Reference Number: UHBOBS196 **Version Number: 2** **Published: 7/2/24**	**Date of Next Review: 7/2/2027** **Previous Trust/LHB Reference Number:**

Title: Fetal Medicine Unit Referral and Specialist Service Guideline

Introduction and Aim

- To provide guidance and a clinical pathway for all clinicians referring and working with the tertiary fetal medicine unit (FMU), UHW, Cardiff.

Objectives

- This guideline aims to clarify the referral and care pathway for all women when a fetal disorder is suspected or detected. The objective of the Fetal Medicine Unit service is to provide additional specialised patient focused high quality evidence-based care, to women with complex pregnancies or whose fetus (or fetuses) has a confirmed anomaly, suspected anomaly or is at risk of a disorder.

Scope

- This policy applies to all healthcare professionals in all locations including those with honorary contracts.

Equality Health Impact Assessment	*An Equality Health Impact Assessment (EHIA) has not been completed.*
Documents to read alongside this Procedure	• *Antenatal Diagnostic Testing - Amniocentesis and Chorionic Villus Sampling (CVS) Guideline* • Antenatal Diagnostic Testing – Amniocentesis Standard Operating Procedure (SOP) • Antenatal Diagnostic Testing - Chorionic Villus Sampling (CVS) Standard Operating Procedure (SOP)
Approved by	*Maternity Professional Forum / Perinatal Guidelines Forum*

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Summary of reviews/amendments			
Version Number	**Date of Review Approved**	**Date Published**	**Summary of Amendments**
1			Changes to criteria in line with ASW 2023

Overview:

The rationale for these services being specialised is the complexity of the investigations and / or treatment involved which requires a sufficient volume of cases to be concentrated in a specialist centre to maintain expertise and links to appropriate specialists to support the service e.g. management of a potentially correctable fetal malformation. There are less than 20 centres providing specialised tertiary Fetal Medicine services in England (NHS 2021), and Cardiff is the only tertiary Fetal Medicine Specialist unit within Wales.

Specialised services for women cover rare or complex conditions and / or unusual treatments as well as more common conditions where the severity or uncertainty of the particular case and / or co-morbidities necessitates treatment in a specialist centre. A Fetal Medicine Unit is one staffed by specialist fetal medicine midwives, consultants/specialists and sonographers (fetal medicine specialist consultants have completed additional training in Maternal and Fetal Medicine) who provide a range of prenatal diagnostic and fetal therapeutic services. It also involves collaborative partnerships with other specialised services such as, neonatology, palliative care, paediatric surgery, paediatric cardiology, clinical genetics and molecular/cytogenetics, virologists/microbiologists and local multidisciplinary teams including, obstetricians, midwives, GPs, health visitors, social workers and bereavement services etc. to maintain effective communication of information and to ensure good standards of care. The need for specialist neonatal care for a high dependency newborn can often be anticipated antenatally. In

addition, in some cases the expertise of multiple specialist services will be needed to plan appropriate care.

Aim:

This guideline aims to clarify the referral and care pathway for all women when a fetal disorder is detected. Fetal medicine is the speciality that focuses on fetal health and its consequences for women and their families. This includes the assessment of fetal growth and wellbeing, the diagnosis and management of fetal disorders (including fetal abnormalities), in addition to offering specific fetal medicine counselling and support to parents. The aim of this service is also to ultimately improve the outcome of some fetal disorders where possible and has developed due to advances in prenatal diagnosis and specialised care / therapy. The fetal medicine team is comprised of a dedicated team of fetal medicine doctors, midwives and support staff who work with neonatal / paediatric specialist services to collectively provide the necessary skills and expertise to ensure the best possible outcome for mother and baby (ASW 2023, PHE 2021 and NHS 2021).

Objectives of the service:

- To provide a tertiary service to support women requiring specialist additional care before, during and after pregnancy.
- To provide a safe and effective collaborative individualised care pathway for women and babies with a fetal abnormality / disorder.
- To provide a high level of specialised support to local and relevant ‘district general hospital and community maternity and obstetric services.
- To optimise social, economic and psychological benefits for the mother and fetus. With provision to ensure equity of access including,

- vulnerable and hard to reach groups, disadvantaged groups, asylum seekers, refugees, travellers, women with learning and physical disabilities, women with translation/interpretation/advocacy issues etc.
- To treat all women and their families with kindness, respect and dignity. The views, beliefs and values of the woman, her partner and her family in relation to her care and that of her baby will be sought and respected at all times.

Service provision:

- Detailed assessment of fetuses at risk of and / or with abnormalities or dysmorphic syndromes which includes specialist ultrasound assessment.
- Detailed specific fetal medicine counselling, including explanation of findings which may include specific diagnosis or differential diagnoses and the implications and prognosis for the baby.
- Fetal cardiology services with a detailed assessment of fetuses at risk of / or with cardiac abnormalities.
- Management planning with the offer of relevant further investigations which may include invasive and non-invasive tests, e.g. genetic testing on free fetal DNA in maternal serum, amniocentisis / CVS (ASW 2008), parental tests, further imaging such as fetal MRI etc.
- Consultations and FMU counselling will include giving information regarding the implications and outlook for the baby, possible invasive therapeutic procedures and, when appropriate the option of terminating the pregnancy or palliative care; these consultations should be multidisciplinary where appropriate and dependant on availability. Due to the specialist nature and complexity of the cases seen within FMU a face-to-face interpreter should be provided where possible for those women who require interpreting services.
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- When referring to specialist neonatal / paediatric services within wales, a copy of the Viewpoint FMU report is available on Welsh Clinical Portal (WCP), outside of Wales a copy is emailed to the referring consultant. We request that following the neonatal / paediatric appointment a copy of the consultation letter should be e-mailed to the FMU department and uploaded onto welsh clinical portal. Where there are implications for the neonate at the time of delivery, the neonatal / paediatric consultant should update the local unit. If the woman is seen by FMU for a follow up appointment after the neonatal / paediatric consultation has been completed and a letter has been provided to FMU, a copy of that consultation will be filed in the UHW maternity record and the maternity record will be updated.

- Fetal medicine specific post-pregnancy counselling for families should be provided, including any identified implications for a future pregnancy.
- A FMU viewpoint consultation summary letter / report will be produced following each appointment. A copy will be placed in the UHW Maternity notes and it will be uploaded to clinical portal; antenatal, intrapartum or neonatal management required will be described within the report. The woman will be provided with their own copy to keep and they are requested to read / review it on receipt.
- Patient information leaflets and national leaflets are issued where available.
- Referral and management of rare and complex tests / therapies that are only provided in a very limited number of centres, for example: Fetal MRI, fetoscopic laser ablation of placental vessels for twin-twin transfusion syndrome (NICE 2006a), fetoscopic tracheal occlusion (FETO) for severe congenital diaphragmatic hernia and FETO

reversal, other fetal procedures (e.g. laser therapy for fetal tumours (NICE 2006e), balloon valvuloplasty (NICE 2006f) etc.

- Cases likely to require immediate neonatal cardiac surgery are referred to the FMU at St Michael's Hospital in Bristol. Their staff will arrange for a paediatric cardiac surgeon to meet the parents and counsel them about possible treatment. Despite plans to birth at St Michael's Hospital Bristol, a woman may present locally in labour so instructions for early neonatal care will be communicated to the referring unit via the FMU report found on WCP.
- Specific intrapartum, antenatal, postnatal plan will be highlighted in the relevant section of the all wales hand-held (Page 29 - as of May 2023).

Referral criteria can be found on the referral form and includes (this is not an exhaustive list):

FETAL ECHO CRITERIA

- Suspicion of fetal cardiac abnormality during an obstetric scan
    a. Most cases of fetal congenital heart disease will occur in this group.
    b. Pericardial effusion > 3mm.
- Fetal arrhythmias
    a. Sustained bradycardia - heart rate <110 beats per minute
    b. Tachycardia – heart rate >180 beats per minute

- Diabetes (Pre-existing and on insulin)
- Paternal congenital heart disease (risk 2-6%)
- Maternal congenital heart disease
- Previous child or fetus with congenital heart disease or congenital heart block
    a. 1 affected child (risk 2-3%, though higher for some lesions, e.g., isomerism)
    b. 2 affected children (risk 10%)
    c. 3 affected children (risk 50%)
- Previous child with congenital complete heart block with maternal auto antibodies (risk CHB 20%)
- Chromosomal anomalies, gene disorders or syndromes associated with congenital heart disease or cardiomyopathy (risk will depend on individual disorder)
- Nuchal translucency under 14 weeks gestation measuring =/>3.5mm

FETAL MEDICINE CRITERIA

- Specialised ultrasound examination and subsequent care of fetuses at risk of or with suspected malformations, dysmorphic or genetic syndromes
- Relevant family history of chromosomal or genetic disorders
- Relevant chromosomal or genetic disorder - will be assessed on individual basis
- Previous relevant structural anomaly - will be assessed on individual basis.
- Ultrasound guided Invasive testing – i.e Chorionic villus sampling, amniocentesis, fetal blood sampling
- Ultrasound guided therapies – i.e Amniotic fluid drainage, transfusion therapy, feto-amniotic shunting,

- Procedures for the selective reduction of high multiple pregnancies (Triplets or greater)
- Complicated multiple pregnancies – TTTS, growth discrepancy etc.

- Feticide in pregnancies greater than 21+6 weeks

If you are unsure regarding referral criteria, please contact the fetal medicine unit at UHW directly to discuss the details t: 029 20 742279.

Referral Process:

When referring to the fetal medicine unit (FMU) specialist service; the FMU referral form should be **typed**, completed accurately and concisely and e-mailed to: fetal.med@wales.nhs.uk. Please note that hand written or paper copy referrals are not accepted. All (e-mail) referrals must be approved by and copied to the named referring consultant, to ensure effective communication the consultant must be named on the form to avoid a declined referral.

The urgency of the referral should be highlighted as 1 of 3 categories by the referrer:

- **Emergency**: *Consultant to Consultant - FMU consultant if available, if not the call On-call Obstetric consultant (UHW switchboard:029 207 47747).*
- **Urgent**: *Seen in FMU within 5 working days*
- **Routine**: *Next appropriate appointment (at appropriate gestation for appointment).*

A recent blood group (current pregnancy) result MUST be included with the referral, if no recent result is available then a rapid 'Group and Save' should be taken by the referring unit and the result should be sent to FMU, UHW prior to the initial appointment.

Any additional information should be attached with the referral where possible, for example the First Trimester Screening result, and this should be indicated on the referral form. It is crucial that any significant medical or social history **including safeguarding concerns** is documented on the referral form.

Triage of referrals received prior to 13.00 hrs, will be carried out daily - Monday to Friday (with the exception of bank holidays) by the Fetal Medicine team; for referrals received after 13.00 hrs the next working day will be classified as the referral date:

An accepted referral; an FMU appointment will be allocated to the woman directly by letter (including the FMU patient information leaflet), which will be posted to the home address on the referral form. However, if it is anticipated that the letter will not be received before the appointment date, the woman will receive a telephone call / text with the appointment details. The woman should ideally be offered an appointment within five working days of the received referral, unless a later appointment is appropriate for the clinical picture. Antenatal Screening Wales – Antenatal Screening Wales Policy, Standards and Protocols (ASW 2023).

A declined referral; if the FMU referral is declined a fetal medicine midwife will contact (usually by replying to the referral email) the referring unit midwife (the midwife named on the referral form if possible) with an

explanation and if relevant a suggested plan of care or re referral criteria (a hard copy is filed in 'Hub and Spoke' file within FMU).

Responsibilities of the Referring unit:

- Where a fetal anomaly is identified, the sonographer must arrange for an appropriately trained midwife or obstetrician to discuss findings with the women as soon as possible (must be within 24 hours) and refer to FMU (with informed consent) where appropriate (ASW 2023).
- To continue to provide local antenatal care to the woman, including in the event of an FMU indicated transfer of care for delivery. The local unit will please note that fetal medicine care is an additional service and does not replace routine antenatal care (NICE 2021). This includes local delivery care or termination services when appropriate.
- To action test results for the woman's convenience, for example providing medication if indicated. Results are available on the Welsh Clinical portal; all tests taken will be documented on the FMU summary viewpoint letter / report which is completed after each consultation available on WCP.
- Send representatives from each referring unit from the Obstetric, Midwifery and Neonatal Teams to attend the weekly FMU MDT.
- Should the woman decide to have an MTOP following any referrals to FMU, the referring unit is required to inform FMU promptly.
- The UHW midwife attending the birth of a baby to a woman that attended FMU antenatally, is responsible for promptly e-mailing birth details to fetal.med@wales.nhs.uk, following the birth.
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- Following birth, miscarriage or termination of pregnancy outside of UHW the referring unit is responsible for updating FMU in a timely manner ('outcome request' compliance audit), to include:
    1. Date of Birth
    2. Time of Birth
    3. If Live birth / MTOP / Stillbirth / NND etc.
    4. Mode of Birth – (IOL / Spontaneous onset) SVD / ELCS / EMCS / Ventouse / Forceps etc.
    5. Sex of baby
    6. Birth Weight
    7. Apgar Scores
    8. Resuscitation information
    9. Ongoing care details
    10. Additional relevant details, including postnatal diagnosis.

***Important note to referring units** – It is their responsibility and role to provide this information (outcome request) and it is vital to the Fetal Medicine Unit audit and evaluation process. The audit and evaluation process are critical to the provision of ongoing NHS tertiary fetal medicine services.*

Fetal Medicine - Multidisciplinary Team Meeting (MDT):

- The MDT takes place weekly on Thursday mornings between 09.00 to 10.00 hrs on the FMU Teams Chanel. Attendees includes consultant obstetricians, specialist midwives, neonatologists, paediatric surgeons, nephrologists, radiologists, cardiologists, geneticists, pathologists, palliative care team etc. Sign in is via the chat function.
- The MDT enables the FMU team to inform / update other specialty colleagues of newly identified and ongoing cases under surveillance. Decisions regarding additional tests, referrals, care planning and place of delivery for complex cases requiring multi-disciplinary input will be discussed and agreed.
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- The Clinical Genetic team will advise both FMU and Neonatal / paediatric colleagues of genetic implications of an anomaly under discussion if applicable.
- A record of antenatal, intrapartum and postnatal cases discussed at the MDT will be kept on the FMU database on the teams chanel. This record will be brief points of pertinent information only. The MDT database record is available on the FMU Teams Chanel.
- The multidisciplinary team will update the FMU team with details of babies currently on the Neonatal Unit and those who remain under paediatric review, who were seen antenatally in FMU (NHS 2013).
- The neonatal team should discuss babies with postnatally diagnosed abnormalities at the MDT and the antenatal sonographic history may be reviewed if relevant. If a missed antenatal diagnosis is probable, the appropriate lead clinician should review the case (ASW 2023).
- Occasionally the MDT will present Learning Opportunities including rare case reviews and disseminating relevant service information.

References:

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