

ANTENATAL GUIDELINES

**No. 45 Fetal Anomaly ultrasound scan and
Referral when abnormality detected**

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1. Background

The fetal Anomaly screening scan should be performed between 18+0 and 20+6 weeks gestation. If a rescan is required when a scan is unable to be completed at the first attempt a follow up appointment should be given within 5 working days and the scan completed by 23+0 weeks gestation.

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

- Anomalies that 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. Process of Screening

Process for anomaly ultrasound screening is shown in appendix 1.

Fetal anomaly screening may have significant clinical and emotional consequences. A rigorous approach to the provision of information and to the consent process is therefore required.

To enable women, and their partners to make an informed choice based on their individual values screening should be preceded by the provision of written information, where possible in the woman's first language, and there should be access to additional information and support in other suitable formats. All women should receive a copy of the National Screening Committee (NSC) leaflet '**Screening Tests for You and Your Baby**' which incorporates information on Physical abnormalities (mid pregnancy scan).

Prior to attending an anomaly ultrasound scan or other types of screening in pregnancy women should be given the opportunity to discuss with the midwife at her booking appointment the intended purpose and possible outcomes of screening. Women and those close to them will vary in how much information they require, However all women should have a broad understanding of the purpose, risks, benefits, limitations and consequences of

fetal anomaly screening. Fetal anomaly screening should be explained as an option rather than an inevitable aspect of routine antenatal care.



These discussions should be documented in the patient handheld maternity notes. It is the responsibility of the Community midwife to sign and date entries to confirm that all pregnancy scans have been discussed with the woman and that the woman has made an informed choice in relation to accepting or declining the anomaly scan.

The main purpose of this guideline is to ensure the timely and accurate referral to specialist clinicians when a fetal abnormality is detected on ultrasound or via any other route by:

1. 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 and private environment.
2. To ensure that the woman and her family are seen promptly (within 5 working days) by a Fetal Medicine Specialist. Organise onward referral to 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.
3. 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.
4. That there is clear documentation in both the hand held maternity record and the hospital 'buff 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 Veivpoint system.
5. 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 midwifery,
 - GP
 - Health Visitor

3. Process for referral to Fetal Medicine team

When a fetal abnormality is suspected a referral is made to Fetal Medicine using a specific referral form. Appendix 2. The fetal medicine lists are held on Tuesday, Wednesday and Thursday mornings



however there may be times when appointments are given outside of these times. Every effort is made to ensure the woman has the contact number of the

screening team and a fetal medicine appointment prior to leaving the scan appointment. Women also have the opportunity to speak to the screening midwives who also support the fetal medicine lists if desired.

When a fetal abnormality is diagnosed or detected via any route of screening and the pregnancy is ongoing a neonatal alert form, (appendix 3), should be completed giving details of the condition and current care plan, this should include the alert sticker on the baby notes and information about an alert completed on page 17 of the patient handheld pregnancy record. A copy of the alert should also be placed in the woman's hospital notes and then transferred to the baby notes once the baby has been born. This system, co-ordinated through the neonatology team, allows all clinicians involved with the care of the family easy access to all information about the plan of care.

During follow up appointments other specialists appropriate for the fetal anomaly maybe involved in planning care and providing further counselling. Fortnightly multi-disciplinary fetal meetings support the cascade of information, updating of a neonatal plan of care and provide educational opportunity for the attendees.

This team includes:

- Fetal medicine Consultants,
- Sonographers
- Obstetricians,
- Neonatologists
- Genetic Consultant
- Specialist teams
- Screening Midwife

The screening team will contact the womans GP and Community Midwife to inform them of the abnormality detected.

4. Process for referral to tertiary centre

It is the responsibility of the lead consultant to initiate referral to a tertiary centre. Dependent upon clinical need, the woman may be referred to any appropriate unit but the most common are the following units:

- Bristol, St Michaels' Fetal Medicine Unit (appendix 4 and 5)
- Royal Devon & Exeter Hospital – clinical genetics (appendix 6)
- Southampton Paediatric Cardiac team - (appendix 7)



- Birmingham Maternity Hospital

The referral forms can be located in Fetal Medicine Room 7 on Day Assessment Unit, level 6 or in the folders on the generic fetal medicine email: fetalmedicine.plymouth@nhs.net
appendices 2 – 6.

Appointments are made in partnership with the lead consultant, specialist hospital and the woman (partner and family to be included with patient consent). A clear, documented management plan must be recorded in the patient notes together with appointment times and location to ensure the patient is fully informed of care and management pathways.

In addition, cases are regularly discussed at MDT meetings to ensure all clinicians and healthcare professionals are fully informed of management plan. Patients must be informed of the fetal medicine meetings to be able to give their consent to discussion.

5. Process for communication

Women and their partners should be offered compassionate support by experienced clinicians and must receive appropriate information and time to enable them to come to an informed decision. This will include time to

- Make decisions after the antenatal testing process
- Come to terms with the fact that their unborn baby has an abnormality
- Make difficult decisions about continuing the pregnancy
- Make difficult decisions about ending the pregnancy
- Cope with complex and painful issues after a decision, including bereavement
- Decide to have a confirmatory diagnostic test.

Documentation of all counselling and discussions, by all clinicians, must be clearly recorded in the hand held record as well as documentation of any patient information leaflets that are given to the woman. The scan printed documentation will contain this information and be saved on the Viewpoint system.

If the abnormality detected is confirmed and the woman has made the decision to terminate the pregnancy she will be counselled and consented regarding the termination of pregnancy process. Information given will depend on the gestation of the pregnancy.

If the pregnancy is over 21+6 weeks gestation it is recommended that fetocide is performed before the termination of pregnancy is commenced.

6. Support for the women and her family



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The diagnosis of a fetal abnormality is a very distressing time for both the pregnant woman and her family. During this time the woman and her family are likely to require a lot of support from hospital staff and other agencies. There are also specific patient information for when an abnormality has been diagnosed in an unborn baby, both for women who choose termination and women who continue with their pregnancy. Parent information for the screened conditions can be downloaded at <https://www.gov.uk/government/collections/fetal-anomalies-screening-conditions-diagnosis-treatment> and given to the woman following confirmation of a suspected anomaly.

7. Audit

Every unit should audit its results with respect to the detection of fetal abnormalities on an annual basis and this forms part of the National Screening Committee annual audit of screening services within the trust. This is completed on an annual basis by a senior sonographer and reported in the Screening Annual Report.

8. Record Keeping

It is expected that every episode of care be recorded clearly, in chronological order and as contemporaneously as possible by all healthcare professionals as per Hospital Trust Policy. This is in keeping with standards set by professional colleges, i.e. NMC and RCOG.

All entries must have the **date and time** together with **signature and printed name**.

9. National Databases

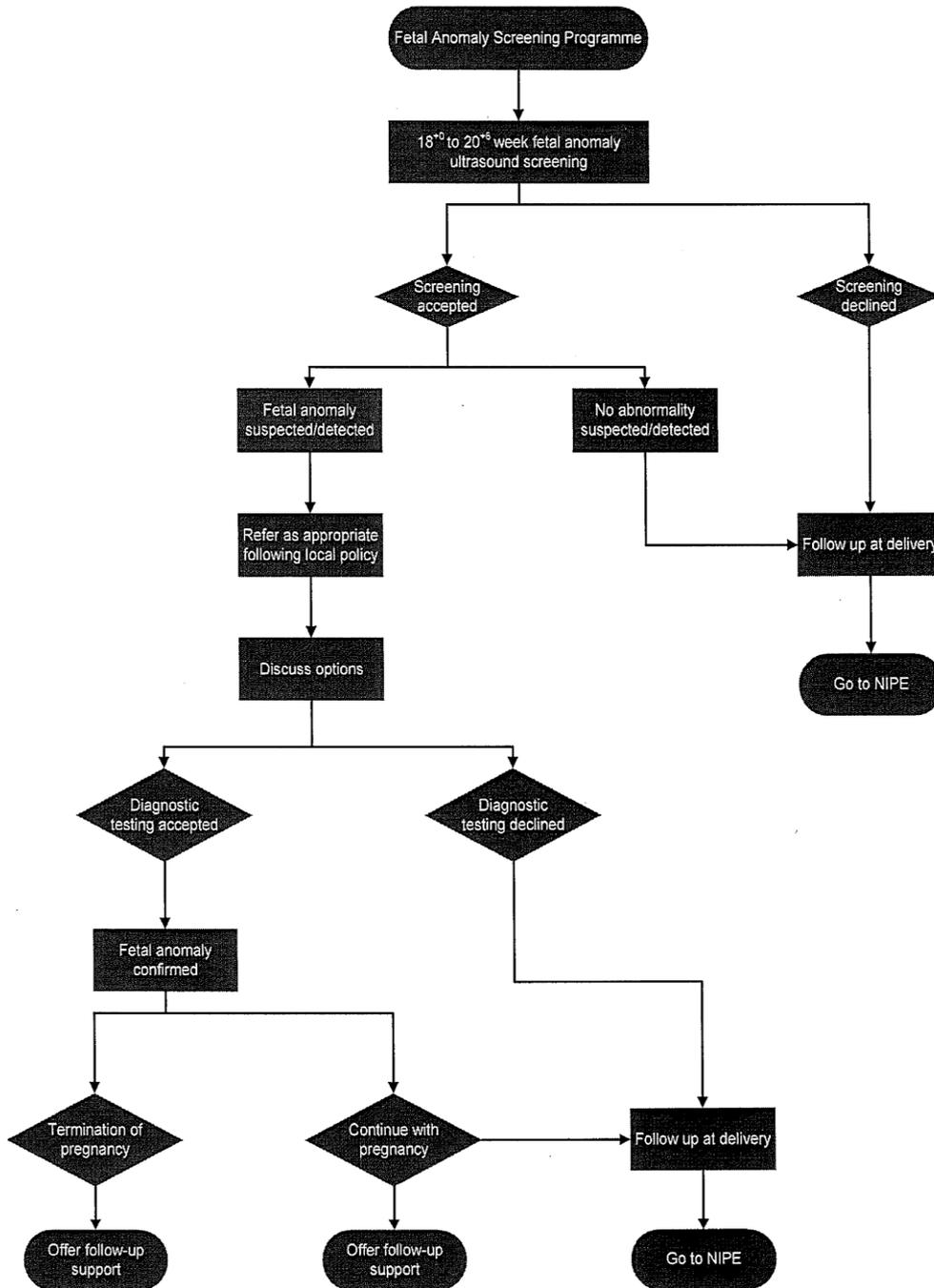
The National Congenital Anomaly and Rare Disease Registration Service (NCARDRs) should be informed of suspected confirmed cases of fetal anomaly. Leaflets are available in the fetal medicine room and should be given to parents where an abnormality has been diagnosed. Information on the anomaly is sent by the screening team but parents have the right to ask for their information to be removed. The form can be found at: <https://www.api.encore.nhs.uk/ncardrs/>. These forms are completed and sent by the screening team and sent by secure email detailed on the form.



Appendix 1



NHS Fetal Anomaly Screening Programme care pathway: 18⁰⁰ to 20⁰⁶ week fetal anomaly ultrasound scan



Public Health England leads the NHS Screening Programmes

Version 1.2



Appendix 2

Referral to Fetal Medicine

Consultant (or CMW lead)

Patient sticker or details

Obstetric history G P

.....
.....

Patient contact details

.....

Home Tel

.....

Mobile Tel

Referred by

Date and Time

Reason for referral (if scan please attach copy of Viewpoint report)

Blood group/HIV status (for invasive procedures)

Appointment Date and Time

Given by

Please inform patient that we will contact them as soon as possible to arrange an appointment. Do not suggest when that is likely to be. Remember the FASP standard is to see Fetal Medicine within 5 working days.

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 one of the screening midwives or



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CLI.MAT.GUI.687.4 Fetal Anomaly Scan and Referral

Surname:
First Name:
Hospital Number:
NHS Number:
DOB:
Postcode:

Affix patient label here

NEONATAL ALERT

Dear Consultant Neonatologist

Please complete all sections of page 1 clearly when making your referral

EDD.....

Midwifery led care Shared care Consultant led care

GP GP Surgery

Team Base.....

Name of referrer Midwife/Obstetrician

Work Mobile No:

Email
address.....

Patient has been informed that this information will be shared with the Neonatologists and a copy of this document will be placed in the Hospital Notes & Patient Hand Held Maternity Notes

Page 17 of Perinatal Notes Paediatric alert form: (please tick)

Patient has been informed that a request for advice has been completed:

Date..... Yes

Please refer to the Neonatal Alert System Standard Operating Procedure when completing this section and give as much information as possible

Antenatal diagnosis/Problem

.....
.....
.....
.....

Send completed form by email to: **plh-tr.Neonatal-alerts@nhs.net**

FOR NICU CONSULTANT USE

Action Plan:



.....
.....
.....
.....
.....

Does Patient need to be seen?

By the Neonatal Team Yes No if yes, please contact NICU secretaries **Ext: 31574/31575**
to arrange appropriate appointment with TCW consultant covering on day of patients next
appointment.

Neonatologist (please print name).....Ext No:

Signed.....Date

Further information required from referrer

Please supply the following information

.....
.....
.....
.....

Date Requested

Date Returned to Obstetrician /Midwife.....

Further information

.....
.....
.....

Admin - One copy to be filed behind the Correspondence Chapter Card & One copy to be filed in unborn baby notes and One to be sent to Community
Midwife for filing into patient handheld notes



Appendix 4

Bristol Congenital Heart Centre



Fetal Cardiology Secretary contact number: 0117 342 5394

Fetal Cardiology Referral
ALL REFERRALS TO BE FAXED TO 0117 342 5688

Please circle to indicate whether routine or urgent

ROUTINE or URGENT	
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Please complete ALL details so that we can deal with your referral as efficiently as possible.

REFERRER DETAILS

Date of Referral		Referring Hospital	
Referring Clinician		Contact numbers	
Reason for Referral			

PATIENT DETAILS

Surname		First Name	
NHS No ESSENTIAL		D.O.B	
Address and Postcode			
Pt.Landline		Patient Mob	
EDD	LMP	Gestation at referral	

GP DETAILS

GP Practice		GP's Name	
GP Address			

If URGENT referral

Appt Made?	Y / N	If Yes: Date: Time:
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For Admin

Triaged by:

AJT

BTG

SB

18 wk		20 wk		Pt No.	Appt	Date Time	Pt. Advised	Letter Phone
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Comments:

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Appendix 5



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St Michael's Fetal Medicine Unit

Referral

Date of Referral:	
Name of Patient:	
Address:	
Postcode (please do not use printed labels.)	
Contact Phone Numbers: (Home and Mobile)	
Date of Birth:	
NHS Number:	
Referring Hospital with Clinician and Contact Number:	
LMP (+ scan gestation if different):	
BMI	
Blood Group (fax path report)	
Virology Status (Hep B and HIV, Hep C if appropriate):	
Working Diagnosis/ Reason for Referral:	
Has an appointment already been made? If Yes, please give time and date:	

Please help us by completing ALL these details so that we can deal with your referral as speedily and efficiently as possible.

Our Contact Number: 01173 425470

Our Fax Number: 01173 425180

Appendix 6



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Peninsula Clinical Genetics Referral

Date of Referral			
Name of patient			
Date of Birth			
Hospital Number		NHS Number	
Address			
Postcode			
Phone Number			
Mobile Number			
GP			
GP Address			
Partner's Name			
Partner's Date of Birth			

Not pregnant / Pregnant LMP / Scan gestation / EDD	EDD
Relevant details of previous pregnancies	
Disorder	
Relevant Family History <i>(Include name and dob birth of affected family member where possible. If Genetics reference number known please include this also)</i>	
Previous / pending investigations	
Prenatal diagnosis requested	
Appointment required	

Referrer		Job title	Screening midwife
Contact no.	01752 439792	Hospital	Derriford
Consultant			
e-mail; fetalmedicine.plymouth@nhs.net			

Please fax completed form

Dr Emma Kivuva, Clinical Geneticist
Fax: 01392 405739 Telephone: 01392 405728
 RD&E Hospital (Heavitree), Gladstone Road, EXETER, EX1 2ED

Appendix 7



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b) Urgent (within 2 working days)

c) Very urgent (same or next day **MUST TELEPHONE TO DISCUSS**)

Scan findings/Referral details:

WHERE POSSIBLE PLEASE E-MAIL COPIES OF ALL SCAN REPORTS

Date/time of appointment (If known):

Is an interpreter required?

Is patient aware of appointment?

Name of person completing referral form:

Contact telephone number:

Please ensure patients are given the information below

- Appropriate information leaflets given where applicable
- Check they have the correct post code **SO16 5YA** and contact details
- Website address: www.uhs.nhs.uk then search Fetal medicine
- Limited parking, allow time to park
- Parking charges apply



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- Women need a comfortably full bladder before 14 weeks. After this there is no need to have a full bladder.
- Please avoid bringing small children as space is limited and it is often not appropriate

Please avoid bringing small children as space is limited and it is often not

Antenatal Results and Choices (ARC) www.arc-uk.org

73 Charlotte Street

London

W1T 4PN

Helpline: 0207 631 0285

Email: info@arc-uk.org

Antenatal Results and Choices (ARC) provides impartial information and individual support to parents whether they are going through antenatal screening or whose unborn baby has been diagnosed with an abnormality.

CLAPA

Green Man Tower, 332B Goswell Road,

London EC1V 7LQ

020 7833 4883

020 7833 5999

info@clapa.com

www.clapa.com

Down's Syndrome Association (DSA) www.downs-syndrome.org.uk

Langdon Down Centre

2a Langdon Park

Teddington

TW11 9PS

Tel: 0845 230 0372

Email: info@downs-syndrome.org.uk

The aim of the Down's Syndrome Association (DSA) is to help people with Down's syndrome lead full and rewarding lives.

Genetic Interest Group (GIG) www.gig.org.uk

Unit 4D, Leroy House

436 Essex Road

London

N1 3QP

Tel: 0207 704 3141



Monitoring Audit

Auditable standards:

Evidence of documented discussion with parents
 Evidence of patient information leaflet having been given to parents
 Review if results undertaken appropriately
 Evidence that women with positive results are managed and referred appropriately and within appropriate

Please refer to audit tool, location: 'Maternity on cl2-file11', Guidelines

Reports to:

Clinical Effectiveness Committee – responsible for action plan and implementation of recommendations from audit

Clinical Governance & Risk Management Committee

Frequency of audit:

Annual

Responsible person:

Antenatal screening midwife

Cross references

PHNT Policy documents for :

- AN 8 Hepatitis B in Pregnancy
- AN 19 1st Trimester Screening for Down's, Edwards' and Patau's Syndromes (T21,T18,13) and Dating Scans
- AN 24 Sickle Cell and Thalassaemia Screening (please rename Haemoglobinopathies)
- AN 25 HIV in Pregnancy
- AN 27 Screening for Infectious Diseases in Pregnancy
- AN 37 Antenatal & Newborn Screening guidelines
- AN 44 Guideline development within the maternity services
- AN 45 When Fetal abnormality is detected

Clinical Records Keeping Policy – Derriford Hospital

References

Fetal Anomaly Screening Programme Standards 2015-2016

Antenatal Results and Choices

<http://www.arc-uk.org>

CVS and Amniocentesis: information for parents

Policy, Standards and Protocols Antenatal Screening Wales & FASP April 2008

Author	Ruth Rice Guideline Committee
Work Address	Maternity Unit, Derriford Hospital, Plymouth, Devon, PL6 8DH
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Changes	Timely review/Every 5 years		
Date Ratified	June 2017	Valid Until Date	June 2022

