

Detection and follow up of fetal abnormality guideline

Key Points

- Fetal abnormality
- Tertiary referral
- Fetal anomaly screening programme

Version: 2.0

Date Issued: 25 May 2023

Review Date: May 2026

Key words: Fetal abnormality, tertiary referral

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Abbreviations

ASTRAIA	Ultrasound IT reporting system
CVS	Chorionic Villus sampling
EPIC	Electronic patient record
FASP	Fetal anomaly screening programme
GP	General Practitioner
MDT	Multidisciplinary team
NCARDRS	National congenital and rare disease register
PN	Post-natal
RL	Trust incident reporting system
SIAF	Screening incident assessment framework
TOP	Termination of pregnancy
T21/T18/T13	Trisomy 21 (Downs syndrome) Trisomy 18 (Edwards Syndrome) Trisomy 13 (Patau's Syndrome)

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1.0 Introduction

Fetal abnormalities are detected via several different routes:

1.1 At routine ultrasound scan

In this circumstance the woman is referred to an obstetrician with special interest in Fetal Medicine within 3 working days. If a more detailed examination of the fetus confirms an abnormality, the implications for the management of the pregnancy will be discussed with the parents and arrangements made for referral to a tertiary center if required. In the event of an obstetrician or a suitable appointment not being available within the time frame, referral to the tertiary center will be made directly by the screening team.

Wexham Park site

For suspected cardiac abnormalities:

- Fetal cardiology at the John Radcliffe Hospital Oxford
- Email fetalmedicine.pnd@nhs.net

For all other abnormalities:

- Fetal medicine unit at the John Radcliffe Hospital Oxford
- Email fetalmedicine.pnd@nhs.net
- Kings College for Diaphragmatic hernia or Twin to twin transfusion syndrome

Kings College email kch-tr.HBUreferrals1@nhs.net

Tracking

Wexham Park cases. All suspected or confirmed fetal abnormalities are recorded on the fetal abnormality data base. This data base is maintained by the screening team and outcomes completed.

A high-risk database is maintained as a tracker used to inform the pediatricians during the monthly communication meeting held on 1st Monday of the month.

EPIC documentation. The problem list on the mother's epic record will be completed and the screening team will schedule an MDT meeting. A pending baby will be created, and a fetal chart commenced with a documented Paediatric plan completed on the fetal chart during the MDT meeting.

Frimley Park site

For suspected cardiac abnormalities

- Fetal Cardiology Unit, Evelina Children's Hospital, Guy's and St Thomas' Hospital

Email gst-tr.fetalcardiologygstatt@nhs.net

For all other suspected anomalies

- St George's Hospital, Fetal medicine unit.

Email fetalreferrals@stgeorges.nhs.uk

Tracking

Frimley Park cases. All suspected or confirmed fetal anomalies are recorded on the high-risk data base. This data base is maintained by the screening team and outcomes completed.

EPIC documentation. The problem list on the mother's record will be completed and the screening team will schedule an MDT meeting. A pending baby will be created, and a fetal chart commenced and completed with a documented Paediatric plan.

Once the diagnosis is confirmed (this may take more than one appointment) the future management is decided in full consultation with the parents. This may include continuing the pregnancy or termination of the pregnancy with or without prior feticide. All tertiary reports are received by email to the generic screening email in box and/or the consultant at the tertiary referral centre will discuss the management directly with the consultant in charge of the woman's obstetric care. All discussions are documented in the maternal epic record.

Should the couple decide to continue with the pregnancy the following support is given:

- Combined scan clinic with consultant in fetal-medicine and specialist screening midwife.
- Antenatal consultation with consultant pediatrician will also be arranged if required.
- Post-natal plan for baby will be written by pediatrician on EPIC record and added to the fetal chart (pending baby) by the screening team.
- Screening teams phone contact details provided for questions and ongoing support.

Should the couple opt for termination of pregnancy by feticide this is performed by a consultant at the Frimley Health site carrying out care or at the tertiary centre, with the woman then returning to the relevant unit for induction of Labour. Timing will be planned with the mother with consideration of unit activity and supported by the maternity bereavement teams. Written confirmation of fetal death should be received prior to induction, which is then carried out in accordance with the Guideline on Termination of Pregnancy. Women can be offered an appointment post-procedure with a consultant to review the outcome of the pregnancy and make plans for the future. This is essential if postmortem is requested to discuss results but may not be required if a clear diagnosis is known in the antenatal period. Bereavement and screening teams can support to ensure this is arranged with the most appropriate clinician. Counselling service is also available, and the screening or bereavement teams can refer to the service maternity counselling service.

1.2 Via high risk combined screening test

See local protocol for T21/T18/T13

1.3 Via abnormal CVS/amniocentesis results - joint site process

These are emailed directly from the external laboratory to the Screening team. The patient is then contacted on the same day. Consideration will be made if a result is received on a Friday afternoon and /or before a bank holiday period. An appointment is offered to discuss the result face to face and outline what options are available.

See local protocol for TOP management appropriate to gestation.

All consultations are documented on the patient's EPIC record. This counselling can be performed by a consultant, a senior registrar and also the specialist midwives in the screening team. Care then continues according to the woman's wishes with appropriate management as per relevant guidelines.

All appropriate fetal anomalies are reported to the regional congenital anomaly register NCARDRS.

2.0 Screening Incident management

Any adverse incident will be reported via the internal RL system for investigation, management and learning. Screening incidents will also be reported in the same way but will also be reported as specified in 'Managing Safety Incidents in NHS screening programmes with the completion of a SIAF.

<https://www.gov.uk/government/publications/managing-safety-incidents-in-nhs-screening-programmes>

National guidance, service specification and other relevant information can be found via <https://www.gov.uk/topic/population-screening-programmes/fetal-anomaly>

3.0 Auditable standards:

In all cases when an FASP reportable fetal anomaly has been detected on ultrasound in pregnancy, the woman will be offered an appointment for a specialist consultant within 3 working days of detection. If due to capacity a local fetal medicine appointment is not available within this time frame a direct tertiary referral will be made. In all cases of abnormal amniocentesis or CVS result, the woman will be contacted within 24 hours of the result being received by the maternity service. An appointment will be offered within 3 working days to discuss results and options.

All referrals to tertiary services for fetal abnormalities will be documented on the maternal health EPIC record.

In all cases of confirmed fetal abnormality in pregnancy, an appointment will be offered with a consultant in fetal medicine, a consultant pediatrician, as appropriate and a specialist Midwife in the screening team. These multidisciplinary consultations will be documented in the maternity EPIC record.

In all cases of confirmed fetal abnormality when it has been decided to continue with the pregnancy a paediatric plan will be devised, and a fetal chart created in the pending baby EPIC record.

4.0 Communication

If there are communication issues (e.g., English as a second language, learning difficulties, blindness/partial sightedness, deafness) staff will take appropriate measures to ensure the patient (and her partner, if appropriate) understand the actions and rationale behind them. Trust interpreter guidance should be considered.

5.0 References

NICE guidance CG62 Antenatal Care March 2016

<https://www.nice.org.uk/guidance/cg62>

NHS England (2022) Fetal anomaly screening programme handbook. Available at: <https://www.gov.uk/government/publications/fetal-anomaly-screening-programme-handbook>

(Accessed 03.11.22

Appendix 1 – Detection and management of anomaly identified at anomaly scan (WPH)

Detection and management of anomaly identified at the anomaly scan 18+6-20+6

Wexham Park

Incomplete anomaly scan: Scan rebooked
< 23 weeks gestation

No ANOMALY DETECTED back to planned
route of care

ANOMALY SUSPECTED

Ultrasound will inform the screening team by phone of all suspected anomalies and the screening team will contact the patient. Screening team can review scan on ASTRAIA/EPIC record. Tel 03006153301

- Suspected FASP auditable anomaly appointment must be within 3 days.
- Suspected FASP auditable anomaly and /or no availability with consultant within 3 days direct referral to tertiary center can be made by the screening team. All referral documentation is available from the screening team and referral is an email request via the screening generic email account

The patient's details and suspected anomaly will be entered on to the fetal anomaly spreadsheet once findings have been confirmed.

Maternal EPIC record problem list will be updated.

Please note EPIC problem: **Fetal Ultrasound scan abnormal or Antenatal screening finding** will be selected when a pregnancy is continuing and a neonatal plan is to be followed. This will generate the EPIC Fetal **Problem Banner** advisory to appear on the maternal record.

High risk spread sheet is maintained as a tracker and presented at the Monthly joint Paediatric meetings held on 1st Monday of the month to ensure fetal chart is created (pending baby) and includes a Paediatric plan after delivery.

Tertiary reports from Oxford and Kings are received via email and are uploaded on to the maternal EPIC media tab.

Anomaly confirmed and tertiary referral required

Cardiac Anomalies
John Radcliffe Hospital Oxford
Cardiac echo referral completed
and emailed to Oxford
fetalmedicine.pnd@nhs.net

All other anomalies**
Fetal anomaly referral
completed and
emailed to Oxford
Fetal medicine:
pnd@nhs.net

**In some
circumstances KINGS
Tertiary CENTRE may
see patients with
suspected
Diaphragmatic Hernia
or suspected Twin/Twin
transfusion syndrome.
Screening team will
email directly with scan

Pregnancy Continuing:

All follow up appointments will be coordinated by the screening team following receipt of tertiary center reports.

Fetal Medicine consultant will coordinate the care pathway for women previously booked under midwifery led care and if appropriate may also take over management of women already under consultant care.

Screening Midwife will update EPIC maternal record, create fetal chart on a pending baby record, update tracker spreadsheet and schedule an MDT to ensure case is discussed and PN plan documented by the Paediatric team. Screening team will remain a support for the family throughout the pregnancy and women are encouraged to contact the team.

Decision to Terminate:

Care will be coordinated by the Fetal medicine consultant, Screening team and tertiary center.

Appointment with the fetal medicine consultant arranged as timely as possible but within 3 days.

Arrangements for TOP will be made following counselling as per guideline.

Screening team the Community Midwife. Digital Midwife will be informed to ensure EPIC record is resolved and all appointments cancelled.

The fetal medicine consultant will take responsibility to ensure all consent and legal documentation is completed.

Appendix 2 – Detection and management of anomaly identified at anomaly scan (FPH)

Detection and management of anomaly identified at the anomaly scan 18+6-20+6

FRIMLEY PARK

Incomplete anomaly scan: Scan rebooked < 23 weeks gestation.

No ANOMALY DETECTED back to planned route of care.

ANOMALY Suspected

Ultrasound will inform the screening team of all suspected anomalies and the screening team will contact the patient. Screening team can review scan on ASTRAIA/EPIC record. Tel 03006136989.

- Suspected FASP auditable anomaly appointment must be within 3 days.
- Suspected FASP auditable anomaly and /or no availability with consultant within 3 days direct referral to tertiary center can be made by the screening team. All referral documentation is available from the screening team and referral is an email request via the screening generic email account.

The patient's details and suspected anomaly will be entered on to the fetal anomaly spreadsheet once findings have been confirmed.

Maternal EPIC record problem list will be updated.

Please note EPIC problem: **Fetal Ultrasound scan abnormal or Antenatal screening finding** will be selected when a pregnancy is continuing, and a neonatal plan is to be followed. This will generate the EPIC Fetal **Problem Banner** advisory to appear on the maternal record.

Anomaly confirmed but tertiary referral NOT required.

Patient will be fully counselled and appropriate management arranged. Fetal medicine consultant /Screening team use EPIC messaging to inform Paediatric team if relevant.

Patient will be booked under the care of fetal medicine consultant or appropriate obstetric consultant if Midwifery led care.

Anomaly confirmed and tertiary referral required

Cardiac anomaly

EVELINA CHILDRENS HOSPITAL

Online Referral form and map kept in the screening office. Email completed referral form to

Gst-tr.fetalcardiologygstt@nhs.net .

Ensure Screening admin is informed to update database.

All other anomalies

refer to St Georges Hospital. Email complete Referral form together with copies of all scans and booking blood results to fetalreferrals@stgeorges.nhs.uk

Referral form and patient leaflet/map kept in the screening office.

Pregnancy Continuing:

All follow up appointments will be coordinated by the screening team following receipt of tertiary center reports.

Fetal medicine consultants will coordinate the care pathway for women previously booked under Midwifery led care or advise appropriate obstetric consultant and transfer care.

Scanning Consultants will ensure Paediatric team are informed via EPIC message and screening team will ensure paediatric plan is received and fetal chart /pending baby made with neonatal management plan documented.

Screening team will ensure Community Midwives are informed:

Screening team will remain a support for the family throughout the pregnancy and women are encouraged to phone.

Decision to Terminate:

Care will be coordinated by the fetal medicine consultant, screening midwife and tertiary Centre.

Appointment with the fetal medicine consultant arranged as timely as possible but within 3 days.

Arrangements for TOP will be made following counselling as per guideline. Screening team will inform the Community Midwife.

Digital Midwife will be informed to ensure EPIC record is resolved and all appointments cancelled.

The fetal medicine consultant will take responsibility for ensuring all consent and legal documentation is completed.

Full version control record

Version:	2.0
Guidelines Lead(s):	Kathy Franks (cross site QA lead for antenatal & newborn screening)
Lead Director / Chief of Service:	Anne Deans (Chief of Service)
Library check completed:	03/11/2022
Ratified at:	Cross Site Obstetrics Clinical Governance Meeting, 22 May 2023
Date Issued:	25 May 2023
Review Date:	May 2026
Pharmaceutical dosing advice and formulary compliance checked by:	R Ahmed, October 2022
Key words:	Fetal abnormality, tertiary referral

This guideline has been registered with the trust. However, clinical guidelines are guidelines only. The interpretation and application of clinical guidelines will remain the responsibility of the individual clinician. If in doubt contact a senior colleague or expert. Caution is advised when using guidelines after the review date. This guideline is for use in Frimley Health Trust hospitals only. Any use outside this location will not be supported by the Trust and will be at the risk of the individual using it.

Version Control Sheet

Version	Date	Guideline Lead(s)	Status	Comment
1.0	Feb 2017	K. Franks	Final	Ratified at Antenatal & new-born cross site screening board (Feb 2017) Obstetrics & Gynaecology Clinical Governance Committee
2.0	Oct 22	K. Franks	Final	Scheduled update. Cross Site Obstetrics Clinical Governance Meeting, 22 May 2023

Related Documents

Document Type	Document Name
Guideline	Termination for fetal abnormality
Guideline	Combined/Quadruple screening SOP FPH site
Guideline	Combined/Quadruple screening SOP WPH site