



Best Practice in Congenital Heart Disease: antenatal screening, diagnosis and audit

Summary of Issues

- 1 in 145 (or 6.9/1,000) babies are born with Congenital Heart Disease (CHD), on average¹
- In the UK, this affects approx. 4,750 babies per annum, based on current birth rates (690,013 births in the UK in 2007 – a 3% increase on 2006 [ref.: www.statistics.gov.uk])
- About half of these babies have serious CHD, requiring surgery / catheter within first year of life. Antenatal detection allows many of these babies to have better outcomes²⁻⁷
- c. 30% of babies with serious CHD have duct-dependent lesions which are life threatening and they will have significantly better outcomes if detected and diagnosed antenatally²
- Serious and life-threatening defects are missed as often as less serious ones^{2,3}
- Current UK-wide screening for CHD **misses** about 70% of all babies born with CHD and there is widespread postcode inequality³

Benefits of improved antenatal cardiac screening

About 670 babies with life threatening CHD are born every year in the UK. If not detected early, they will collapse in the first few days of life as their arterial duct closes and may suffer mortality or morbidity - ranging from poor quality of life to increased risk of brain damage, requiring more hospitalisation & specialist care.

Improved antenatal cardiac screening will improve the quality of life of these babies, allow medical services to avoid emergency situations and brings further benefits to families.

With antenatal detection	Without antenatal detection
Parental involvement - enables parents to be informed and involved; support from relevant agencies	Shock of baby collapsing - severe impact on families: lack of information; uncertainty about future; not knowing where to go for support/advice
Planned delivery in the right place at the right time	Undiagnosed emergency – cost of emergency services; baby may be distant from suitable expertise (increasing delay); delayed diagnosis worsening outcome
Earlier intervention - improved quality of life and less time spent in hospital	Delays, greater damage, illness, or death Poorer quality of life and increased risk of brain damage (need for more hospitalisation and specialist care)



Recommendations for best practice in antenatal screening, diagnosis and audit

We present six recommendations for improving antenatal screening, diagnosis and audit of congenital heart disease to give hundreds of babies a better start in life every year.

This is also shown in the Diagram on the following page.

1. Standardised Training and Accreditation for all health professionals, using a systematic approach to screening and diagnosis (e.g. the Five Transverse Views⁹).

- Standardise training of sonographers/midwives in cardiac screening at the ‘20-week’ scan
- Exit exam for local “gatekeepers” and specialists performing fetal cardiac diagnosis

This involves: Universities, Consortium for the Accreditation of Sonographic Education (CASE), National/regional screening programmes and Professional bodies. This crosses borders and must be UK-wide, not just regional (e.g. Bristol University trains Welsh sonographers).

2. Hospital screening protocols and practice should reflect this standardised training and support sonographers to screen the fetal heart to a higher standard.

Audit and digital data collection (ideally a sweep of the fetal heart) should be mandatory; Consent from women for antenatal audit collection should be part of screening protocols.

3. Standard referral protocols need to be developed for referral of suspected cases of CHD, to know how and when to refer and give screeners a sense of ownership. Feedback from referrals (via audit) is essential to improve performance and highlight training needs, particularly if original sweep is retrieved for review.

4. Local “gatekeepers”: Sonographers may refer to local obstetric/radiology “gatekeepers”, to identify false positives. This should not create a bottleneck or fail to refer true positives. Local gatekeepers should have appropriate standards for accreditation, audit and feedback.⁸

5. Diagnostic Specialists: Referral to tertiary centre for diagnosis should be timely and effective, with accredited specialists and standard audit, reporting and feedback.

6. Closing the audit loop: Antenatal audit captured at all stages of the patient pathway (referral, diagnosis, missed cases) via CCAD, BINOCAR & Mortality registers can improve screening, diagnosis and care by monitoring performance and identifying training and resource needs at all stages.

Steering the process

Following our workshop at the RCOG, Tiny Tickers & advisors are creating a patient pathway, to inform teaching courses and relevant organisations and to lobby for national standards.

This will also be built on guidelines produced by the AEPC (European Association for Paediatric Cardiologists) and by ISUOG (International Society of Ultrasound in Obstetrics and Gynaecology) for all those performing fetal cardiac scanning.

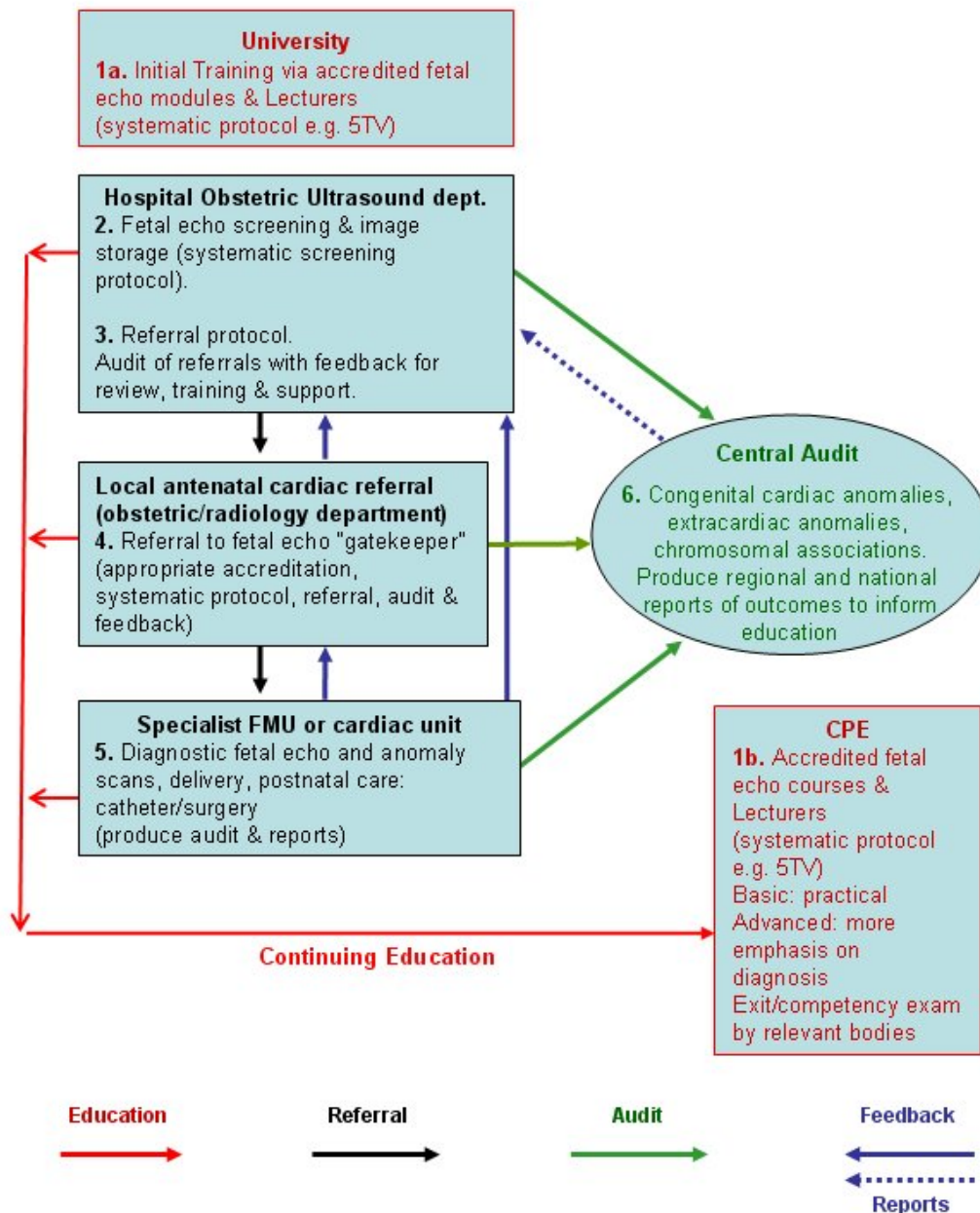
Who needs to know this information to effect change?

- Health Commissioners, PCTs, National Directors (“Cardiac & Children’s Czars”)
- Health professional bodies (BMUS/ CASE/ Universities/ SoR/ RCOG / GPs etc.)
- CHF members, Parent-groups, CVC, the press and public



Diagram

Recommendations for Initial and Continuing Education, Audit and Reporting of Congenital Heart Disease





APPENDIX

Life threatening CHD

Based on a 20 year demographic study in the Northern region of 5% of the UK population¹

- 690,215 live births (i.e. equivalent to UK births in 2007)
- 4,444 were diagnosed in infancy with CHD (6.4/1,000)
- **669 (c. 15% of babies with CHD) had life threatening CHD (see Table, below) and will have significantly better outcomes if detected antenatally²⁻⁷**

CHD conditions	Detected by 4-chambers or Outflow Tracts (OT) view	Total
coarctation of the aorta ⁶	OT	170 *
transposition of the great arteries ⁵	OT	170 *
hypoplastic left heart ⁷	4-chambers	83
pulmonary atresia with ventricular septal defect	4-chambers	48
interruption of the aortic arch	OT	41 *
total anomalous pulmonary venous connection	Veins (if isolated)	38
pulmonary atresia with intact ventricular septum	4-chambers	33
tetralogy of Fallot	OT	33 *
aortic valve stenosis	4-chambers / OT **	32
pulmonary stenosis	4-chambers / OT **	21
Total		669

Table. Life threatening CHD (duct dependent lesions)¹

* Over 60% of life threatening lesions are only detected by Outflow Tracts screening

** can be detected by 4-chambers if severe, but only by Outflow Tracts if less severe

Implications for updating hospital screening protocols

Many hospital screening protocols **do not** routinely include the Outflow Tracts and so major life-threatening lesions continue to be missed. More than 60% of life-threatening CHD can only be detected by screening the Outflow Tracts.

NICE Guidelines for antenatal cardiac screening 2008⁸ include a requirement to include the Outflow Tracts in routine screening. Implementation of these guidelines as soon as possible is vital.

References

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9. Yagel S, Cohen SM, Achiron R. Examination of the fetal heart by five short-axis views: a proposed screening method for comprehensive cardiac evaluation. *Ultrasound Obstet Gynecol* 2001; 17(5):367-369