National Audit of Congenital Heart Disease

Executive Summary 2009

Prepared in partnership with:

The Healthcare Quality Improvement Partnership (HQIP) promotes quality in healthcare. HQIP holds commissioning and funding responsibility for the National Audit of Congenital Heart Disease and other national clinical audits.

The NHS Information Centre for Health and Social Care (The NHS IC) is England's central, authoritative source of essential data and statistical information for frontline decision makers in health and social care. The NHS IC managed the publication of the 2009 annual report.

The Society for Cardiothoracic Surgeons in Great Britain and Ireland (SCTS) was set up by the profession to develop cardiothoracic surgery. The Society represents the views of Cardiothoracic surgeons and develops guidelines on clinical management and working practices. The SCTS was jointly responsible for providing clinical leadership and strategic direction to the 2009 annual report.

The British Congenital Cardiac Association (BCCA) aims to promote the study and care of infants, children and adults with congenital heart disease in the United Kingdom and the Republic of Ireland. It is affiliated to the British Cardiovascular Society (BCS). The BCCA was jointly responsible for providing clinical leadership and strategic direction to the 2009 annual report.

The British Cardiovascular Society (BCS) provides a pivotal role in the delivery of cardiovascular health across the UK.
The British Congenital Cardiac Association (BCCA) is an affiliated association of the British Cardiovascular Society (BCS) and plays a leading role in the strategic oversight of national audit in congenital heart disease in liaison with the BCS.

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Key findings about the quality of care for children and adults with congenital heart disease.

Executive Summary

Congenital heart disease refers to any defect of the heart present from birth. It includes structural defects, congenital arrhythmias, and cardiomyopathies. Approximately eight in every 1,000 babies are born with a heart or circulatory condition.

The national congenital heart disease audit's purpose is to improve availability of outcome data to the profession, healthcare managers, public and other stakeholders following surgery or therapeutic catheterisation for congenital heart disease in children and adults in the United Kingdom (UK). This will allow:

- Identification of best practice and improving the results of treatment;
- Comparisons of survivals between different centres, with identification of centres whose performance falls below acceptable standards;
- Access to long term survival data after specific types of treatment;
- Secure access to individual operator outcomes as an aid to local clinical governance and revalidation;
- Provision of feedback data to the National Institute of Clinical Excellence (NICE) for specific new procedures for which they have published guidance.

The audit described here allows clinicians to assess key aspects of the quality of their care when performing cardiac surgery and cardiac catheter interventional procedures. This is a UK wide audit which is clinically led by representatives from the Society for Cardiothoracic Surgeons in GB and Ireland (SCTS) the British Congenital Cardiac Association (BCCA). In addition there is direct input from lay representation (the Chief Executive of the Children's Heart Federation). The data is collected through the Central Cardiac Audit Database (CCAD) which allows electronic transfer of much more detailed information. This data collection and analysis for centres in England and Wales has project management and specialist IT support provided by the National Clinical Audit Support Programme (NCASP), which is part of the NHS Information Centre for health and social care (The IC). This portion of the audit is funded by the Healthcare Quality Improvement Partnership (HQIP).

Participation

- Data has been collected from all 13 UK tertiary paediatric congenital cardiac centres since April 1st 2000.
- Data for adults undergoing procedures for congenital heart disease is collected from the majority of tertiary adult congenital centres as well as from a number of "general" cardiac centres who also carry out some congenital procedures. Recruitment efforts continue in the hope of achieving complete data acquisition for adults.
- Over 70,000 patient records are held within the central database with 58,000 patients records included in the analysis.
- Interaction with the contributing centres takes place through biannual email newsletters and at an annual contributors' meeting (usually held each February, at the Royal College of Surgeons in London). Each centre is represented at this meeting, usually by at least one surgeon, one cardiologist and one member of their audit staff.

Data collection, validation and quality

- Data is submitted electronically to CCAD by each centre on all patients undergoing surgery or therapeutic cardiac catheterisation for congenital hart disease.
- Data is collected electronically in a secure format to preserve patient confidentiality.
- Each year every centre has an independent data validation visit during which case ascertainment is maximised by checking CCAD data returns against operating theatre and catheterisation laboratory logbooks. A sample of 20 case notes is also reviewed to assess data quality, and a data quality index score (DQI) is calculated for each trust after the visit. The DQI forms part of the centre specific data available on the public portal. This external validation process over the years has seen major improvements in the quality of data submitted by units and is vital for accurate survival analysis.
- The National Information Governance Board (NIGB) has previously recommended that informed consent should be taken from patients for these visits to continue. All contributing centres now have a consent process in place.

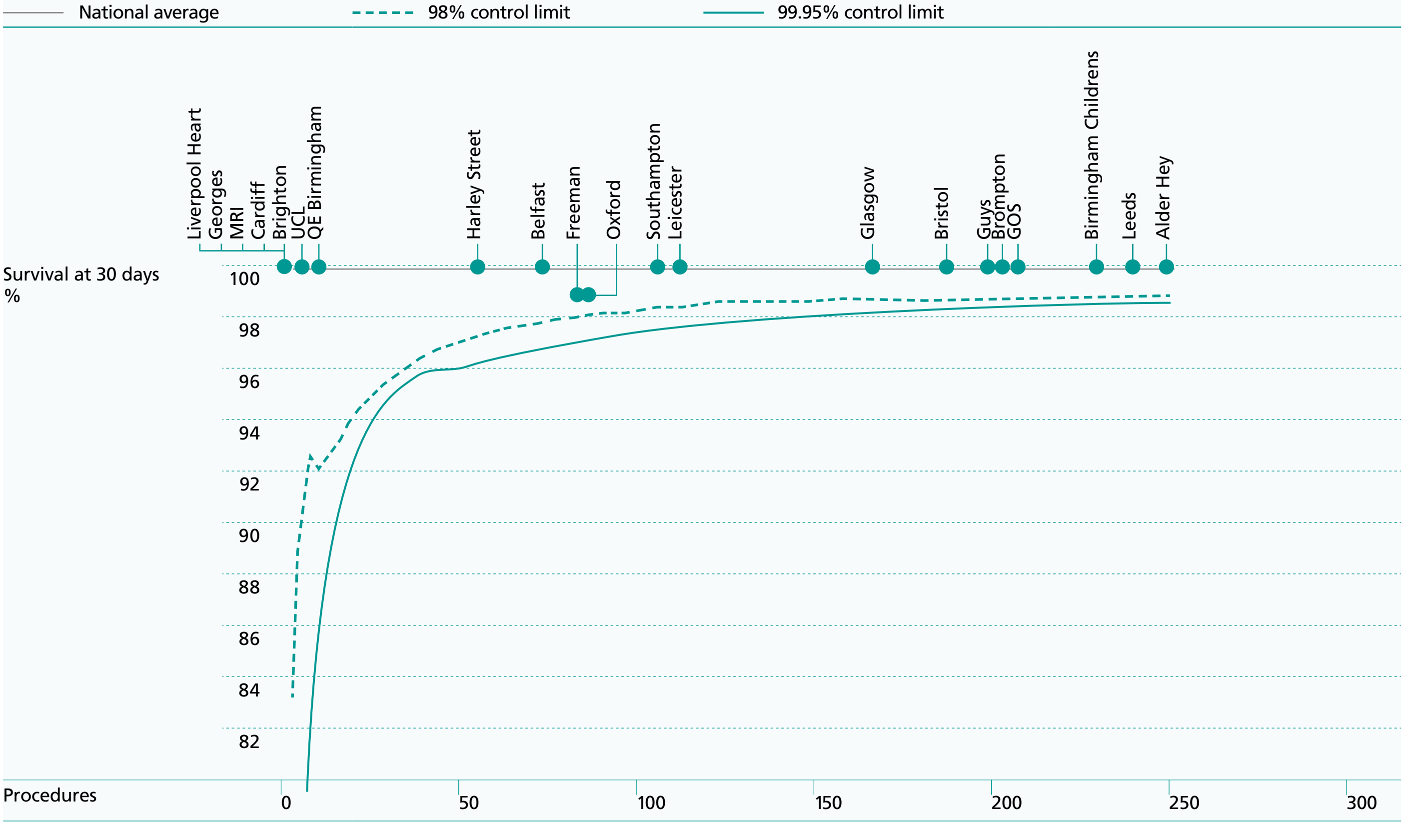
Cardiac centres participating in the congenital heart disease audit

Data analysis and presentation

- The national congenital heart disease audit monitors activity levels and uses 30 day and 1 year survival statistics to judge individual hospital performance against the standards of confidence limits around the national mean survivals, thereby helping to ensure patient safety. Results are publicly available via the congenital heart disease website[1]. The Information provided can be used by patients and carers to make informed choices about their care and treatment. The website also provides some general information about specific congenital cardiac abnormalities.
- This national audit holds the only complete and validated database for congenital heart disease in the world. Also a great strength is the ability to do long term follow up and track re-interventions.
- Operator specific data is made available to each centre via secure, password protected access as an aid to local clinical governance and revalidation.
- Funnel plots for survival at 30 days after the 48 most common procedures are used for purposes of comparison of performance between centres, data being pooled for the most recently analysed 5 year period.
- Survival is tracked centrally using links to the Office for National Statistics (ONS) in England and to the General Register Offices of Scotland and Northern Ireland, allowing perpetual tracking of outcome using the patient's unique NHS number.
- In addition to this central tracking of life status, each centre has undergone annual, independent data validation visits to maximise case ascertainment and data quality.
- Our ability to track life status steadily improves with each year, but at present there are a proportion of patients for whom life status cannot be confirmed centrally. Survival percentages analyses are restricted to cases where we have confirmed life status.

Figure 1

Funnel plot showing the distribution of survival by centre for Catheter PDA closure procedures (01/04/2002 to 31/03/2007)



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[1] Congenital Heart Disease (public portal) website allows patients, carers to see results for their local congenital heart disease centre: http://www.ccad.org.uk/congenital

- Congenital heart disease takes many different forms and there are numerous different treatment procedures, making interpretation of outcome data far more complex than for other forms of surgery. Case mix varies considerably between different centres and between individual operators.

- There is no existing validated means of risk stratifying these treatments, so it is not valid to analyse any given centre's or operator's overall survival data. Survival data is therefore presented for the "mainstream" specific procedures for each centre and for the national aggregate of these specific procedures. This does cause statistical difficulties due to small sample sizes for some procedures, but as cumulative data is collected, the statistical ability to detect differences in outcomes will strengthen progressively. To date we have chosen to place centre but not operator specific survival data in the public domain.

- In the absence of any validated risk adjustment tool for congenital heart disease, results have been analysed for some 48 specific procedures to minimise the effects of case mix.

- Data related to morbidity has also been collected (duration of ventilation, neurological performance scores, length of stay) but these parameters have not yet been analysed.

- During 2009 data analysis will be expanded to include long term survival curves for the most common procedures as well as performance data on antenatal diagnosis within strategic health authorities.

- In future years we will also assess other measures of outcome such as freedom from re-intervention and change in neurological status.

Table 1
List of 48 specific procedures for which analysis is provided on the congenital heart disease portal

Surgical Procedures	Catheter Procedures
Anomalous coronary artery repair	Aortic balloon valvotomy
Aortic root replacement (not Ross)	ASD closure (catheter)
Aortic valve replacement – Ross	Blade atrial septostomy
Aortic valvotomy	Coarctation stenting
Aortopulmonary window repair	PDA closure (catheter)
Arterial shunt	PFO closure (catheter)
Arterial switch (for isolated transposition)	Pulmonary artery stenting
Arterial switch + VSD closure	Pulmonary balloon valvoplasty
ASD repair	Pulmonary valvotomy (radiofrequency)
Atrioventricular septal defect and tetralogy repair	Recoarctation angioplasty
Atrioventricular septal defect (complete) repair	VSD closure (catheter)
Atrioventricular septal defect (partial) repair	
AVR – non Ross	
Bidirectional cavopulmonary shunt	
Cor triatriatum repair	
Fontan procedure	
Interrupted aortic arch repair	
Isolated coarctation repair	
Isolated Pulmonary artery band	
Mitral valve replacement	
Multiple VSD Closure	
Norwood procedure (Stage 1)	
PDA ligation (surgical)	
Pulmonary atresia VSD repair	
Pulmonary valve replacement	
Rastelli procedure	
Repair of total anomalous pulmonary venous drainage	
Senning or Mustard procedure	
Subvalvar aortic stenosis repair	
Supravalvar aortic stenosis repair	
Tetralogy repair	
Tetralogy with absent pulmonary valve repair	
Tricuspid valve replacement	
Truncus and interrupted repair	
Truncus arteriosus repair	
VSD Repair	

Adult congenital heart disease

- Case ascertainment for children (under the age of 16 years) is robust, this is not yet the case for adults with congenital heart disease, some of whom are treated outside tertiary congenital cardiac centres by staff who do not currently submit data to CCAD.
- Some hospitals undertaking adult congenital procedures are participating in the audit although there are a number of centres who are known to carry out these procedures, who have made no attempts to submit data to the national audit.
- The Department of Health (DH) guide to Adult Congenital Cardiac services states specifically that all consultants carrying out these procedures should be actively involved in national audit.
- The potentially serious governance issue of some centres failing to send data to CCAD is currently being addressed jointly by the British Congenital Cardiac Association (BCCA), the British Cardiovascular Society (BCS) and the British Cardiac Intervention Society (BCIS). It is envisaged data on adults will improve substantially over the coming year.

Key findings include

- The number of congenital procedures undertaken in UK centers has grown steadily over the last 7 years. Between April 2000 to March 2007 a total of 52,342 procedures had been performed.
- Altogether data concerning 31,112 surgical procedures and 21,230 therapeutic cardiac catheterisations has been collected.
- Overall national survival has remained unchanged in recent years. 30 day survival after procedures for congenital disease is 98.6% and after 1 year 93.7%.
- Overall survival for surgery after 30 days is 97.74 %, and decreasing to 91.03% at one year. For therapeutic cardiac catheterisation survival at 30 days is 99.38% and decreasing to 97.54 % at one year.
- There has been a marked improvement in the quality of data submitted in the last 2 years, particularly for ascertainment of NHS number which is important for tracking purposes. In the last 5 years this has increased steadily (69% in 2000 to 92% in 2008).
- The audit is capturing increasing numbers of procedures in adult patients with congenital heart disease.
- Centre specific data analysis shows the quality of treatment is high throughout the UK.

Table 2
Data completeness for 2006/7

Gender	100.0%
Weight	85.0%
Date of Birth	100.0%
NHS Number	89.1%
Postcode	99.0%
Procedure Date	100.0%
Diagnosis	95.8%
Procedure	99.0%
Consultant	99.8%
Operator	99.8%
Procedure Type	100.0%
Operator Grade	99.7%
Sternotomy Sequence	52.8%
Date of Discharge	96.8%
Status at Discharge	99.9%
Total	**94.4%**

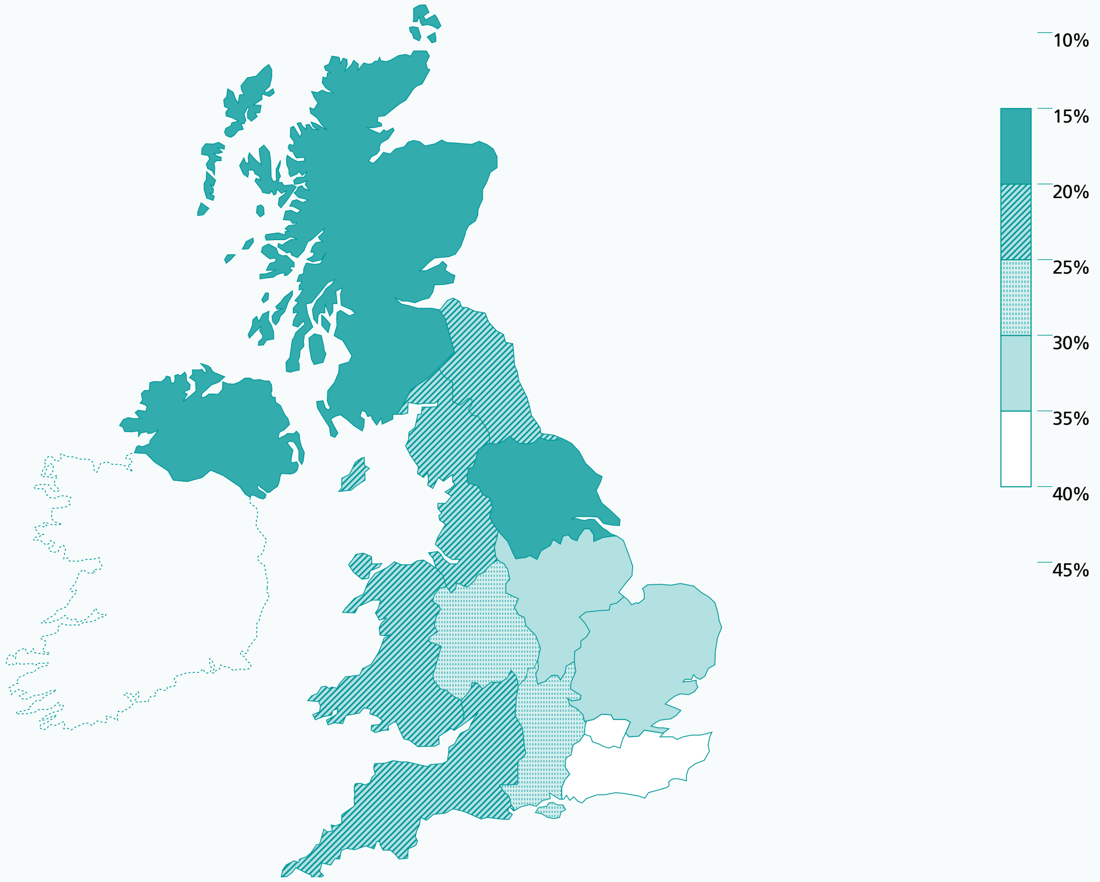
- The majority of centres have been performing within statistical measures of safety. Although more recently for the first time, a centre was found to lie outside the confidence intervals for survival for 1 of the 48 different procedures, for the 5 year period 2002–7. In line with the audit governance protocol, this triggered an investigation by the SCTS and BCCA after those organisations were alerted by the CCAD Project Board. This investigation revealed that the outcomes for this particular patient group had already been detected by local audit processes and appropriate action had been taken by the Trust medical director in liaison with the Royal College of Surgeons. The Trust medical director has been invited to write a short explanation of his action to be published on the public portal alongside the survival data.
- We are unable to asses how the results from the UK compare with other nations, although the data seems to compare favourably with unvalidated registry reports from North America and Europe.
- Recent data analysis has shown a marked difference in quality of antenatal diagnosis of major congenital cardiac anomalies in different parts of the UK.

Recommendations

- All consultants carrying out adult congenital procedures should be actively involved in national audit.
- Hospitals undertaking adult congenital procedures must submit data to the national audit.
- Centres should move towards sharing of best practice for improved care.
- While many centres provide very complete data, submissions need to be on a regular basis.
- Trusts need to provide appropriate resources for data collection. The Care Quality Commission (CQC) have included a measure of participation in their 'Annual Health Check' since 2008/9. For future years there will be a measure of data quality.

More detailed analysis of the data from the audit from 2000 to 2007 is available on the congenital heart disease audit portal. http://www.ccad.org.uk/congenital.

Percentage of infants who required treatment who were antenatally diagnosed by English Strategic Health Authorities and their equivalents in Scotland, Ireland and Northern Ireland. (Average 2004–08)



Notes

The NHS Information Centre for health and social care (The NHS IC) is working to make information more relevant and accessible to the public, regulators, health and social care professionals and policy makers, leading to improvements in knowledge and efficiency. The NHS IC is a NHS special health authority that collects, analyses and distributes data to reduce the burden on frontline staff, releasing more time for direct care.

For further information please contact our Contact Centre, quoting document reference IC23090309 for the executive summary. Printed copies of the summary can be ordered from the NHS Information Centre.

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