Increasing Early Screening and Detection of Congenital Heart Disease.

Clinical Advisory Panel
18 December 2013

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Antenatal testing: baseline

- Only 35-50% of heart problems which could be detected are picked up at 20 week anomaly scan – a low detection rate amongst all congenital anomalies
- Detection rates vary across England
- Variable uptake of national (FASP) guidelines
- Congenital Anomaly Registries only exist in some parts of country so incidence data is patchy.
- BINOCAR, the National Congenital Anomaly Register, only covers about 50% of England, so comparisons are not robust.
- 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
Why does this matter?

• Early detection of congenital heart disease ensures booking of the pregnant mother at a major unit linked to a Paediatric Cardiac Surgical service

• managed process
• reduced morbidity / ?mortality
• fewer emergency transfers at birth
• better family experience throughout pathway
Training 1

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

- **Specialist confirmation / diagnosis**: higher specialist scientific cardiac echocardiography levels training programmes include developing skills knowledge and competence in the detection and diagnosis of cardiac congenital abnormalities.
Training 2

• Training to support 2010 FASP standards
  • Regional approach, funded by FASP.
  • Previously supported by either Tiny Tickers or local fetal cardiologists.
  • Content based on FASP specification

• 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 HEE and LETBs
Standards: screening

• Standards for screening are set by FASP – currently NUSS 2010 [http://www.fetalanomaly.screening.nhs.uk/standardsandpolicies](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 view. Approval by UK NSC anticipated c. May/June 2104
Standards: specialist CHD practice

- Safe and Sustainable standards cover specialist pathway
- Reflect FASP and BCCA recommendations
- Refreshed as part of work of the new review
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.

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
Inform women and Multidisciplinary Team Counsel on options including further testing, continuing the pregnancy and termination of pregnancy

No abnormality detected
Continue with pregnancy care

Reflux screening pathway post delivery

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

No abnormality detected
Continue with pregnancy care

Isolated CHD/CHD and additional anomalies confirmed
Refer to Fetal Cardiologist/Fetal Medicine Centre
Inform women and Multidisciplinary Team Counsel on options including further testing, continuing the pregnancy and termination of pregnancy

No abnormality detected
Continue with pregnancy care

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

No abnormality detected
Continue with pregnancy care

Isolated CHD/CHD and additional anomalies confirmed
Refer to Fetal Cardiologist/Fetal Medicine Centre
Inform women and Multidisciplinary Team Counsel on options including further testing, continuing the pregnancy and termination of pregnancy

Woman declines further tests or further tests not appropriate

Woman chooses further prenatal tests (may include amniocentesis/karyotyping)
Inform woman of results
Counsel on options with multidisciplinary team input as required
Continue with pregnancy management

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

BIRTH
Postnatal Cardiac Assessment & Treatment
Confirm diagnosis
Continue with pregnancy management

Obtain maternal consent
Termination of pregnancy
Offer fetal pathology
If declined offer karyotyping storage if not already performed
Fetal pathology with consent and obtain outcome
Follow up consultation (ARC offer specialised post TTO support & CRUISE offer bereavement counselling)

Local team contact details
Tel no. ____________________________
Fetal Medicine Unit
Tel no. ____________________________
Fetal Cardiology Unit
Tel no. ____________________________
Specialist Fetal Centre
Neonatal testing

• NSC review of neonatal testing expects to complete March 2014.
• 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
  • Additional counselling / reassuring parents

• More information needed on management pathways for newborns with screen positive results and on the outcomes for newborns with non-cardiac conditions.
• Recommends 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.
  • resource implications arising from pulse oximetry screening
CRG Pathfinder bid

• Aims 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
  • 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
  • genetic services will also be involved in some cases.
Plan

• NHS England to facilitate multi-agency working to support improved antenatal testing
  • Establish co-ordinating group
  • Provide project support
• HEE: responsible for sonographer training
• PHE: responsible establishing central registry
• FASP/NSC: new guidelines on screening and connect early detection with specialist services
• New review: standards for specialist services – pathway, communication; counselling
• CRG: specification; pathfinder bid
• CCGs: routine maternity services including early detection and have responsibility for clinical governance
• Await outcome of NSC review of neonatal testing