Update on neonatal and antenatal detection of congenital heart disease (CHD)

Introduction and background

This is an update on the progress on the review’s sixth objective: to improve antenatal and neonatal detection of congenital heart disease.

We last updated the Programme Board at its meeting on 13 May 2014, outlining the project and progress to date. A link to the slides presented at that meeting can be found here. At that meeting we explained that a project group had been established to lead work required to improve antenatal detection. We also reported that the National Screening Committee (NSC) had just approved a trial of pulse oximetry in newborns.

What’s the issue and why does it matter?

Detecting congenital heart anomalies before birth enables referral to a fetal medicine unit for a definitive diagnosis and further checks for associated anomalies. It enables discussion between the family and specialist staff about prognosis for baby / child which may influence parents’ decision about the outcome for the pregnancy. Parents are able to be prepared emotionally for what they and their baby will face after delivery. It facilitates planned delivery in a particular hospital, with appropriate neonatal facilities. Evidence shows that distance from a surgical centre influences mortality, Morris et al, 2014i. Pre-natal detection also enables neonatal team to co-ordinate the care and transport of this and other babies in the region. Pre natal diagnosis reduces preoperative intubation and reduces perioperative morbidity Tworetzky et alii, and Morris et al, 2014.

The current rate of detection according to the National Institute for Cardiovascular Outcomes Research (NICOR) shows that in England 35% of anomalies that could be detected before birth were detected before birth. The chart below shows some improvement over the 4 years from 2009-2012 however this does not take England to the current target of 50% as required by the Fetal Anomaly Screening Programme (FASP).

**Figure 1. National detection rates**

<table>
<thead>
<tr>
<th></th>
<th>2009-10</th>
<th>2010-11</th>
<th>2011-12</th>
<th>Trend</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>31%</td>
<td>33%</td>
<td>35%</td>
<td>improving</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>36%</td>
<td>32%</td>
<td>no data yet</td>
<td></td>
</tr>
<tr>
<td>Scotland</td>
<td>29%</td>
<td>23%</td>
<td>36%</td>
<td>improving</td>
</tr>
<tr>
<td>Wales</td>
<td>34%</td>
<td>42%</td>
<td>52%</td>
<td>improving</td>
</tr>
<tr>
<td>UK</td>
<td>31%</td>
<td>33%</td>
<td>35%</td>
<td>improving</td>
</tr>
</tbody>
</table>

*Data source: NICOR*
What's being done?

The project group was formed by the Women and Children’s Programme of Care (POC) Board by Julia Grace, the accountable commissioner for the congenital heart services clinical reference group (CRG). The Women and Children’s POC Board had identified fetal detection of CHD as a potential pathfinder programme. Due to oversubscription of the pathfinder programme and the identification of improved fetal detection as an objective on the new CHD review it was agreed that the new CHD review would take the objective forward as a project.

The chair of the project group was already working closely with the CHD review and is keen for the Programme Board to oversee the recommendations and to ensure that the programme structure is used to get agreement on how to operationalise the recommendations. The group will therefore report to the Programme Board in December 2014 with recommendations to improve detection rates of congenital heart disease.

The membership consists of fetal, neonatal and obstetric clinicians, representatives from Public Health England (PHE), NHS England commissioners and the national clinical directors for maternity and women’s health, children, young people and the transition to adulthood, and diagnostics and imaging. The group has met every two months. The purpose of the group is to work across the health service to:

- understand why we have the problem;
- identify the key partners, their roles and what NHS England could do to influence partners to ensure that this issue is treated as a priority;
- understand what improvements are already in train;
- identify where improvements could be made; and
- identify what NHS England can do to support an improvement in detection rates.

The project group is gathering information about the reasons behind low detection rates. These reasons are complex and not always clear. Three issues have come up repeatedly in discussions. These are the target of the project group presently however it may be that as the project continues that more reasons are identified. The three issues for initial work to improve antenatal detection are:

- development of a single national anomaly register;
- commissioning to improve detection; and
- sonographer workforce and training.

This paper describes progress so far on each work stream as well as the relationship between this work and the wider work of the review.

Single national anomaly register

In England at present, only some areas are covered by registries, with the result that only 49% of pregnancies are covered by the regional congenital anomaly registers (CAR’s). These registers work as separate entities, collecting and submitting data to the European register of congenital anomalies (EUROCAT) which then reports back to British Isles Network of Congenital Anomaly Registers (BINOCAR). There is variation in data collection across the existing CARS.
A single anomaly register would enable national surveillance of congenital heart disease. Registers facilitate research and surveillance concerning environmental causes of congenital anomalies. The registry can provide comprehensive data on the proportion of cases of congenital heart disease diagnosed prenatally, the proportion of positive antenatal screening results which were confirmed as cases of congenital anomaly, and the proportion of antenatally diagnosed cases which led to termination of pregnancy or intrauterine death, as well as related information about prenatal screening methods.

In addition the information supports the planning and evaluation of health services. Population-based registries are a particularly powerful tool for the evaluation of health services, because they represent the experience of a whole community.

Locally the information available provides an understanding how providers are doing to drive improvements.

Public Health England (PHE) are progressing work to create a single register for congenital anomalies and rare diseases. This is a complex task and NHS England understands that by April of 2016 there will be 100% coverage in England. This involves establishing a single database and setting up congenital anomaly registers in the five areas not covered currently.

PHE are working together with NICOR, the National Screening Committee (NSC), the British Congenital Cardiac Association (BCCA) and the congenital heart CRG to agree the anomalies that should be recorded in the register as well as enabling the IT systems from NICOR and the new anomaly register to be able to communicate and share information initially.

The Programme Board will be asked to note reports of progress against the plan. The decision making body is PHE who will be briefing the Programme Board in a later section of this meeting, providing an opportunity to understand and test the timetable.

**Commissioning to improve detection**

Commissioning is one of the mechanisms available to improve antenatal detection of congenital heart disease. The antenatal screening programme is commissioned by NHS England under Section 7A of the National Health Service Act 2006: Public health functions to be exercised by the NHS England but is funded by CCGs through the maternity tariff.

Congenital heart disease can be detected before birth at the routine antenatal screening at the 18+0–20+6 scan or at any other scan after this date.

The Fetal Anomaly Screening Programme (FASP), part of the National Screening Committee (NSC), creates the standards and the service specification for all antenatal screening. The service is commissioned by the NHS England Area Public Health commissioners.

Public Health England (PHE) is responsible for the quality of the screening and screening is monitored by quality assurance (QA) leads who are PHE staff embedded within NHS England. The QA leads who carry out quality assurance visits to ensure that providers are delivering the antenatal screening programme. Their priority regarding screening is availability of scanning, informed consent and outcomes data – knowing whether detection
rates are improving. Area Health Commissioners and quality assurance leads tell us that there is not sufficient information regarding this screening programme making it difficult to know how their providers are doing. This also supports the case for the creation of a national registry.

Providers submit the following key performance indicator data to PHE and at present that there are no indicators for congenital heart disease.

**Antenatal screening KPIs**

- Antenatal infectious disease screening – HIV coverage
- Antenatal infectious disease screening – timely referral of hepatitis B positive women for specialist assessment
- Down’s syndrome screening – completion of laboratory request forms
- Antenatal sickle cell and thalassaemia screening – coverage
- Antenatal sickle cell and thalassaemia screening – timeliness of test
- Antenatal sickle cell and thalassaemia screening – completion of FOQ

Engagement with commissioners has been established by the project group and the next steps will be to raise the profile of congenital cardiac disease screening, to understand more about how the service specification is currently monitored and what levers are available to drive improvement.

**Sonographer training and workforce**

We have been informed by stakeholders that there are challenges in both sonographer training and the workforce. We have been working with stakeholders to understand what could be done to improve antenatal detection of CHD.

**Training**

When the NSC makes changes to antenatal screening programmes, FASP is responsible for education and training for sonographers in the English screening programmes.

Prior to 2010 there was great variation in practice for antenatal screening of congenital heart disease around England. In 2010 FASP developed standards for antenatal screening which stated how the heart should be screened (the four chambers and three vessel view) and to allow an increase of 10 minutes to 30 minutes for the scan. FASP provided funding regionally to support the training in England following the 2010 standards. How the training was organised was left to the regions and there was a mixture of approaches using either an education charity (Tiny Tickers), the local Fetal Cardiologist, the fetal medicine consultants or a combination of the three. Some regions also provided extra money from their regional training budgets to supplement the training but the approach was not standardised in any way except that the training had to ensure that the three vessel view was included. A recent audit by FASP noted that this has not resulted in universal implementation of the required three vessel view.
The standards and service specifications have been revised again for implementation in 2015/2016. The standard now includes a third view of the heart, which improves the chances of detecting CHD.

In support of this new specification, FASP will be facilitating training for sonographers across England over 18 months starting in January 2015 to ensure all sonographers are able to conduct the scan as required. There will be both online and practical elements to the training. There are 152 units in England which carry out antenatal scanning hence FASP are proposing a cascade approach to training working closely with the fetal networks and regional PHE quality assurance leads to ensure that the training is delivered consistently.

After this initial training, FASP will require that practitioners complete the online training at regular intervals which FASP will be able to monitor uptake of this and to assess compliance. Release of staff for ongoing training is the responsibility of the provider.

**Sonographer Workforce Issues**

We have been told by stakeholders that there are several workforce issues with sonographers. There have been attempts to resolve these issues however stakeholders agree that we may need different solutions.

Sonographers are trained initially as radiographers. Radiographers interested in becoming sonographers will then complete further training on the job with formal education. It has been reported that there is little incentive to train as a sonographer after graduating as a radiographer due to restrictions of the agenda for change (AFC) pay scheme.

Our stakeholders tell us that there is a shortage of sonographers which is not a new problem but dates back at least 5 years. There have been attempts to solve the problem by training other staff to carry out the scans: midwives can complete a module to qualify to carry out early scans which has helped particularly for emergency admissions for bleeding and with growth scans. Whilst it is not the remit of NHS England to resolve this issue we will work with Health Education England to feed back our findings. Other issues relating to the sonography workforce are:

- the sonography workforce in some areas are moving close to retirement age;
- a high incidence of repetitive strain injury further reducing availability of sonographers;
- fear of litigation in the event of missing the views; and
- increased scrutiny on the discipline, more so than for other disciplines within radiography.

**Link with new congenital heart disease review standards**

The recommendations made by this group support the fetal section of the standards.

There is a possibility that the changes FASP want to make would require strengthening of the proposed standards and we anticipate we may get responses to that effect during consultation.
Next steps

- Progress with this work and developing recommendations.
- Take recommendations to the review’s Clinical Advisory Panel for their advice before the Programme Board sign-off in December 2014.
- Identify where this work sits once the programme has completed.

The Programme Board are asked to note progress on the sixth objective to improve antenatal and neonatal detection of congenital heart disease.

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i Morris, Shaine A., Ethen, Mary K., Penny, Daniel J; Canfiel., Mark A; Minard., Charles G., Fixler, David E., Nembhard, Wendy N., 2014, Prenatal Diagnosis, Birth Location, Surgical Center, and Neonatal Mortality in Infants With Hypoplastic Left Heart Syndrome Circulation. 2014; 129: 285-292