Referral Pathway for Suspected Fetal Abnormality - Full Clinical Guideline

Reference No.: UHDB/ Operational/09:22/F3

Contents

1. Introduction

Where fetal anomalies are diagnosed or suspected antenatally, prompt specialist Fetal Medicine input is required to ensure that the parents receive accurate, comprehensive information and support. The involvement of staff experienced in non-directive counselling with access to diverse specialist input is essential to allow the parents to feel confident in making decisions about their pregnancy and in preparing them for the consequences of those decisions. Good communication between professionals will ensure that these women and babies are cared for in the most suitable environment.

The aim of screening for fetal anomalies is to identify specific malformations for example:

- Anomalies those are not compatible with life
- Anomalies associated with high morbidity and long-term disability
- Fetal conditions with potential for intrauterine therapy

Fetal conditions that may require postnatal investigation or treatment This then allows the parents and health care professionals to plan appropriate care for:

- Reproductive choice (termination of pregnancy)
- Parents to prepare for any treatment, disability or palliative care

- Managed birth in a specialist centre
- Intrauterine therapy

2. Purpose and Outcomes

Ensuring that when a fetal anomaly is detected, the situation is dealt with sensitively and that the woman and her family are seen in a timely manner, in an appropriate environment.

To ensure that the woman and her family are seen promptly by a Fetal Medicine Specialist. Organise onward referral to other specialist services at a tertiary centre if required. Involve neonatologists to explain a given condition to the parents and explain possible on-going care for the baby.

To ensure that the woman and her family are kept fully informed throughout the process and have the opportunity to talk fully to any relevant professionals who may be able to offer them information and support with contact number of the screening team given who can help coordinate appointments and seek the information they require.

That there is clear documentation in both the handheld maternity record and the hospital notes of management plans together with all care given, conversation and counselling undertaken. The documentation can also be included within the printed scan report and saved on the CRIS system.

To ensure that there are acceptable lines of communication between all professionals caring for the woman and her family, including,

- Fetal medicine Consultants
- Sonographers
- Obstetricians,
- Neonatologists
- Specialist teams
- Community midwife
- GP
- Health Visitor

3. Abbreviations

CRIS	–	Computerised Radiography Information System
FASP	-	Fetal Anomaly Scan in Pregnancy
FM & NN	–	Fetal Medicine & Neonatology
MDT	–	Multidisciplinary Team
NTD	-	Neural Tube Defect
OCRR	–	Ordering Communications and Results Reporting

4. Key Responsibilities and Duties

Women with suspected fetal abnormality on obstetric ultrasound examination will be seen, where possible, within 3 working days (FASP) by a Fetal Medicine consultant.

It is the responsibility of each health care individual involved in a woman's care to keep her fully informed at all stages.

5. Referral to Fetal Medicine

These are some of the common conditions where fetal medicine referral is indicated. This list is not exhaustive and if in doubt, opinion from a fetal medicine consultant should be sought after.

ABNORMAL MATERNAL SERUM SCREENING
NIPT
Quad test
Combined test

FETAL ANOMALY
Fetal congenital malformation on USS
Fetal cardiac arrhythmias
Fetal hydrops
Inherited fetal metabolic disorders
Second Opinion for Ultrasound

CURRENT/PREVIOUS PREGNANCYCOMPLICATION
Severe early onset IUGR requiring extended fetal Doppler
Maternal Anti-Ro and/or Anti-La antibodies
Rhesus and other blood group incompatibilities
Infection with parvovirus / varicella / CMV etc.
Exposure to teratogens
Previous spontaneous (non-iatrogenic) pre-term births < 36 weeks gestation
Previous LLETZ (>15mms depth) without term delivery follow this
Previous Mid T loss
Previous CS with low lying placenta /suspicion of morbidly adherent placenta
Vasa previa.
Placental localisation (posterior placenta)

COMPLEX MULTIPLE PREGNANCY
Monochorionic / Monoamniotic (MCMA) Twin Pregnancy
Monochorionic / Diamniotic (MC/DA) Twin Pregnancy
Triplet and Higher order multiple pregnancies
DCDA twins with IUGR

PREVIOUS POOR OBSTETRIC HX
Fetal anomaly
Stillbirth or IUFD to discuss with fetal medicine consultant to be seen at their discretion only

SEVERE MATERNAL MEDICAL CONDITIONS
Antiphospholipidsyndrome
Sickle Cell anaemia or G6PD deficiency
Cardiac disease in either of the parents / affected baby needing surgery
Maternal transplant
Renal failure with dialysis

The **FASP** standard is to see Fetal Medicine within 3 working days for:
Anencephaly, Neural tube defect(NTD), cleft lip, congenital diaphragmatic hernia, gastroschisis, exomphalus, cardiac abnormalities, bilateral renal agenesis, lethal skeletal dysplasia, multiple abnormalities indicating possible trisomy 18/13.

If you believe there is imminent risk of demise (gross hydrops, reversed end diastolic flow, or significant heart rate abnormality {<100 >200}) then please contact the consultant on call out of hours.

6. Documentation(See section 9)

Assessments and individual plans of care are to be documented clearly in the CRIS report and or medical records. These should include discussions with the parents and the outcomes from these discussions.
Antenatally, some of these discussions may also be documented in the maternity clinical system (Lorenzo).
Discussions between the feto-maternal team and the neonatal team in the monthly shared meetings are documented on the NN alert forms and or baby notes. These are then filed in the medical records. **See Appendix A**
Any referrals, whether to a tertiary centre or specialist neonatal services are to be documented in electronic records (Lorenzo) and a copy filed in the medical records. This is to ensure clear communication between the professionals e.g. obstetric/ neonatology/midwifery and other specialist staff regarding the care, support and management of the woman and her family.

7. Lead Carer

- If a fetal abnormality is confirmed the care of a woman under midwife led care will be transferred to the Feto-maternal consultant involved in the diagnosis/counselling after discussion with the consultant if appropriate.
- When a woman is already booked under the care of another consultant the consultant obstetrician with a specialism in Feto-maternal medicine will liaise with that consultant and a decision made as to whose care would be most appropriate. This will be clearly documented in the notes.

8. Informing Women when an Abnormality has been Detected or Suspected Poor Outcome for the Newborn

- When a fetal abnormality is diagnosed or suspected by sonographers or screening midwives at any stage of pregnancy a referral should be made at that time to a member of the Fetal Medicine Team (FM consultant, FM specialist midwife or antenatal screening midwife). In the first instance this will usually be the FM specialist midwife.

- Referrals from RDH sites will be made directly by telephone/in person to the fetal medicine department. The woman will be seen by the Fetal Medicine Team within 3 working days of the referral being received (in exceptional circumstances where not seen within this timeframe the woman will have been contacted by the Fetal Medicine Specialist Midwife for a discussion). Referral from QHB cannot be made directly by telephone/in person; a referral letter is emailed to the fetal medicine generic e-mail address and the woman can be seen within 5 working days.

- The woman/couple will be seen by the FM team (FM consultant, FM specialist midwife or antenatal screening midwife) and informed of the scan/test findings, the implications for the pregnancy & baby and available options. Ideally this initial counselling consultation will be provided by both the FM specialist midwife/antenatal screening midwife together with one of the FM consultants.

- If none of the FM team are available (for referrals from RDH sites directly), the woman's details and scan/test findings will be recorded in the FM office to enable the FM specialist midwife to make contact with her as soon as she is able to do so.

- An appointment will be made for a detailed fetal anomaly follow-up scan on a dedicated FM list. Additional regional FM services (e.g. fetal echocardiography, MRI) can be accessed and organised following this detailed scan depending upon the opinion of the FM team.

- The FM team will provide comprehensive care during the pregnancy including performing serial scans to assess the fetal condition, offering & performing invasive testing (amniocentesis/CVS) as required and planning and documentation of care, especially antenatally and at time of delivery. The FM team will be available, both in person and by telephone, to provide continued support and counselling and will provide the woman/couple with verbal and written information including access to additional support services.

- The woman/couple will be part of planning the pregnancy care and decision making and will be informed of available options throughout the pregnancy. Where necessary the woman/couple must be given time to make the right decisions for them in their pregnancy.

9. Multidisciplinary Care

- When a fetal abnormality is confirmed the specialist fetal medicine midwives will inform the community team or on call midwife by telephone and also the General Practitioner.

9.1 Referring women to neonatal/specialist services

- The Fetal Medicine Team, under the leadership of the Consultant in Fetal and Maternal Medicine will liaise with the Consultant Neonatologists to ensure appropriate planning for neonatal care and parental counselling where appropriate.
- When referral to the Neonatologist is appropriate, an appointment can be booked for consultant review.
- Cases will usually be discussed jointly at the monthly Fetal Medicine meeting.

- Urgent reviews are arranged directly with the neonatologist covering for that service week.
- Where input from other specialist services is required (e.g. Cleft Lip and Palate Surgical Team, Clinical Genetics, Paediatric Surgery) this will be co-ordinated by the Fetal Medicine Team.

9.2 Referring women to a tertiary centre where appropriate

- In some instances, referral to a tertiary centre may be required for treatment, paediatric cardiology input or a second opinion. This referral will be co-ordinated by the Fetal Medicine Team with the consent of the woman. This is documented in the maternal notes & Lorenzo.

10. Support for Women with communication/language needs

- It is essential that the woman/couple are involved in their plan of care and are included in any discussion if plans have to be changed.
- Women who do not speak English must be offered the services of an interpreter. The interpreter must be booked in advance of the consultation and informed.
- Following consultation with the woman, family members may contact the FM team on behalf of the woman should she have further concerns with her consent. The FM team will arrange a further appointment for the woman to be seen with an interpreter to discuss her concerns.

11. Record Keeping

- At the time of initial obstetric ultrasound scan the report of the ultrasound examination will be filed in the medical records and handheld records. It will also be available in the electronic records. A record of attendance is made onto the maternity computer system (Lorenzo).

- Following examination by the Fetal Medicine Specialist a report will be written in the obstetric notes or ultrasound report documenting the abnormality and the discussion with both parents with a plan of care.

- Information regarding the abnormality, if a pregnancy is to continue, is recorded in the ultrasound report on the CRIS system and copies are filed in the maternity and handheld records. The NN Alert form is duly completed after the MDT and filed in the baby notes section of the maternal health record.

- All ultrasound scan findings are entered on CRIS, two copies of this report are printed off, one is filled in the handheld records and the other filed in the maternity records. These reports can also be viewed on Lorenzo.

- There will be documented discussion of new cases at a monthly Fetal Medicine and Neonatology MDT meeting, with copies of the discussion placed in the baby notes and the 'Expected Baby file' held by the paediatric team. This will include an initial plan for neonatal care.

12. Support for parents

- It is essential that the woman/couple are involved in their plan of care and are included in any discussion if plans have to be changed.

- The FM team will meet with the woman/couple and provide full counselling regarding the scan/test findings, the implications for the pregnancy & baby and available options.

- The FM team will provide additional support, counselling and guidance, including verbal and written information, to the woman/couple and will signpost/provide information on additional support services e.g. ARC, national support groups (Spina Bifida Association etc.)

- If a decision to terminate the pregnancy has been made, following full counselling from the FM team, the FM specialist midwife and bereavement support midwife will liaise to support the woman/couple through this time & procedure.

- This will include organising medical or surgical TOP (appointments, medication), fetocide if required (pregnancy > 21 weeks gestation at time of decision for TOP), discussion of post-mortem investigations, organising disposal of fetal remains (according to couple's wishes) and

providing psychological support both during and after TOP or death of the baby. The associated documentation, including information leaflets e.g. information and advice following the loss of your baby, care plans specific to pregnancy loss, consents, covering these areas will be completed and filed in the woman's hospital notes.

- Packs relating to pregnancy loss are available on the delivery suite & fetal medicine or from the bereavement midwife.
- The bereavement midwife will be available to offer support via telephone or in person if the woman consents to this service.
- The paediatric team will be alerted about all ongoing pregnancies after 22 weeks gestation with known/suspected fetal abnormalities through the monthly FM MDT meeting (2nd Monday lunchtime). Where required, an appointment to meet with the woman/couple antenatally will be made by the FM specialist midwife to provide information relating to the care and support which will be available following birth of the baby.
- Midwives will be sensitive to the needs of the woman/couple, respecting their choices and providing emotional support, empathy and guidance as needed.
- If the delivery results in an unexpected poor outcome, support for the parents will be offered by the relevant specialty.

13. Neonatal team management plan

13.1 Antenatal involvement

- After request from fetal medicine team, the neonatal consultant on call will meet the couple to discuss the neonatal management of the unborn child with suspected fetal abnormalities. All discussions including details about resuscitation plan will be recorded in the maternal notes and feedback to fetal medicine/obstetric team. The management plan may be updated if needed. In case of impending delivery, the neonatal consultant also informs the neonatal nurse in-charge and the rest of the neonatal team about the expected problems and management plan as appropriate.

13.2 Involvement during delivery

- Neonatal team involvement will be needed for all significant problems and the place of postnatal care will be decided as per MDT discussion. In cases of stillbirth, if parents decline post-mortem, the obstetric team may request assessment by neonatal SpR or consultant to help identification of suspected syndrome.

13.3 Postnatal management

- Postnatal management will be carried out as per existing management plan (sometimes changes to plan may be needed according to clinical condition).
- If no plan is available, neonatal consultant on-call will make appropriate management plan. This may involve discussion with obstetric/fetal medicine team and paediatric specialist (like cardiologist, geneticist, surgeons etc. as appropriate). The woman will be updated by neonatal senior doctor (SpR or Consultant) soon after delivery of the baby with fetal anomalies. After discharge from hospital, follow-up will be arranged as needed along with the provision of information leaflets regarding support services in the community.
- In case of life-limiting conditions, the neonatal consultant will make appropriate emergency care and resuscitation plan after discussion with parents, this discussion must be documented in the baby notes. (**see palliative care pathway**)
- In case of neonatal death (with fetal abnormalities), parents will be provided support by the neonatal team (along with support from fetal medicine / obstetric/midwifery / bereavement team). Death certificate will be issued as appropriate and need for post-mortem discussed.
- All discussions with parents must be documented in the baby notes.

14. Monitoring Compliance and Effectiveness

Monitoring requirement	Where a Fetal abnormality has been detected health records of women will be reviewed on an individual basis and data recorded on a local database
Monitoring method	Prospective case note review
Undertaken by	Specialist Midwives in Fetal Medicine Specialist Midwife in Antenatal Screening Consultant Lead in Fetal Medicine
Monitoring report sent to:	Trust Antenatal and Newborn Screening Board and the National Screening Committee
Frequency of report	Annually

15. References

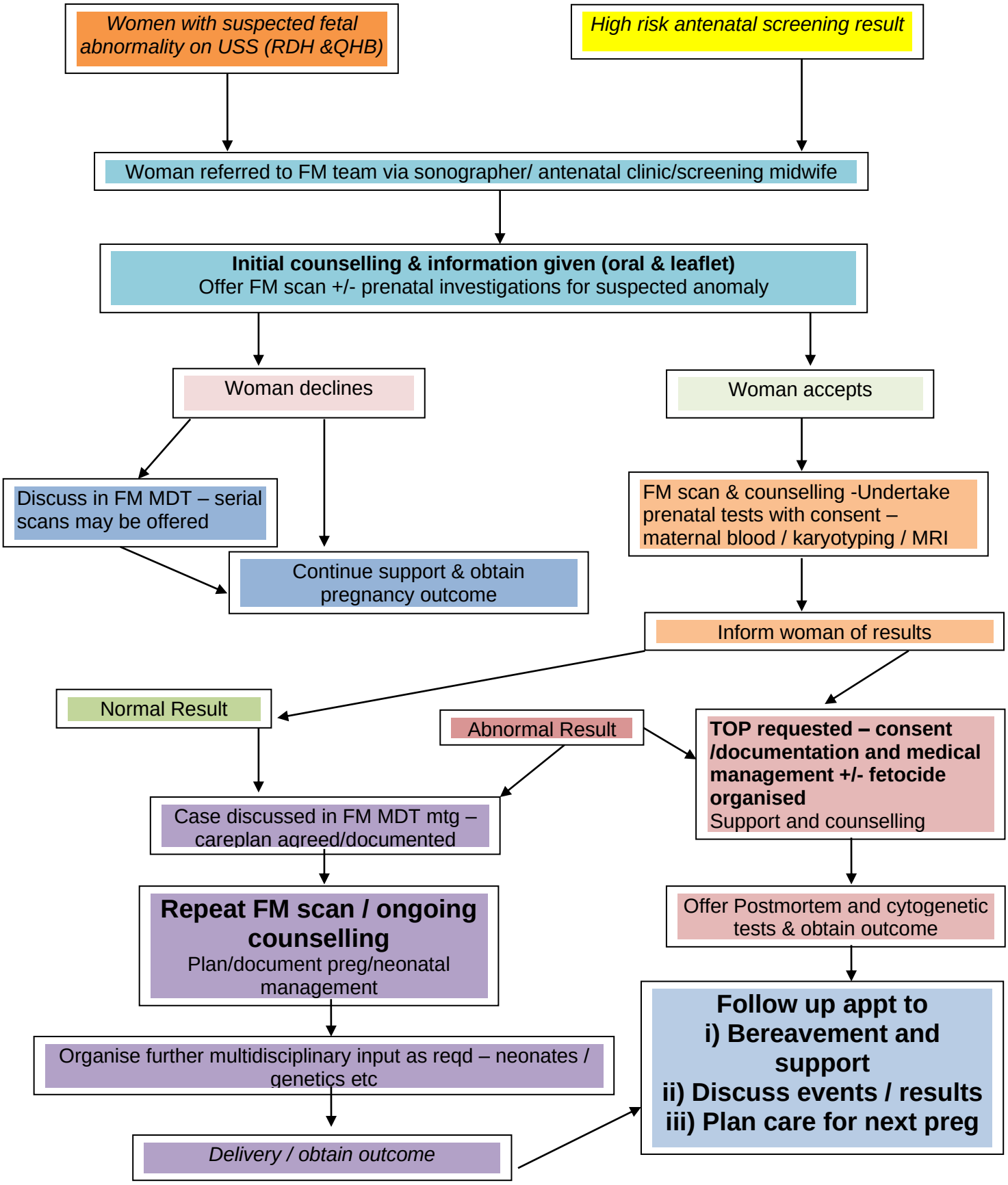
National Institute for Health and Clinical Excellence. (2008). *Antenatal care: Routine care for the healthy pregnant woman*. London: NICE. Available at: www.nice.org.uk

Royal College of Anaesthetists, Royal College of Midwives, Royal College of Obstetricians and Gynaecologists, Royal College of Paediatrics and Child Health. (2007). *Safer Childbirth: Minimum Standards for the Organisation and Delivery of Care in Labour*. London: RCOG Press. Available at: www.rcog.org.uk

National Standards and Guidance for England, London (2010) *NHS Fetal Anomaly screening Programme – 18+0 to 20+6 weeks Fetal Anomaly Scan.*

Royal College of Obstetricians & Gynaecologists (2008) *Standards for Maternity Care: Report of a Working Party.* RCOG Press, London, June 2008.

FETAL ABNORMALITY – flowchart



Contact Details for FM Team

NAMES	CONTACT No.
Ms Ashworth (consultant - FM lead)	Via switchboard
Ms Hamilton (consultant)	Via switchboard
Mrs Dent (consultant)	Via switchboard
Ms Raouf (consultant)	Via switchboard
Ms Devendran (consultant)	Via switchboard
Claire Davenport (lead midwife)	Extn-85409
Carol Adcock (midwife)	Extn-85409
Abigail Whitehall (midwife)	Extn-85409
Sarah Noble(midwife)	Extn-85409
Verity Bradshaw (midwife)	Extn-85409
Paulina (HCA)	Extn-85409

Antenatal Results and Choices (ARC) 0171 631 0285

Stillbirth and Neonatal Death Society - Sands National Helpline: 020 7436 5881

Fetal Medicine and Neonatology Liasion (FMNN)

NHS
University Hospitals of Derby and Burton
NHS Foundation Trust

The following antenatal patient is referred for neonatal input:

Woman's Name: DOB: Hospital No:	EDD: Date of referral: Gestation at referral:

Isolated findings

Finding	✔	Action taken	✔
Polyhydramnios		Fill in baby's notes	
Talipes		Refer to Paediatric Orthopaedics	
Isolated renal pelvis dilation up to 10mm		Fill in baby's notes	
Cleft lift / palate		Referral to Cleft team	
Antibodies		Update pink sheet & copy to expected baby's file	
Physically normal, sex chromosome anomaly		Fill in baby's notes	
Date and time:		Named consultant:	

Palliative care

	✔
Agreed with parents	
Referred to bereavement midwife	
Please refer to documentation	

Date and time:	Named consultant:

Complete other side of page in case of complex cases and multiple anomalies

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To be discussed at MDT meeting - Multiple anomalies or complex cases	
Findings	
Plan of care	
Date and time:	Named consultant:

Documentation Control

Reference Number: **UHDB/Operational/09:22/F3**	**Version: 1**		**Status: FINAL**	
Version / Amendment	Version	Date	Author	Reason
	1	January 2006	Miss A Fowlie Service Director	New guideline
	2	December 2009	Dr J Ashworth Consultant Obstetrician	Revised
	3	Dec 2011	Mrs K Dent Consultant Obstetrician	Revised
	4	July 2015	C Adcock, specialist midwife Fetal medicine Fetal medicine Team	Reviewed
UHDB	1	May 2021	Ms. S. Devendran Consultant Obstetrics & Fetal Medicine.	Revised
Intended Recipients: All staff with responsibility for caring for women antenatally where there is suspected fetal anomaly				
Training and Dissemination: Cascaded through lead sisters/midwives/doctors; Published on Intranet; NHS net circulation list. Article in BU newsletter				
To be read in conjunction with: Maternal Transfer (T5)				
Consultation with:	Obstetricians & Maternity staff			
Business Unit sign off:	29/06/2021: Maternity Guidelines Group: Miss S Rajendran – Chair 15/07/2021: Maternity Governance Committee/ACD - Miss S Raouf			
Divisional sign off:	27/07/2021			
Implementation date:	15/09/2022			
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Key Contact:	Cindy Meijer			