already been made?

Absolutely not. We take the process of the review – and the consultation – very seriously. We would like to hear from anyone with a view on the future of congenital heart services, including the people most affected: parents, young people and NHS staff.

Will you be reimbursing travel expenses for the consultation events?

We have given careful consideration to requests for the NHS to reimburse travel expenses for those attending consultation events. We have checked with the ten Strategic Health Authorities which have advised *Safe and Sustainable* that it is not recognised policy to reimburse travel expenses for public consultation events. We have also considered the rules set out by the Department of Health in this area. The Department encourages the NHS to reimburse expenses for 'engagement' events but not for 'consultation' events. We have therefore reluctantly decided that travel expenses will not be reimbursed.

We have ensured that there are a number of different ways for people to participate in the consultation. It is important that young people with congenital heart disease, parents, staff and stakeholders can easily participate in the consultation. The consultation events are only one of the ways in which individuals can get involved. The consultation materials including the response form are available online and can be provided in hard copy on request. Hard copies of the consultation document and response form will also be available through parent groups, NHS Trusts and professional associations.

Requests for hard copies of the consultation document and the consultation response form can be emailed to nhsspecialisedservices@grayling.com or alternatively you can call 0207 025 7520.

Why did you reimburse travel for the engagement events last year?

The Department of Health makes a distinction between 'engagement' and 'consultation' events. The DH encourages the NHS to reimburse travel fares to engagement events because attendance in person is considered necessary for effective engagement to take place. This is why we offered reimbursements for attendees of the engagement events that took place in 2009 and 2010.

In view of the population size, why are you only holding one event in London?

We are holding three events for the catchment area served by the London centres. We are holding them in London, Cambridge and Gatwick to make it easier for people to attend.

Will petitions be counted if submitted in response to the consultation?

All views count but this is not a 'vote'. All reports, letters and petitions will feed in to the formal consultation process. However, the most effective way to have your say is by filling out the response form with the consultation document on the website at www.specialisedservices.nhs.uk

We encourage people to respond to the consultation by completing the consultation response form (www.ipsos-mori.com/safeandsustainable). The form includes a number of questions enabling you to set out your preferences. It also includes spaces for you to add your comments and suggestions.

We are aware of numerous petitions that people have signed to express their support for a particular surgical centre. Whilst we will be considering all forms of response, it is worth noting that petitions themselves will not carry any extra weight than a consultation response form. We encourage you to use the consultation

response form as this is the best way for your views to be analysed by Ipsos Mori, an independent third party. After the consultation period a detailed analysis of the response forms will be carried out and Ipsos Mori will deliver a report to help inform the JCPCT's final decision.

You are also invited to register to attend consultation events to put your questions to expert clinicians (www.eventsforce.net/safeandsustainable). Comments made at these events will be summarised in a report for the JCPCT to consider before it makes its final decision.

Who will make the final decision on these proposals after consultation?

Following full consideration of the views of the public during the consultation phase and taking into account tests done on the viability of each option during the same period the Joint Committee of Primary Care Trusts plans to meet in November 2011 to make a final decision on the best configuration of services.