OVERVIEW OF SAFE AND SUSTAINABLE REVIEW OF PAEDIATRIC CARDIAC SURGERY SERVICES IN ENGLAND

PURPOSE
This paper reports on the Safe and Sustainable review of paediatric cardiac surgical services in England as at August 2010.

INTRODUCTION
The Safe and Sustainable review of paediatric cardiac surgical services in England was instigated in 2008 in response to long-standing concerns held by NHS clinicians, their professional associations, national parent groups and NHS commissioners around the sustainability of the current service configuration. Surgeons are spread too thinly across surgical centres (31 congenital cardiac surgeons spread over 11 surgical centres), leading to concerns around lack of 24/7 cover in smaller centres and the potential for sudden closure or suspension of smaller centres.

Two previous reviews in 2000\(^1\) and 2003\(^2\) recommended the establishment of fewer, larger paediatric cardiac surgical centres, though Ministers of the day did not accept these specific recommendations. Concerns persisted; in 2006 a national workshop of experts chaired by Professor Roger Boyle\(^3\) and Dr Sheila Shribman\(^4\) concluded that the current configuration of services was unsustainable and in 2007 the Royal College of Surgeons called for the concentration of surgical expertise into fewer, larger specialist centres\(^5\).

The review is led by the National Specialised Commissioning Team (NSC Team) on behalf of the 10 Specialised Commissioning Groups (SCGs) in England and their constituent Primary Care Trusts.

GOVERNANCE ARRANGEMENTS
In July 2010 the Secretary of State for Health endorsed the recommendation made by the National Specialised Commissioning Group (December 2009) to establish a joint committee of PCTs with delegated powers for consultation and decision making. PCT Boards have been asked to resolve to accept this recommendation at their September 2010 meetings.

The joint committee of PCTs (JCPCT) will comprise the Chair (or PCT Chief Executive nominee) of each SCG in England and the Director of National Specialised Commissioning. It will be chaired by the Chief Executive of the East of England Strategic Health Authority (this region does not have a paediatric cardiac surgical service within its borders).

STEERING GROUP
A Steering Group was convened in January 2009, chaired by Dr Patricia Hamilton CBE, Director of Medical Education for England and Immediate Past President of the Royal College of Paediatrics and Child Health. The Steering Group comprises representatives of relevant professional and lay associations (membership is attached at Appendix A).

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\(^1\) The Bristol Royal Infirmary Inquiry (which led to the report ‘Learning from Bristol: the report of the public inquiry into children’s heart surgery at the Bristol Royal Infirmary - 1914-1995’

\(^2\) Paediatric and Congenital Cardiac Services Review

\(^3\) National Director for Heart Disease and Stroke, DH

\(^4\) National Clinical Director for Children, Young People and Maternity Services, DH

\(^5\) ‘Delivering a First Class Service’, Royal College of Surgeons, 2007
The role of the Steering Group has been to:

- Develop and communicate the clinical ‘Case for Change’
- Consider the available research evidence around the relationship between larger surgical centres and clinical outcomes
- Develop designation criteria that surgical centres must meet in the future
- Develop a proposed model of care for regional paediatric cardiology networks
- Oversee stakeholder engagement and communication
- Endorse the process for the assessment of the current surgical centres

ADULTS WITH CONGENITAL HEART DISEASE
The scope of the Safe and Sustainable review excludes the designation of surgical services for adults with congenital heart disease, for which a separate designation process will be led by individual SCGs once the paediatric review has concluded. However, the Safe and Sustainable review and the paediatric clinical standards give prominence to the transition to adult services.

DEVOLVED ADMINISTRATIONS
The scope of the Safe and Sustainable review excludes the paediatric cardiac surgical services in Glasgow and Belfast, though representatives of the devolved administrations were invited to join the Steering Group to identify relevant cross-border issues.

There are no paediatric cardiac surgical services in Wales, but the Director of the Welsh Health Specialised Services Committee has been invited to join the JCPCT given material use of the English service by the Welsh population.

STAKEHOLDER SUPPORT
There is strong professional and lay stakeholder support for the notion of fewer, larger surgical centres. A ‘Need for Change’ document published in April 2010 was endorsed by the relevant professional bodies and patients associations.

THE NEED FOR CHANGE

- Children’s heart surgery is becoming increasingly complex
- Services have developed on an ad hoc basis; there is a need for a planned approach for England and Wales
- Surgical expertise (31 surgeons) is spread too thinly over 11 surgical centres
- Some centres are reliant on one or two surgeons and cannot deliver a safe 24 hour emergency service
- Smaller centres are vulnerable to sudden and unplanned closure
- Current arrangements are inequitable as there is too much variation in the expertise available from centres
- Fewer surgical centres are needed to ensure that surgical and medical teams are seeing a sufficient number of children to maintain and develop their specialist skills
- Available research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes
OVERVIEW OF SAFE AND SUSTAINABLE PAEDIATRIC CARDIAC SURGERY PROGRAMME

- Having a larger and varied caseload means larger centres are best placed to recruit and retain new surgeons and plan for the future
- The delivery of non-surgical cardiology care for children in local hospitals is inconsistent; strong leadership is required from surgical centres to develop expertise through regional and local networks
- Increasing the national pool of surgeons is not the answer, as this would result in surgeons performing fewer surgical procedures and increase the risk of occasional surgical practice

THE BENEFITS OF CHANGE

- Better results in the surgical centres with fewer deaths and complications following surgery
- Better, more accessible diagnostic services and follow up treatment delivered within regional and local networks
- Reduced waiting times and cancelled operations
- Improved communication between parents and all of the services in the network that see their child
- Better training for surgeons and their teams to ensure the sustainability of the service
- A trained workforce expert in the care and treatment of children and young people with congenital heart disease
- Centres at the forefront of modern working practices and innovative technologies that are leaders in research and development
- A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network

DESIGNATION CRITERIA

The criteria were developed by a working sub-group of experts chaired by the President of the British Congenital Cardiac Association. The final version of the standards was informed by contributions from a range of stakeholders following public circulation of the draft standards in September 2009.

Core designation criteria include:

- A minimum of 4 full-time congenital cardiac surgeons in each surgical centre
- A minimum volume of 400 paediatric surgical procedures per year in each surgical centre and ideally 500 paediatric surgical procedures
- 24/7 cover in each surgical centre
- Co-location of surgical centres with interdependent services as described in the Critical Interdependencies Framework
- Development of paediatric cardiology networks via the proposed model of care

THE MODEL OF CARE

The proposed model of care seeks to develop regional paediatric cardiology networks led by the surgical centres. The features of the proposed networks are:

- strengthened arrangements for the delivery of non-interventional diagnostic and follow-up care in local hospitals
- formal pathways from antenatal screening to the transition to adult services
OVERVIEW OF SAFE AND SUSTAINABLE PAEDIATRIC CARDIAC SURGERY PROGRAMME

- formal protocols agreed by the surgical centre with local services
- delivered in local settings
- development of the role of Paediatricians with Expertise in Cardiology across the networks
- strengthened Cardiac Liaison Teams

PARTNER ENGAGEMENT AND COMMUNICATION
The following organisations have endorsed the case for change:

- British Congenital Cardiac Association
- Children’s Heart Federation
- Paediatric Intensive Care Society
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Surgeons of England
- Society for Cardiothoracic Surgery in Great Britain and Ireland
- Specialised Healthcare Alliance

In October 2009 a national partnership event was attended by 200 people from across the country. The outcome of this event informed the development of the clinical standards and the clinical case for change.

There have also been further local partnership engagement events, held between June and July 2010. These visits are not complete but agenda item 5.1 does give interim feedback on the visits already held as of 30 June.

Partners have been kept informed of the review’s progress via quarterly newsletters, publication of all relevant papers on the NSCT website and presentations at patient group conferences.

ASSESSMENT OF CURRENT CENTRES
All 11 centres have submitted applications for designation as paediatric cardiac surgical centres. The centres were assessed against the core clinical standards between May and June 2010 by an independent expert panel chaired by Professor Sir Ian Kennedy.

EVALUATION OF CONFIGURATION OPTIONS
Potential options for change are currently being assessed against evaluation criteria. A number of configuration options will be approved by the JCPCT on 28 September 2010, with formal public consultation to commence in October 2010.

QUALITY ASSURANCE OF THE PROCESS
This is a robust process, which is subject to a number of quality assurance mechanisms. On behalf of the 10 Strategic Health Authorities in England NHS London will quality assure the consultation, in particular, the pre-consultation business case (including the consultation document) and the compliance with the Secretary of State’s four tests for reconfiguration.

The National Clinical Advisory Team (NCAT) will review the clinical case for change. The outcome of the NCAT review will be reported to the NSC Team on 1 September 2010. The Office of Government Commerce (OGC) Gateway team will review the
OVERVIEW OF SAFE AND SUSTAINABLE PAEDIATRIC CARDIAC SURGERY PROGRAMME

robustness of the process in September. The outcome will be reported to the NSC Team on 9 September 2010.

SECRETARY OF STATE’S FOUR TESTS FOR RECONFIGURATION

The NSC Team is ensuring compliance with the Secretary of State’s four principles of reconfiguration (published July 2010).

i Support from GP commissioners

The National Specialised Commissioning Team (NSC Team) has asked to meet with the Chairman of Council of the Royal College of General Practitioners to plan how best to canvass the views of GPs across the country on the Safe and Sustainable clinical standards and proposed model of care. Additionally, at the request of the proposed Joint Committee of PCTS the NSC Team will circulate materials that will be used by the 10 Specialised Commissioning Groups for direct engagement with GP commissioning leads over August 2010.

ii Strengthened public and patient engagement

Public engagement activities to date include:

- In June and July 2010 the NSC Team held ten public engagement events across the country. Each event was well attended and the outcome of the events will inform the development of the process for the delivery of recommendations for reconfiguration.

- In October 2009 the NSC Team held a national stakeholder event, attended by 200 people from across the country, at which the Safe and Sustainable Steering Group presented the process and the ‘Case for Change’ and sought to canvass the views of stakeholders.

- For the benefit of people who could not attend this event the NSC Team filmed the day’s discussions and made videos available on the website.

- The Safe and Sustainable steering group sought views on the draft quality standards by widely circulating the document for comment between September and December 2009. All of the comments received were published on the NSC Team website, and the final version of the document takes account of contributions from patients, parents, NHS staff and other stakeholders from across the country.

- The NSC Team has published the proposed criteria against which potential reconfiguration options will be assessed over the summer, and all parents who registered for the engagement events were asked to give their views on the importance of those criteria.
OVERVIEW OF SAFE AND SUSTAINABLE PAEDIATRIC CARDIAC SURGERY PROGRAMME

- All relevant documentation, including agendas, minutes of meetings and briefings on the review process, have been made available to the public on the website.

- The NSC Team has also been working with the Children’s Heart Federation to publicise the review to its twenty-one member groups across the country and to make relevant review literature available on its own website.

- The NSC Team has published quarterly newsletters.

- In all relevant literature and on the website the NSC Team has invited stakeholders to submit their views at any stage in the process.

- By invitation the Safe and Sustainable Programme Director has made a number of presentations to parent and patient groups and scrutiny committees across the country over the past year in order to explain the process for review and to canvass opinions.

Further public events will be held in the autumn of 2010, including events aimed specifically at children and young people. Preliminary details on the planned consultation are set out in a separate paper.

**iii Clinical evidence base**

There is strong clinical support for the review. The ‘case for change’ was endorsed by the relevant Royal Colleges and other professional associations.

The steering group has considered the available research evidence as part of the process for the development of clinical standards and proposed model of care. The steering group’s recommendations are consistent with available research evidence that identifies a relationship between larger volume centres and better clinical outcomes and with the findings of an independent literature review in 2009 commissioned by the steering group and carried out by the Oxford Public Health Resource Unit.

Nevertheless, the NSC Team and Steering Group members - with the relevant professional associations – are continuing to develop the evidence base in line with the Secretary of State’s outcomes framework (July 2010).

**iv Develop and support patient choice**

The Children’s Heart Federation reports that the overwhelming majority of parents with children with congenital heart disease support the principles of the review. The NSC Team will continue to work closely with the CHF and other groups to ensure that review continues to have the support of parents and patients.
## APPENDIX A

### Steering Group Membership (as at 1 August 2010)

<table>
<thead>
<tr>
<th>Name</th>
<th>Constituency</th>
<th>Role</th>
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<tbody>
<tr>
<td>Dr Patricia Hamilton CBE</td>
<td>Chair of the Steering Group</td>
<td>Director of Medical Education for England; Immediate Past President of the Royal College of Paediatrics and Child Health</td>
</tr>
<tr>
<td>Dr Martin Ashton-Key</td>
<td>Specialised Commissioning / Public Health</td>
<td>Public Health Medical Adviser, NSC Team</td>
</tr>
<tr>
<td>Mr William Brawn</td>
<td>British Congenital Cardiac Association (Immediate Past President)</td>
<td>Consultant Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust</td>
</tr>
<tr>
<td>Dr Geoffrey Carroll</td>
<td>NHS in Wales</td>
<td>Medical Director, Welsh Health Specialised Services Team</td>
</tr>
<tr>
<td>Katherine Collins</td>
<td>NHS in Scotland</td>
<td>Programme Director, National Services Division</td>
</tr>
<tr>
<td>Dr Sarah Crowther</td>
<td>Commissioner / SCG representative</td>
<td>Executive Chairman, Commissioning Support for London / Board member of London SCG</td>
</tr>
<tr>
<td>Sue Dodd</td>
<td>Department of Health (observer)</td>
<td>Emergency &amp; Acute Care Manager, Vascular Programme, Department of Health</td>
</tr>
<tr>
<td>Professor Martin Elliott</td>
<td>British Congenital Cardiac Association</td>
<td>Consultant Paediatric Cardiac Surgeon, Great Ormond Street Hospital for Children NHS Trust</td>
</tr>
<tr>
<td>Deborah Evans</td>
<td>Commissioner / SCG representative</td>
<td>Chief Executive, Bristol PCT / Chair of South West SCG</td>
</tr>
<tr>
<td>Jeremy Glyde</td>
<td>National Specialised Commissioning Team</td>
<td>Programme Director, NSC Team</td>
</tr>
<tr>
<td>Dr Kate Grebenik</td>
<td>Association of Cardiothoracic Anaesthetists</td>
<td>Consultant Anaesthetist, Oxford Radcliffe Hospitals NHS Trust</td>
</tr>
<tr>
<td>Catherine Griffiths</td>
<td>Commissioner / SCG representative</td>
<td>Chief Executive, Leicestershire County and Rutland PCT / Chair of East Midlands SCG</td>
</tr>
<tr>
<td>Mr Leslie Hamilton</td>
<td>Society for Cardiothoracic Surgery in Great Britain and Ireland (Immediate Past President)</td>
<td>Consultant Cardiac Surgeon, Newcastle upon Tyne Hospitals NHS Foundation Trust</td>
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## OVERVIEW OF SAFE AND SUSTAINABLE PAEDIATRIC CARDIAC SURGERY PROGRAMME

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<tr>
<td>Maria von Hildebrand</td>
<td>Patients and public</td>
<td>Independent Patient Advocate</td>
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<tr>
<td>Dr Sue Hobbins</td>
<td>Royal College of Paediatrics &amp; Child Health</td>
<td>Consultant Paediatrician, South London Healthcare NHS Trust</td>
</tr>
<tr>
<td>Dr Ian Jenkins</td>
<td>Paediatric Intensive Care Society (President)</td>
<td>Consultant Intensivist, University Hospitals Bristol NHS Foundation Trust</td>
</tr>
<tr>
<td>Anne Keatley-Clarke</td>
<td>Patients and public</td>
<td>Chief Executive, Children's Heart Federation</td>
</tr>
<tr>
<td>Candy Morris CBE</td>
<td>Strategic Health Authorities</td>
<td>Chief Executive, South East Coast SHA</td>
</tr>
<tr>
<td>Teresa Moss</td>
<td>National Specialised Commissioning Team</td>
<td>Director of National Specialised Commissioning</td>
</tr>
<tr>
<td>Dr Sally Nelson</td>
<td>Public Health</td>
<td>Medical Adviser, South Central SCG</td>
</tr>
<tr>
<td>Dr Shakeel Qureshi</td>
<td>British Congenital Cardiac Association (President)</td>
<td>Consultant Paediatric Cardiologist, Guy’s and St Thomas’ NHS Foundation Trust</td>
</tr>
<tr>
<td>Chris Reed</td>
<td>Commissioner / SCG representative</td>
<td>Chief Executive, NHS North of Tyne PCTs / Chair of North East SCG</td>
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<tr>
<td>Dr Tony Salmon</td>
<td>British Congenital Cardiac Association (President Elect)</td>
<td>Consultant Paediatric Cardiologist, Southampton University Hospitals NHS Trust</td>
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<tr>
<td>Fiona Smith</td>
<td>Royal College of Nursing</td>
<td>Adviser in Children and Young People's Nursing, RCN</td>
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<tr>
<td>Dr Graham Stuart</td>
<td>British Congenital Cardiac Association</td>
<td>Adult Cardiologist, University Hospitals Bristol NHS Foundation Trust</td>
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<td>Vacant</td>
<td>NHS Northern Ireland</td>
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