University Hospital Southampton
NHS Foundation Trust

Fetal Abnormality – Referral Pathway Guideline, 5.0

Description	Clinical guideline
Target audience	Midwives, obstetricians, neonatologists, EPU nurses, gynaecology nurses, gynaecologists
Related documents / policies (do not include those listed as appendices)	Obstetric ultrasound Guidelines for sonographers and clinicians. UHS 2017 Condition specific patient information leaflets available on UHS Staffnet
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Policy sponsor	Freya Pearson – Divisional Clinical Director
Is there any non-compliance with NICE guidance?	No
First Consultation	**May 2022:** W&N Anaesthetic Guideline Consultation Group W&N Gynaecology Guideline Consultation Group W&N Midwifery Guideline Consultation Group W&N Neonatal Guideline Consultation Group W&N Obstetric Guideline Consultation Group
Second Consultation	**July 2022:** UHS Fetal medicine team

Approval committee	Approval date
Women and Newborn Governance Steering Group	07/10/2022

UHS reference	Version	Publication date	Next review due
N/A	5.0	October 2022	October 2025

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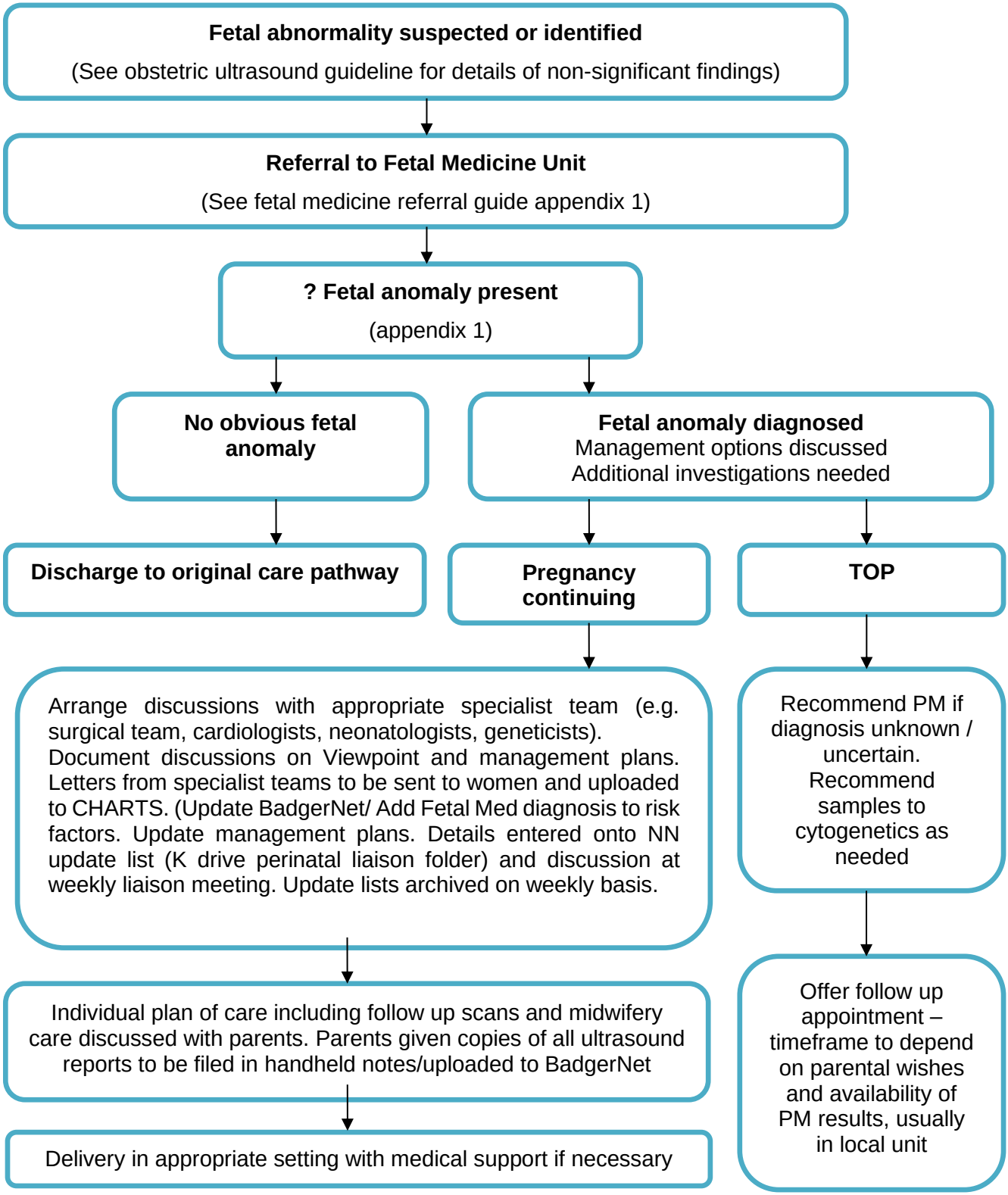
1 Version control

Date	Consultation / Comments	Version created	Page	Key changes
Oct 22	Fetal medicine team: D Howe, G Verma, R Parasuraman, K Brackley	5.0		Updated version, clarity over referral criteria.

2 Index

3 Executive Summary / Introduction

Flow Chart for referrals following fetal diagnosis of an abnormality



3.1 Introduction

This guideline outlines clinical practice in the event of suspicion or diagnosis of a fetal abnormality. Its remit extends from the point of diagnosis, be it in the ultrasound department or fetal medicine unit. Its purpose is to define the appropriate referral pathways and documentation. Diagnosis of a fetal abnormality is most often an unexpected event and parents need sensitive and clear information, not only about the nature of the abnormality but also about the management plan for the rest of the pregnancy.

4 Scope and purpose

These guidelines apply to all women with suspected or diagnosed fetal abnormalities at all stages of pregnancy.

4.1 Guideline aims

This guideline outlines clinical practice in the event of suspicion or diagnosis of a fetal abnormality including the referral to appropriate neonatal services

4.2 Guideline objectives

- To support staff in the management of women with suspected or diagnosed fetal abnormality
- To ensure appropriate referrals to neonatal or specialist services are made and documented

5 Definitions

University Hospitals Southampton NHS Foundation Trust – UHS
Wessex Fetal Medicine Unit – FMU
Princess Anne Hospital - PAH

6 Details of policy/procedure to be followed

6.1 Diagnosis of fetal abnormality

Diagnosis of a fetal abnormality may happen as a result of an ultrasound scan, or invasive diagnostic testing

Consideration should be given to how best to disclose the information to the parents and information should be given in a sensitive and empathetic manner, in an appropriate setting. The information given should be congruent with the ability of the woman to understand the information. It may be necessary to use diagrams, or simplified language or arrange interpreting services.

6.2 Referral from UHS Maternity Services or District General Hospitals to Wessex Fetal Medicine Unit (FMU)

Timely and appropriate referral from the antenatal screening service or obstetric ultrasound department is key. In general, referral to the tertiary FMU for suspected fetal abnormality should happen at the point of diagnosis so that the woman is given an appointment leaflet with contact and website information before she leaves hospital. The woman should be aware of the reason for referral and should see someone competent to give advice and any appropriate information leaflets. The local consultant should be informed of the referral. If the referring clinician (midwife, sonographer, and obstetrician) does not have enough information to answer the parents' questions, they should say so and avoid being led into answering inappropriately. Referral documentation should include a copy of the scan report and a completed referral form (see attached form appendix 1 The woman's blood group and viral screen should also be attached in case invasive prenatal diagnosis is required.

The FMU will arrange an appointment date according to the referral criteria (see appendix 2). If the woman leaves hospital before an appointment has been made the staff in the FMU can communicate this to the woman by telephone or letter depending on time scales, or the referring unit can contact. **This should be clearly documented on the fetal medicine referral form, which includes an ongoing prospective record of meeting referral criteria for audit purposes.** All referral information should be sent via secure email to the fetal medicine office.
(suh-tr.WessexFMU@nhs.net)

Unless there is high confidence about the exact diagnosis the FMU would prefer that specific information about the significance of an abnormality is not given until the diagnosis is confirmed. Misleading information can be particularly frustrating for the parents especially when there are subsequent significant differences in the diagnosis and outlook.

6.3 Communication

The mother/parents are the focus of all communication, and they should be kept fully informed at all times as to the nature of the anomaly and its implications. Verbal communication should be backed up with written information. Any face-to-face verbal communication should be documented in the woman's hand-held notes and/or hospital records (BadgerNet), and/or within a scan report; telephone discussions should be documented within the Viewpoint database.

For women for whom English is not their first language it is recommended that the services of an independent interpreter should be offered to the woman. In some situations, a repeat appointment with such an interpreter may be necessary. Information leaflets are available for certain conditions or procedures in different languages and their use should be considered.

Accurate communication of the diagnosis and management plan to other caregivers is important to ensure consistency of care. Verbal communication with other relevant health professionals is valuable, especially in the event of a very significant anomaly. It may be appropriate to directly approach the woman's own midwife, GP or referring consultant / unit if there are concerns that the woman requires more support.

6.4 Record keeping

All scans should be entered onto the Viewpoint ultrasound database and copies of any scan reports should be given to the woman for inclusion in her hand-held records, a copy will be automatically uploaded onto BadgerNet and sent to her GP, and any relevant specialists. A copy will also be sent via email to the referring hospital

The FMU retains a separate 'scan bag' containing information relating to a single referral. Records of chromosome or DNA results should be included in the FMU records, uploaded into the Viewpoint database and also copies sent to the referring hospital or in the woman's hospital records (uploaded onto eDOCS/BadgerNet) if booked locally.

6.5 Referral to Neonatal Specialist Services

The woman should be referred to the appropriate specialist team (e.g., neonatal surgery, cardiology, neonatology, genetics, neurology, orthopaedics, cleft team or nephrology) by the fetal medicine team as soon as it becomes apparent that input from that team will be necessary or helpful. Such referrals may be by phone; ~~fax;~~ secure nhs.net email (suh-tr.WessexFMU@nhs.net) or letter and the referral documented in the fetal medicine records and BadgerNet management plan.

It may be appropriate to complete investigations such as fetal karyotyping before the specialist team meets the woman as inappropriate counselling based on incomplete information may lead to parental confusion.

Referrals to tertiary neonatal specialist services in Southampton should not be accepted unless the woman has been scanned in the FMU.

In most situations the woman and her family will be seen by the specialist team in conjunction with the fetal medicine team, although occasionally the woman may be seen in other locations or outside of fetal medicine clinics. Effective communication is vital between all professionals, who often operate across multiple sites, to deliver a high standard of care and consistency of information. Information from other professionals such as letters or scan reports or a summary of a discussion should be documented in the woman's handheld record (if applicable) and made available electronically on eDOCS and BadgerNet. If the women are out of area, a separate letter should be sent to the local obstetric team.

6.6 Ongoing care

Women who plan to continue with the pregnancy should be supported in their decision-making and a management plan agreed with them. It may be appropriate for the planned delivery location to be changed. The woman may be booked for delivery in the Princess Anne Hospital, but ongoing routine antenatal care and support should continue as planned by the local obstetric and midwifery team.

The woman and her family should be offered the opportunity to visit specialist wards such as the neonatal unit, paediatric intensive care unit or paediatric cardiology unit to familiarise themselves prior to birth. The support of specialist nursing services such as the cardiac liaison team, the neonatal surgical team and the neonatal family support team should be offered and arranged.

Documentation of these referrals and visits should be made on a checklist placed on the front of the fetal medicine records and within Viewpoint. This checklist also indicates if the woman has been booked for delivery at UHS and if relevant information leaflets have been given.

A list of those women who plan to give birth in the PAH, or those whose babies may be referred postnatally to the paediatric services should be maintained to ensure communication between obstetric and neonatal services. This neonatal update list is on the shared 'PAH' drive (K: Perinatal liaison folder) and is password protected. It should be reviewed weekly at the combined neonatal / obstetric liaison meeting and any new information added. The updated list is archived following each weekly review including details of those present at the review.

Where appropriate, a plan should be made for care of the baby at delivery and documented on the Neonatal Care Plan sheet. A copy of this should be kept in the neonatal unit in the file recording anticipated deliveries and is available on eDOCS and BadgerNet. It should also be noted on the neonatal update list that a plan has been made. The woman should receive a copy of this plan, and it should also be communicated to the neonatal team in the referring hospital in case the birth occurs there.

If the nature of the abnormality is such that the woman can give birth in her local unit, it is advisable that copies of any correspondence and/or management plans are copied to the local neonatal services.

If the woman makes a decision not to continue the pregnancy, she should be referred for management of termination of pregnancy. Concise and timely communication of the woman's wishes and a plan for review should be documented in the FMU records, within the viewpoint database, on BadgerNet and the woman's hand-held notes. (if applicable)

6.7 Referral to supra-regional specialist units

Occasionally women may be referred from FMU to centres offering expertise in certain procedures not available locally. Referral to these units should be made on an individual basis with full clinical and demographic information. A clear ongoing management plan should be agreed with the supra-regional centre including follow up arrangements.

7 Roles and responsibilities

This guideline applies to all clinical staff employed or contracted by University Hospital Southampton (UHS) Foundation Trust who provide care to women and baby. Staff have a responsibility to ensure that they are aware of this guideline and its contents. They should clearly document their rationale if they have not complied with the recommendations detailed in this guideline. It is the responsibility of department managers, consultants, team leaders and education leaders to ensure staff are aware of this guideline.

8 Communication and training plans

The guideline will be displayed on Staffnet and sent to the relevant Care Group clinical teams. The team leaders will be expected to cascade to all relevant staff groups. All medical, nursing and midwifery staff caring for women and newborns should have support and training in implementing the contents of the guideline. In addition, the guidelines will be included in local induction programmes for all new staff members.

9 Process for monitoring compliance

The purpose of monitoring is to provide assurance that the agreed approach is being followed. This ensures that we get things right for patients, use resources well and protect our reputation. Our monitoring will therefore be proportionate, achievable and deal with specifics that can be assessed or measured.

Audit results will be circulated and presented at the multidisciplinary audit meetings, identified in the monitoring table. Any areas of non-compliance or gaps in assurance that arise from the monitoring of this guideline will result in an action plan detailing recommendations and proposals to address areas of non-compliance and/or embed learning. Monitoring of these plans will be coordinated by the group/committee identified in the monitoring table.

Those responsible for instigating the resulting actions will be identified in the audit meeting minutes. The resulting actions will be reviewed or followed up at the subsequent multidisciplinary audit meeting(s).

Key aspects of this policy will be monitored:

Element to be monitored	Referral of women to neonatal/specialist services as per guideline Documentation when a woman is referred to neonatal/specialist services Documentation of communication between obstetric, neonatal and specialist staff in the antenatal period. Referral of women to a tertiary centre where appropriate Whether the woman informed throughout the process
Lead (name/job title)	Specialist Midwife in fetal medicine
Tool	10 patients with an identified fetal anomaly and an on-going pregnancy, will be audited using the audit tool (appendix 1)
Frequency	6 monthly following implementation of the guideline and then three yearly.
Reporting arrangements	MDT Audit meetings

Where monitoring identifies deficiencies actions plans will be developed to address them.

10 Document review

Guideline to be reviewed after three years or sooner as a result of audit findings or as any changes to practice occurs.

11 References

a. Ultrasound screening for fetal abnormalities, report of RCOG working party RCOG 1997
b. Obstetric ultrasound Guidelines for sonographers and clinicians. UHS 2017
c. NHS FASP National Standards 2015

12 Appendix 1 – Fetal Abnormality Referral Guideline

The table below gives general guidance on when a referral should be made to fetal medicine and the time within which the team aim to see women with each condition. These times may change due to individual circumstances: in particular if abnormalities are noted after 22 weeks and before 24 weeks gestation. A more urgent appointment may be indicated if termination of pregnancy is an option that may be considered.

FASP standards of 2015 suggest 97% of women with a suspected or confirmed fetal anomaly should be seen by an obstetric ultrasound specialist locally within three working days of the referral being made, and 97% of women with a suspected or confirmed fetal anomaly should be seen by a fetal medicine sub specialist in a tertiary fetal medicine centre within five working days of the referral being made.

URGENT: **please phone first – aim to see within 24-48 hours**	
Hydrops	Discuss with Fetal Medicine Team
?TTTS	Discuss with Fetal Medicine Team
Severe IUGR <28 weeks	Discuss with Fetal Medicine Team
Anti D antibodies >4iu	Discuss with Fetal Medicine Team
Arrhythmia (SVT : Bradycardia)	Discuss with Fetal Medicine Team
Aim to see within 3 Days:	
Brain anomalies:	
Holoprosencephaly Ventriculomegaly Cranial anomaly Posterior fossa anomaly Cysts Haemorrhage Calcification	See within 3 days. Discuss Invasive testing Consider TORCH testing Discuss MRI scan Give FASP information leaflets (if available)
HC ≤ 3rd centile	See within 3 days. Must have two sonographers to check measurements before referral.
Neural Tube Defects:	
Anencephaly / Acrania	No need to see in Fetal Medicine tertiary unit. Scan images can be emailed and reviewed for confirmation if necessary.
Spina Bifida	See within 3 days. Discuss invasive testing. Give FASP information leaflet.

Facial anomalies:	
Cleft lip and / or palate	See within 3 days. Discuss invasive testing. Give FASP information leaflet.
Micrognathia / Retrognathia	See within 3 days. Discuss invasive testing.
Neck anomalies:	
Nuchal Oedema / Cystic Hygroma NT≥3.5mm	See at appropriate gestation – it would be worth waiting for screening result before referral. Discuss invasive testing, NIPT if increased chance screening. Arrange detailed cardiac scan at 16-20 weeks with local fetal medicine consultant or trained sonographer. Give FASP information leaflet.
Thorax:	
Diaphragmatic Hernia	See within 3 days. Discuss invasive testing. Give FASP information leaflet.
Pleural effusions	See within 3 days. Discuss invasive testing. Discuss and offer TORCH and PARVO screen.
Cystic Lung Lesion (CCAM)	See within 5 days unless hydropic. Advise serial scans will be required to exclude hydrops.
Cardiac:	
Abnormal Heart	See with 3 days normally with paediatric cardiologist. Discuss invasive testing.
Pericardial effusion (≥3mm) normal anatomy, rhythm, and function.	See within 1 week. Discuss TORCH/PARVO.
Ectopic beats	Manage locally and refer if any concerns – give leaflet.
Family history of CHD requiring surgery in mother/ father / previous child	Arrange detailed cardiac scan at 20 weeks with local fetal medicine consultant or refer.

Abdominal wall defects:	
Exomphalos	See within 3 days. Discuss invasive testing. Give FASP leaflet.
Gastroschisis	See within 3 days. Give FASP leaflet.
Renal:	
Bladder Outflow Obstruction	See within 3 days. Discuss invasive testing.
Renal agenesis	**Bilateral** see within 3 days. Discuss invasive testing in the presence of other anomalies. Give FASP information leaflet. **Unilateral** manage locally.
Multicystic Dysplastic Kidney	See within 1 week.
Dilated Renal Pelvis	Discuss with the fetal medicine team. Use postnatal management of antenatally detected renal pelvis dilatation.
Gastro-intestinal Tract:	
Tracheo-Oesophageal Fistula (TOF) / Small / absent stomach	See within 3 days. Discuss invasive testing
Duodenal Atresia	See within 3 days. Discuss invasive testing
Echogenic Bowel	Manage locally if normal cardiac views. Offer CF screening. Offer TORCH and Parvo Virus screen. Arrange serial growth scans. Consider invasive testing. Discuss with fetal medicine team as needed.
Abdominal cysts	Manage locally. Refer to tertiary unit if large and surgical opinion needed.

Extremities:	
Talipes	See within 3 days locally or refer to tertiary unit. Discuss invasive testing. Refer to orthopaedic team.
Skeletal Dysplasia	See within 3 days. Discuss invasive testing (pre or post-natal).
Femur ≤3rd centile	See within 3 days. Must have had two sonographers to check measurements before referral. Discuss invasive testing. Consider growth scans
Chromosomes:	
High chance NIPT / High chance screening chance	If structural abnormality is suggestive of a chromosomal defect refer to tertiary unit. See within 3 days Discuss invasive testing – refer for invasive test if not available locally.
Confirmed T21	Recommend referral to fetal medicine team for joint cardiac scan with paediatric cardiologists. Arrange serial growth scan locally. Consider late presentation of Duodenal atresia. Deliver by 38-39 weeks
Confirmed other chromosomal anomalies	Liaise with tertiary unit if needed, otherwise manage locally with paediatric input if continuing pregnancy. Give FASP information leaflets.
Amniotic fluid:	
Oligohydramnios <5cm AFI	Exclude bilateral renal agenesis, PPROM, growth restriction. Refer to tertiary unit if concerns about dopplers and less than 28 weeks
Polyhydramnios	AFI <30cm manage locally. Confirm normal stomach / fetal movements. Consider steroids. Refer to tertiary unit only if anomaly seen or if possible, therapy needed.

Antibodies:	
Antibodies	Discuss with fetal medicine team if: Anti D > 4iu. Anti c > 7.5 iu or as soon as detected if co-existing anti E. Anti-Kell as soon as detected. Anti FY, Anti JK, Anti C & CE greater than titre 1:32. Consider paternal / fetal genotyping.
Women who have had parvovirus in pregnancy.	MCA's to be done locally by appropriately trained sonographer for 12 weeks from infection. Also look for hydrops.
Previous pregnancy with structural abnormality	Only refer to FM if the problem was not detected antenatally in a previous pregnancy
Concerns with fetal growth restriction > 28 weeks	Do not need referral – need normal obstetric review and management locally

13 Appendix 2 – E-referral form

Wessex Maternal and Fetal Medicine Unit
Electronic referral form

Please e-mail referrals to: suh-tr.WessexFMU@nhs.net

Tel: 02381 204228/204727
Midwives office 02381 206025

PLEASE DO NOT FAX REFERRALS
URGENT REFERRALS CAN BE TELEPHONED PRIOR TO E-MAIL
E-MAILS ARE CHECKED REGULARLY THROUGHOUT THE DAY DURING OFFICE HOURS

YOU WILL RECEIVE CONFIRMATION OF THE REFERRAL BY E-MAIL

Title: Patient Name**:** DOB: BMI:	Referral date/time: Referring Unit: Local Consultant:
Address: Post code:	Contact Tel No: Email:
GP & Surgery address:	Ethnic origin:
Blood Group: Virology (HIV/Hep B status):	NHS No:
EDD by scan:	Gestation:

Urgency a) Routine (at appropriate gestation) ☐

b) Urgent (within 3 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, BLOOD RESULTS & OTHER INVESTIGATIONS
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 plenty of time to park
- Parking charges apply
- Women need a comfortably full bladder before 14 weeks. After this there is no need to have a full bladder.