Objective 6: to improve antenatal and neonatal detection rates - scoping

Programme Board

11 March 2014
Why does this matter?

• Early detection of congenital heart disease (CHD) improves outcomes:
  • Postnatal management optimised by the choice of birth place.
  • Avoidance of complications, morbidity and mortality associated with cardiovascular collapse subsequent to delayed diagnosis.
  • Fewer emergency transfers at birth.
  • Improving family experience throughout pathway.

• This are 2 opportunities to increase detection - antenatal and neonatal screening
Antenatal screening

• Standards for screening are set by NHS Fetal Anomaly Screening Programme (FASP) – currently NUSS 2010 http://www.fetalanomaly.screening.nhs.uk/standardsandpolicies

• Current requirement 4 chamber view and outflow tracts (3 vessel view)

• Proposal to move add 3 vessel plus trachea (3VT) view. Approval by UK National Screening Committee (NSC) anticipated c. May/June 2014
Antenatal pathway for CHD (FASP)

Women at an increased risk of CHD may be offered specialist scans. For further information please see:
British Congenital Cardiac Association (BCCA)
Fetal Cardiology Standards
NHS Fetal Anomaly Screening Programme Pathway for nuchal translucency (NT) ≥ 3.5mm

CHD identified / suspected
Inform woman
Offer onward referral for specialist scan

FETAL MEDICINE CENTRE and FETAL CARDIOLOGY SERVICE

All women with identified / suspected CHD must be seen within a maximum of 5 working days from referral

Cases may be seen jointly by Fetal Medicine and Fetal Cardiology (recommended) or independently depending upon the anomalies detected:
1. Isolated cases of CHD may be referred to Fetal Cardiology first or seen jointly with Fetal Medicine.
2. CHD and additional anomalies may be seen by Fetal Medicine followed by Fetal Cardiology.

Isolated CHD or CHD and additional anomalies confirmed
Inform woman and Multidisciplinary Team Counsel on options including further testing, continuing the pregnancy and termination of pregnancy

LOCAL HOSPITAL

Re-scan and consultation by local fetal medicine specialist within 3 working days of referral

Isolated CHD/CHD and additional anomalies confirmed
Refer to Fetal Cardiologist/Fetal Medicine Centre

No abnormality detected
Continue with pregnancy care

NIP screening pathway post delivery

No abnormality detected

Woman chooses termination of pregnancy

Obtain maternal consent
Termination of pregnancy
Offer fetal pathology

If declined offer karyotyping/DNA storage if not already performed

Fetal pathology with consent and obtained outcome
Follow up consultation (ARC offer specialise post TOP support & CRUSE offer bereavement counselling)

Planning for birth
Local and specialist centre multidisciplinary team input for active treatment or palliative care

BIRTH

Postnatal Cardiac Assessment & Treatment
Confirm diagnosis
active treatment or palliative care

1. Tel no: ........................................
2. Tel no: ........................................
3. Tel no: ........................................

Local team contact details
Fetal Medicine Unit
Fetal Cardiology Unit

Specialist Fetal Centre
Antenatal Registries

• There is no single Congenital Anomaly Register.

• 2 sources of data for CHD:
  
  • British Isles Network of Congenital Anomaly Register (BINOCAR) – only represent 50% of England therefore unreliable.
  
  • National Institute for Cardiovascular Outcomes Research (NICOR) – represent children who went on to have a procedure and only 30% of these children were diagnosed antenatally.

• Variation in results depend on type of defect, expertise of person screening, standards of equipment, gestation and maternal Body Mass Index (BMI).

• Variable uptake of national (FASP) guidelines.
Antenatal Registries

- Public Health England (PHE) intend to develop a national registry to give full national coverage.

- Providers will then have a denominator for comparison, and this should support targeted action both by providers, commissioners and PHE.
Antenatal screening: Training (1)

- **Initial screening and detection**: better detection requires some antenatal sonographers to be up skilled to FASP standards

- **Training to support 2010 FASP standards**
  - Regional approach, funded by FASP.
  - Previously supported by either TinyTickers or local fetal cardiologists.
  - Content based on FASP specification
Antenatal screening: Training (2)

- Survey (2012) showed:
  - Training variable depending on provider
  - Many practitioners trained in 3VT view even though not part of the spec at that time.
  - 3VT used but not reported routinely.
- Further work needed to identify training requirements and develop plan to support new standards.
- Need to involve Health Education England (HEE) and Local Education and Training Boards (LETBs).
Standards: specialist CHD practice

• CHD service standards cover specialist pathway and refreshed as part of work of the new review.

• Reflect NHS FASP and British Congenital Cardiac Association (BCCA) recommendations.
Neonatal Testing (1)

- Not all CHDs can be detected antenatally and some get missed.
- Detection after birth currently involves a cardiovascular examination as part of new-born and infant physical examination (NIPE) which involves listening to the heart, checking pulses and feeding.
- Newborn screening (above) detects less than half of all CHDs before discharge home.
- Some form of new born screening will remain clinically effective and cost-effective until antenatal detection rates are above 85-90%.
Neonatal testing (2)

- Proposal to add **pulse oximetry** to NIPE to pick up more cases of CHD who are likely to present clinically between 24 and 48 hours after birth.

- Pulse oximetry is non invasive and involves placing a probe on the babies foot which detects the oxygen levels circulating in the babies blood.

- Currently 1 in 5 hospitals have implemented the test.

- Some concerns about “false positives” creating additional burden.
Neonatal testing (3): Case study

Birmingham Women’s Hospital

Implemented pulse oximetry 4 years ago:

- 8,000 deliveries a year
- Of which 60 newborns detected
- 4 out of 5 of those who test positive have a significant problem that requires medical intervention.
- 1 out of 5 perfectly healthy (i.e. 12 out of 60 p.a.)
- So only 12 out of 8,000 babies screened each year are healthy “false positives” - these are identified quickly and no further treatment required.
Neonatal Testing (4)

- UK National Screening Committee review of neonatal testing expects to complete March 2014; recommendation not known
- Evidence suggests pulse oximetry clinically useful and increases the number of CHD defects detected but optimal approach not clearly defined.
- Concern that high false positive rates require:
  - additional work (with resource implications) to confirm diagnosis; and
  - additional counselling / reassuring parents.
Neonatal Testing (5)

- More information needed on management pathways for newborns with screen positive results and on the outcomes for newborns with non-cardiac conditions.

- Potential for pilots to explore the issues including:
  - the information requirements of parents and health professionals;
  - training needs for midwives and others involved in using pulse oximetry;
  - data and systems requirements for audit, quality assurance and monitoring of longer term outcomes; and
  - resource implications arising from pulse oximetry screening.
Build on/align with previous CRG Pathfinder bid

We understand that Pathfinder bid aimed to improve patient pathway from the detection through to treatment, in particular:

- reducing variation in antenatal detection rates;
- improving onward referral for diagnosis, counselling and management;
- scoping access to fetal cardiology services; and
- developing a network model with Local and Specialist Children’s Cardiology Centres.

The pathway includes:

- obstetric screening fetal anomaly scan (as per FASP guidelines);
- fetal medicine and fetal cardiology services;
- obstetric and neonatal services for the delivery and early postnatal care of a baby with a cardiac abnormality;
- paediatric cardiology and paediatric cardiac surgery services; and
- genetic services will also be involved in some cases.
Initial development of Plan (1)

- NHS England to facilitate multi-agency working to support improved antenatal testing
  - Establish co-ordinating group
  - Provide project support
- Discuss with HEE: responsible for sonographer training.
- Discuss with PHE: responsible establishing central registry, and NIPE.
Initial development of Plan (2)

- FASP/NSC: new guidelines on screening and connect early detection with specialist services.

- New CHD review: standards for specialist services – pathway, communication; counselling.

- CRG: specification; pathfinder bid?.

- Clinical commissioning groups (CCGs): routine maternity services including early detection and have responsibility for clinical governance.

- Await outcome of UK NSC review of neonatal testing.