NHS
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Fetal Cardiology Handbook

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1.0: Introduction

The University Hospitals Bristol (UHBFT) NHS Foundation Trust Fetal Cardiology Service provides a tertiary level screening and diagnostic service to the 22 obstetric ultrasound departments within the South West and South Wales region. The provision of a timely and accurate diagnosis aims to facilitate informed choice to women and their families affected by fetal Congenital Heart Disease (CHD).

The fetal cardiology service has two key components which consist of a diagnostic service to provide diagnosis, counselling and support to women when a fetal cardiac defect is detected and the screening service provided to those women at a higher risk of developing fetal CHD.

It is vital that tertiary fetal cardiology services offer evidence based, high quality, standardised care and the following handbook reflects the UHBFT commitment to providing this level of care.

2.0: Background

Congenital Heart Disease (CHD) is known to be among the most prevalent anomalies detectable in fetal life (Yagel et al 2001) with as many as 8 per 1000 live births affected (British Heart Foundation BHF 2009).

Ultrasound screening is currently the most sensitive and reliable modality used to facilitate the pre-natal detection of fetal CHD (Sharland 2004) with the objective being to identify fetuses with major lesions for which postnatal cardiovascular surgery or palliation is required. Screening for congenital cardiac malformations has developed to facilitate enhanced reproductive choice and appropriate care/management
to women and their families (National Institute Clinical Excellence NICE 2008). Research evidence has also demonstrated that anticipatory care plans for delivery and immediate neonatal care have the capacity to prevent life threatening clinical deterioration prior to surgery (Bonnet et al 1998, Verheijen et al 2001 and Franklin et al 2002).

3.0: Service Remit

To provide screening and diagnostic fetal cardiology services to women and their partners within the SW and referring region (referrals are welcomed from outside of this region). The provision of a timely and accurate diagnosis aims to facilitate informed choice to women and their families diagnosed with fetal CHD.

3.1: Service Aims

- To establish normality or the presence of CHD in an accurate and timely manner.
- To detect the presence of structural, functional or rhythm abnormalities and provide a full and accurate diagnosis.
- To initiate prenatal treatment where applicable.
- To provide non- directive counselling and support services to women diagnosed with fetal CHD.
- To facilitate ongoing pregnancy care to those women wishing to continue their pregnancy following diagnosis of fetal CHD.

- To facilitate onward referral and where appropriate ongoing care to those women wishing to end their pregnancy following diagnosis.
- To facilitate onward referral and where appropriate ongoing care to those women wishing to continue their pregnancies but choose palliative care post-delivery.
- To facilitate close liaison with all multidisciplinary team members involved in the woman's care particularly regarding follow up and outcome information.
- To develop and maintain the regional cardiac network.
- To develop a robust method of outcome data collection and to undertake regular audit and service assessment.
- To provide high quality patient information to those women accessing the service.
- To facilitate teaching and education on a local and regional level.
- To enter a data sharing agreement with the National Institute for cardiovascular Outcome Research (NICOR) and The National Congenital Anomaly and Rare Disease registration Service.
- To adhere to national standards and protocol as a mandatory requirement (NHS England Congenital heart Disease Standards and Specifications (2016) and the British Congenital Cardiac Association BCCA guidelines 2012)

4.0: Service Staffing and Requirements

The service will be run and staffed by a dedicated multidisciplinary team trained in the detection and management of Fetal Congenital Heart Disease. All staff must have a good understanding of the process, research evidence and legal framework pertaining to prenatal cardiac screening and diagnosis.

Staff	Requirements (in accordance with BCCA 2012) & (NHS England Congenital Heart Disease Standards and Specifications 2016)
Service Leads	Designated paediatric cardiology consultant(s) with a special interest and expertise in fetal cardiology, who have fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology Special Advisory Committee (SPC) or the Association of European Paediatric Cardiologists
Fetal Medicine Cardiac Lead	A designated fetal medicine consultant will provide ongoing care, counselling and support to women with fetal congenital heart disease.

Health Professionals performing scans	Health professionals performing ultrasound scans in a screening or diagnostic capacity must have a formal ultrasound qualification including training regarding the safe and appropriate use of ultrasound. Supervision will be provided by the service leads and associated consultants in the Fetal Medicine Unit. The degree of supervision required will be assessed by the service lead. Trainees working within the service must be supervised at all times whilst performing ultrasound scans. The following health professionals can perform ultrasound scans within this service: • Specialist Cardiac Registrars • Sub Speciality Fetal Medicine Registrar's • Sonographers
Specialist Support Practitioners	Designated Cardiac Nurse Specialists will be accessible to patients in the event of an abnormal finding. Their role involves providing on going information and support to families and acting as a direct point of contact.
Administration	Dedicated administration support is provided.

5.0: Related Services

Well established links with the following services are integral to the function of the fetal cardiology service:

- Paediatric Cardiology and Cardiac Surgery/Intervention Team
- Cardiac Nurse Specialists
- Fetal Medicine Unit
- Maternity Services
- Neonatal Unit
- Ultrasound Department
- Genetics Department
- Pathology Department
- Social services and support services
- Charities and national support groups
- Regional cardiac network and paediatricians with an expertise in cardiology (PECSIG)

6.0: Ultrasound Machine Specification

Equipment	Specification
Machine Screen Display Console Ergonomics	Flat screen, LCD or similar monitor – high definition. Adjustable Easily accessible, streamline, customisable (height adjustable) Repetitive Strain Injury (RSI) considerations. Light weight Transducer. Slave Monitor.
Transducers	Curvilinear, broadband, pulsed, high pulse repetition frequency (PRF). Spatial/Frequency compounding. Beam steering – multidirectional.
Storage	Extensive Cine-Loop function. Hard Drive storage. CD/DVD writing and display equipment. Ability to save in JPEG, DICOM and PC format.

Instrument Functions	2D Functions to produce reproducible, quantifiable images Advanced Read/Write Magnification – improved resolution and definition using small field of view. Ability to adjust magnification box size. Capability to produce short pulse lengths/ improved axial, spatial and contrast resolution. Focal zone control/improved lateral resolution. Contrast/Compression/Persistence control. Calliper measurements accurate to 0.1mm
Image Optimisation	Spatial and Frequency Compounding Tissue Harmonics – Increased sensitivity/resolution 2D Image Optimisation Tissue Aberration Correction Compatible with 2D and Doppler Mode.

M Mode	M Mode Capability
Doppler Imaging Spectral Colour Power	Advanced Triplex Imaging with an acceptable frame rate. High resolution colour flow imaging (Advanced Dynamic Flow). Tissue Doppler Imaging – High amplitude low velocity signals of myocardial motion?

7.0 Ultrasound Safety and Internal Quality Assurance of Equipment

The ultrasound equipment used meets national specification guidelines (RCR 2014) and is only operated by qualified health professionals trained in its usage or under the supervision of those trained in its usage

Health professionals adhere to British Medical Ultrasound Society (BMUS 2009) guidelines for the safe use of diagnostic ultrasound equipment

Ultrasound equipment must be maintained for working use via internal quality assurance. This is achieved in collaboration with the Radiology and Medical Physics Dept.

8.0: Clinical Service Provision

The UHBFT Fetal Cardiology service clinical guidelines (Diagnostic/Therapeutic and Screening) compliment this document and can be accessed via the fetal cardiology workspace. The information below regarding clinical care and service management is congruent with the service guidelines.

8.1: Referral Criteria

Research evidence highlights that the majority of cases of Congenital Heart Disease occur in the low risk population (Chaoui 2003) for whom a robust local screening programme (in the form of the 18+0-20+6 week anomaly scan) is provided in adherence to the NHS Fetal Anomaly Screening Programme (FASP) 2018 guidance and the National Institute of Clinical Excellence (NICE 2008) Antenatal Guidelines. Referrals in this group are accepted when either an abnormality is suspected or inadequate images are obtained. These referrals are treated as urgent.

It is also known that there are risk factors associated with CHD and the following criteria are accepted as referral criteria for those women at a higher risk of fetal CHD. These criteria also adhere to the BCCA (2012) and BHF (2009) guidance.

8.2 Referral Timeliness

Urgent Referrals: See referrals within 3 calendar days and preferably 2 following detection of cardiac abnormality. (NHS England 2016, BCCA 2012)

Screening Referrals: (for those women at high risk of CHD): 18+0-20+6 weeks of gestation, clinical discretion can be used to with regard to earlier referrals.

Extenuating Circumstances:

Routine referrals received after 20+6 weeks will be seen in the next available clinic unless the referral is urgent (in which case it will be triaged as detailed above).

8.3 Appointment Duration

Appointments will be a minimum of 45 minutes in duration (UHBFT local policy decision based on expert opinion and current resource availability)

Appointments for multiple pregnancies will be duration of 45 minutes per fetus.

8.4 Appointment Administration

Please refer to the fetal cardiology administration Standard Operating Policy

Urgent appointments must be booked onto the attending consultants FC or FCU clinic on Medway. Once attended the follow up must be recorded on Medway to ensure the appointment is listed and charged appropriately**.**

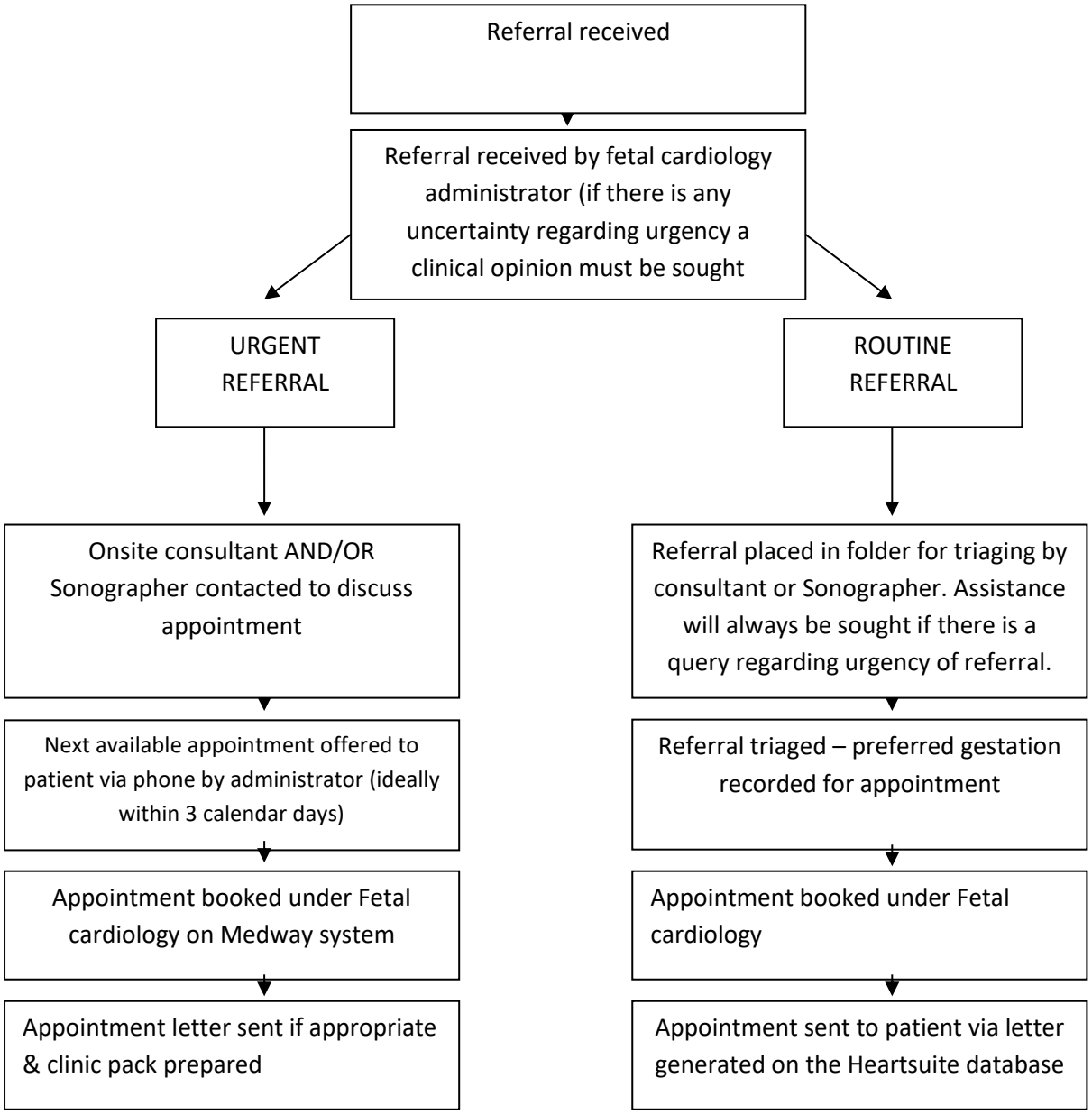
Routine screening appointments must be booked onto the attending/covering consultants FC clinic or the screening sonographer clinic on Medway. Once attended the follow up must be recorded on Medway to ensure the appointment is listed and charged appropriately.

8.5: - Referral Criteria

Maternal/Familial Indications	Fetal Indications

• Maternal /Paternal Congenital Heart Disease (CHD)
• Maternal Metabolic Disorders
  ○ PKU
  ○ Diabetes Mellitus- Type I /Type II /Gestational – **Only if Poorly controlled – HbA1c >6%**
• Maternal Exposure to:
  ○ Cardiac Teratogens
  ○ Anticonvulsants
  ○ Lithium
  ○ Retinoic acid
  ○ ACE Inhibitors
  ○ Anticonvulsants
• Maternal Collagen Disease
  ○ Anti Ro/SSA or Anti La/SSB
• Maternal Viral infection
  ○ Rubella
  ○ CMV
  ○ Coxsackie
  ○ Parvovirus
  ○ Toxoplasma
• Maternal NSAID after 25 weeks
• Previous child with CHD or congenital heart block
• First Degree relative with CHD
• Familial chromosomal or genetic conditions related to CHD.
• In Vitro fertilisation.
	• Suspicion of a fetal cardiac abnormality
	• Extra cardiac malformation
	• Chromosomal aberration + genetic syndromes
	• Nuchal Translucency > 99th centile for gestational age (3.5mm)
	• Monochorionic Twins
	• Fetal Arrhythmias
	• Pericardial Effusions
	• Pleural Effusions
	• Polyhydramnios
	• Fetal Hydrops
	• Other states known to cause fetal cardiac failure:
	  ○ Absence of Ductus Venosus
	  ○ Acardiac Twin
	  ○ Twin to twin transfusion

8.6: Referral Pathway



8.7: Fetal Echocardiography Scan Procedure

The following details the baseline procedure and serves as a guide only; clinical and professional discretion as per the procedure must be exercised. For full scan procedure see the fetal echocardiography SOP

The ultrasound images must be of an acceptable quality to confirm or exclude abnormality. Images compromised by fetal or maternal factors must be assessed on an individual basis and further ultrasound investigation is facilitated ideally within the next available clinic or at the attending consultant's or sonographers discretion.

8.8: Image and Database Storage

The women's attendance will be recorded on the UHB Medway system and the cardiology database Heart Suite. All ultrasound findings proved to be normal should be recorded on a database in line with the NHS data protection act. Formal reports and a digital recording of every scan must be maintained and securely stored for 25 years. Disposal after this time must be confidential according to the Department of Health records management guidance

Where images are stored for teaching purposes the woman will be informed and consent documented. Information pertaining to the storage of images for teaching purposes will be provided in the patient information leaflets.

Mandatory data items for the fetal dataset required by NICOR are to be completed in the Heartsuite system by the consultant who confirms the diagnosis and are to be uploaded to NICOR by the administration staff within 1 month of diagnosis.

All new diagnosis should be uploaded to the NCARDRS database via the online data collection portal, by the administrative staff.

Where a fetal echocardiogram had been undertaken by the cardiac sonographer, the echo should be reviewed by the fetal cardiology consultant on the day the echo has been performed. This is an internal quality assurance mechanism.

8.9: Care following the Echocardiogram

The findings of the ultrasound examination must be clearly communicated to the woman and if she wishes , those attending with her. This must be undertaken in an appropriate manner for the woman considering language, sensory and cognitive requirements. Where necessary cardiac nurse specialist support will be provided.

Normal Findings: This must be explained to the woman alongside the limitations of fetal echocardiography.

A formal report must be generated. This is ideally completed on the day of attendance however if this is not possible the woman's attendance must be documented in the hand held pregnancy notes (UHBFT Local Policy).

Once generated the report should be sent to the woman, her referring clinician and GP ideally within 5 working days of the appointment. This should be undertaken with the woman's consent.

Abnormal Findings: In the event that a fetal cardiac defect is detected the woman must be provided with adequate written and verbal information, counselling and support. This must be undertaken in an appropriate manner for the woman considering language, sensory and cognitive requirements (NHS FASP 2018)

8.10: Ongoing Care and Management – ***Please refer to the service guideline for specific practice, the following information provides an overview only***

Normal Findings: No follow up or ongoing care/management

Abnormal Findings - Cardiac Nurse Specialist support must be provided at the time of diagnosis or if not available a telephone consultation offered for the same day

Continuing Pregnancies:

Following diagnosis a care plan will be agreed between the fetal cardiology service, the cardiology surgical service, the allied fetal medicine unit, the referring obstetric unit, the neonatal team and paediatricians and the women and family regarding the ongoing care and delivery. This care plan will be updated throughout the pregnancy. Women will be supported throughout this process by specialist consultant and cardiac nurse specialist support

Due to the complexities of congenital cardiac defects care and delivery location plans will be individualised and updated throughout the pregnancy. The woman and her family will be provided with counselling and information following each fetal cardiology appointment during the pregnancy.

If appropriate the woman and her family will be offered appointments with the paediatric surgical team, neonatologist or clinical geneticist.

Following delivery all outcomes will be recorded on Heart Suite and maternal/child records must be linked (UHBFT local policy).

32 Week Joint Appointments for delivery and surgical care planning:

Women continuing their pregnancies will be offered an appointment at 32 weeks of pregnancy with fetal cardiology and fetal medicine (UHBFT local policy). Where possible this appointment will be offered on the same day.

This appointment aims to finalise delivery care plans and allow fetal medicine assessment of the fetus in terms of inter-uterine growth and wellbeing.

Where possible the CNS will be present at this appointment to ensure women and their families can visit the delivery suite, neonatal intensive care unit, paediatric intensive care unit and children's cardiac ward 32.

Palliative Care

Following diagnosis a care plan will be agreed between the fetal cardiology service, the cardiology surgical service, the allied fetal medicine unit, the referring obstetric unit, the neonatal team and paediatricians and the women and family regarding the ongoing care and delivery. This care plan will be updated to reflect the woman's choice to withhold treatment and completed throughout the pregnancy (BCCA 2012)

Termination of Pregnancy

Women who choose to terminate their pregnancy will be referred to either the tertiary fetal medicine unit of if appropriate a local fetal medicine unit to discuss and plan the care and treatment. Should the woman consent to an autopsy this should be completed by a pathologist experienced in CHD.

Counselling post termination or post pregnancy loss should be performed by the obstetric team approximately 6 weeks later. All outcomes must be updated on Heart Suite. Follow up should be offered with the fetal cardiologist to discuss post mortem findings, if the patient wishes.

8.11: Women who do not to attend appointments

Non-attendance is documented within clinic records and on the Medway system. Due to the possible sensitivities surrounding non-attendance a formal letter must be sent to the referring clinician. This letter must be copied for filing. Where appropriate the woman and her family may be contacted to discuss non-attendance.

9.0: Information Provision

Screening for fetal anomalies during pregnancy can have significant clinical and emotional consequences and therefore it is vital that a rigorous approach to information provision and the facilitation of informed consent is required (NHS FASP 2018). The following initiatives will be utilised within the fetal cardiology service to achieve a high standard of information provision.

- Fetal Cardiology Appointment Letters: Information pertaining to the place, date and time of the appointment is included alongside a summary of the reasons for undertaking a fetal echocardiogram. The referral is undertaken in the district hospital setting and it is therefore the responsibility of the referring clinician to ensure the woman understands the need for referral and consents to a referral being initiated.

- Information Leaflets: In addition to the appointment letter a fetal cardiology information leaflet will also be provided including a more in depth explanation of the process this can be used within the district hospital at the time of referral.

- Post Fetal Echocardiogram Information (Normal Findings): The woman and those who accompany her will be informed of the findings of the scan immediately after the scan has been undertaken, this will be explained verbally and a written report will be issued (the written report may follow after the initial appointment depending on the scan findings). This will include an explanation of the limitations of the scan.

- Post Fetal Echocardiogram Information (Abnormal Findings): It is vital that appropriate and adequate information is provided in the case of an abnormal result, this should be combined with counselling and ongoing support (BCCA 2012). Counselling should be undertaken by a Consultant Cardiologist with support from an appropriately trained nurse or midwife practitioner (who should be present during the counselling session). Information should be provided in a quiet and secure environment preferably separate from the ultrasound room (BCCA 2012). The following tables details the requirements of a counselling session:

9.1: Counselling session requirements

1. Information regarding the type of cardiac abnormality including the prevalence, structural composition, function, prognosis, and surgical procedures required and long term outcomes for the child should be provided.
2. Management options should be discussed including continuing with the pregnancy and opting for surgical procedures or palliation, continuing with the pregnancy without any surgical intervention which would result in fetal demise and termination of pregnancy.
3. Emphasis must be placed on the parent's right to choose the correct option for them and their family.
4. Appropriate information must be supplied in the form of pictorial diagrams of the fetal heart and leaflets provided by the British Heart Foundation and/or Little Hearts Matter, Children's Heart Federation.
5. Appropriate contact details and follow up appointments must be communicated to the parents.

10.0: Service Governance

Processes to be followed to ensure safe and high quality running of the service. These include:

- **Monitoring outcomes of pregnancy.**
- **Compliance with incidence reporting procedures**
- **A record of compliments and complaints**

Service audits e.g.:

- **Adherence to 3 calendar day referral time**
- **Record of delays leading to altered maternal options.**
- **Lesion specific audit e.g. SVT**
- **Submissions to national databases**
- **Participation in relevant research**

11.0: References

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