Early detection of congenital heart disease

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Programme Board
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Objective 6: to improve antenatal and neonatal detection rates of congenital heart disease.

• **Aim:** to increase congenital heart disease detection before, or soon after birth to ensure that the care of the family and child is optimised to improve outcomes.

• The review is facilitating multi-agency working to support improved antenatal detection and reporting.

• The aim is to support mainstream rather than ‘take over’. 
Objectives / linkages

• To identify causes of variable antenatal detection rates.

• To develop a plan address variable detection rates.

• To hand over responsibility for delivery to relevant partners.

• To ensure that the results of this work feed into the other objectives of the review – especially those related to the demand and function, form and capacity of future service.
Benefits

- Improved family experience throughout pathway.
- Improved immediate postnatal management optimised by birth place at or close to a paediatric cardiac surgery centre.
- Potential reduction complications, morbidity and mortality associated with cardiovascular compromise subsequent to delayed diagnosis.
- Reduction in the number of emergency transfers of undiagnosed babies at birth.
- Improved detection of all anomalies.
Early findings

• No national register of congenital anomalies
  • Unable to track performance of in utero detection.
  • On average detection rate below target set by FASP with a high degree of variability – the reason for variability is unclear – one element could be sonographer training.
  • Unable to trace fetal diagnosis to outcome – to congenital centre, terminations, death in utero, death before transfer to congenital centre.
  • Weakens our understanding of the rest of the congenital heart disease service.
• Public Health England (PHE) intend to develop a national register which should be functional by April 2015.
British Isles Network of Congenital Anomaly Registers (BINOCAR) reports the proportion of births covered by regional congenital anomaly registers: country percentage coverage

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>England</td>
<td>49</td>
</tr>
<tr>
<td>Ireland</td>
<td>52</td>
</tr>
<tr>
<td>Scotland</td>
<td>24</td>
</tr>
<tr>
<td>Wales</td>
<td>100</td>
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New Congenital Heart Disease Review

BINOCAR: Current contributors

NorCAS: Northern Congenital Abnormality Survey

YHCAR: Yorkshire & Humber CAR – do not submit data to BINOCAR

EMSYCAR: East Midlands and South Yorkshire CAR

WMCAR: West Midlands CAR – do not submit data to BINOCAR

CARIS: Welsh CAR

CAROBB: CAR for Oxfordshire, Berkshire and Buckinghamshire

SWCAR: South West CAR

WANDA: Wessex Antenatally Detected Anomalies Register
Variable rates by region

Proportion of All Anomalies (Excluding chromosomal) cases prenatally diagnosed, 2008-2012

% Prenatally diagnosed

- French West Indies (France)
- Wessex (UK)
- Paris (France)
- Northern England (UK)
- Île de la Réunion (France)
- Thanes Valley (UK)
- Vaud (Switzerland)
- Hainaut (Belgium)
- Wales (UK)
- Basque Country (Spain)
- Tuscany (Italy)
- Odense (Denmark)
- S Portugal
- N Netherlands (NL)
- Ukraine
- Emilia Romagna (Italy)
- Saxony-Anhalt (Germany)
- Valencia Region (Spain)
- Zagreb (Croatia)
- Norway
- Innsbruck (Germany)
- Cork and Kerry (Ireland)
- Hungary
Neonatal detection

- Newborn and infant physical examination (NIPE) picks up approx. 30% of possible cases of congenital heart disease (CHD) before discharge.

- On 7 May 2014, the National Screening Committee (NSC) announced a one year pilot of pulse oximetry screening in six parts of the country, which could demonstrate the potential to increase the neonatal detection of CHD to 70%.
Stakeholders

- **PHE**: screening committee and extending National Registry
- **Health Education England (HEE)**: enhanced education for sonographers
- **Clinical Commissioning Groups (CCGs)**: commissioning of the maternity pathway including early detection and accountability for quality, safety and clinical governance.
- **Fetal Anomaly Screening Programme (FASP)/National Screening Committee (NSC)**: new guidelines on screening and recommendations to connect early detection with congenital cardiac specialist services.
- **Clinical Reference Groups** (Congenital Heart Services, Fetal and Maternal Medicine).
Early feedback from stakeholder discussions

- Variable uptake of national (FASP) guidelines.
- Variation in results depend on type of defect, expertise of person screening, standards of equipment, gestation and maternal Body Mass Index (BMI).
- Problems may include numbers of sonographers (with relevant training).
- Variable baseline training and ongoing competency of sonographers – unpublished papers show improvement in detection rate when booster training carried out.
- No formal feedback to sonographers about their performance.
Fetal Leads Group

This group is scoping and planning the aims and objectives. The membership of the group consists of:

- Julia Grace (Chair), Regional Programme of Care Lead
- Catherine Calderwood, National Clinical Director for Maternity and Women’s Health, NHS England
- Dr Jacqueline Cornish, National Clinical Director for children, young people and the transition to adulthood
- Pran Pandya, Fetal Anomaly Screening Programme (FASP)
- Gurleen Sharland, Vice-Chair of the Congenital Heart Services CRG
- Professor Steve Robson, Chair of the Fetal Medicine CRG
- Christine Harvey, Programme Director for the development of national anomaly register, PHE
Outstanding issues

• resources to complete the work.

• engagement from clinical commissioning group commissioners.

• potential cost implications related to training/education.
Next steps

• Pathway map.

• A report on the causes of variable detection rates.

• A plan to deliver improvement in antenatal detection.

• Sustainable governance and delivery arrangements.
Plan / timetable

- Plan to be presented to Fetal Leads Group in mid June 2014 and to the review’s Programme Board in July 2014.

- To complete the work by the end of December 2014.