The Newcastle upon Tyne Hospitals NHS Foundation Trust

Maternity: Fetal Abnormality Referral Pathway

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1 Introduction

Pregnant women are routinely offered two scans to screen for fetal abnormalities during their pregnancy. This is in keeping with guidance from the National Screening Committee. The first scan, performed between 11 and 14 weeks gestation, provides an estimated due date following measurement of a fetal crown rump length (CRL). Basic fetal anatomy is assessed at this point and screening for Trisomies 21, 18 and 13, is offered by means of the Combined Test. The second scan, performed between 18+0 and 20+6 weeks gestation, provides a detailed anatomical assessment of the fetus.

If a fetal structural anomaly is suspected at either of these scans, the woman is an offered an appointment in the Fetal Medicine Unit (FMU) for further assessment.

2 Scope

The guideline relates to all women who require referral to the RVI Fetal Medicine Unit due to a suspected fetal anomaly. Specific guidance is given regarding those women who are advised to deliver at the RVI on fetal grounds. The guideline also covers standards of diagnostic accuracy in those women who have their 18+0 – 20+6 screening ultrasound at the RVI.

2.1 Aims

To outline the referral process to the Fetal Medicine Unit and proposed timing for review of a suspected fetal anomaly from the point of referral.

To comply with the NSC standards for detection rates for the 11 auditable conditions.

To give guidance as to which specialist clinic within the FMU is appropriate for initial referral or subsequent follow up**.**

To outline procedures for informing allied specialities (midwives, obstetricians, paediatric surgeons, cardiologists or neonatologists) of the suspected diagnosis and the expected delivery date of a baby in whom their input is anticipated.

3 Fetal Abnormality Referral pathway

3.1 If a fetal anomaly is suspected

Fetal Medicine Unit (FMU) referrals are accepted internally, from the RVI, and externally from obstetric units across the North East and Cumbria. Referrals are managed electronically. With the adoption of BadgerNet referrals are now being sent to the fetal medicine inbox (tnu-tr.fetalmedicine-nuth@nhs.net). If there are issues with BadgerNet then a standardised e-referral form should be sent to tnu-tr.fetalmedicine-nuth@nhs.net. Referrals are reviewed every working day by a consultant.

A Fetal Medicine Unit (FMU) appointment will subsequently be arranged as soon as possible. Please see appendix 1 for the agreed referral criteria and expected time frames.

Structural problems not considered “major or life threatening” will be offered an appointment as soon as possible, ideally within a week. In some instances (i.e. early booking following a previously affected pregnancy) or if specific expertise of a specialist clinic is indicated, an appointment will be organised at an appropriate time for the patient.

In the event of possible fetal compromise identified on an ultrasound scan, the referrer is advised to telephone the Fetal Medicine Unit directly on 0191 28(25837) to make an urgent referral. Please see appendix 1.

3.2 Anomaly detection rates (screening US)

Antenatal ultrasound is a screening tool for fetal anomalies. To comply with the current National Screening Guidelines we audit data on the 11 auditable conditions; the NSC standards for predicted detection rates are given below.

1.	Anencephaly	98%
2.	Open spina bifida	90%
3.	Cleft lip	75%
4.	Diaphragmatic hernia	60%
5.	Gastroschisis	98%
6.	Exomphalos	80%
7.	Serious cardiac anomalies	50%
8.	Bilateral renal agenesis	84%
9.	Lethal skeletal anomaly	60%
10.	Trisomy 18	95%
11.	Trisomy 13	95%

For Trisomies 13 and 18, if it is documented that invasive diagnostic testing has been offered but declined and the subsequent neonatal diagnosis is Trisomy 13 or 18 then this will not constitute a missed diagnosis.

For audit purposes, a serious cardiac anomaly is defined as one that might have been identified antenatally, and required medication or surgical intervention in the early neonatal period. Some of the more common cardiac conditions that the definition therefore excludes are:

- Atrial septal defects (typically postnatal failure of foramen ovale closure)
- Isolated ventricular septal defect(s) (many asymptomatic)
- Late presenting coarctation of the aorta (may develop after delivery on closure of the ductus venosus)
- Bicuspid aortic valve
- Cardiomyopathy (serious condition but a paediatric diagnosis)
- Trivial valve regurgitation or stenosis
- Recognised variations of normal cardiac anatomy, bilateral superior vena cava, uncomplicated situs anomalies.

3.3 Documentation following fetal medicine review

Viewpoint software is used to document the ultrasound findings, including specific measurements taken during the ultrasound scan, structures that have been identified and a comment on their appearance. In the event of identifying an anomaly, additional text will describe the explanation to the patient, options for further testing, likely prognosis and proposed plans for the remainder of the pregnancy. This documentation is also entered into the patients BadgerNet record under ‘fetal medicine specialist review’. The ultrasound report will also be uploaded to the patients BadgerNet record.

Electronic copies of reports will be sent to NCARDS and specialities involved that are not using BadgerNet.

3.4 Communication between obstetric, neonatal and specialist staff

3.4.1 Neonatal unit referral and fetal care plans

In order to inform the neonatal team about a fetus with a problem that may require neonatal input a neonatal unit referral will be filled out on the patients BadgerNet record. All ongoing fetal medicine patients should have this done by 32 weeks. There referrals will be reviewed by the neonatal consultants and a fetal care plan will be entered onto the patients BadgerNet record. Any significant change in the fetal condition should trigger the need for a further updated neonatal unit referral.

3.4.2 Fetal / Neonatal Meeting

A regular combined fetal medicine and neonatal is held usually every 2 weeks. At these meetings, all cases of fetal anomaly expected to deliver at the RVI prior to the next meeting are discussed. Recently delivered FMU cases or cases of unsuspected anomaly may also be presented by the neonatology team. Fetal care plans can be checked as up to date as part of this MDT review

3.4.3 Joint Surgical clinic

Women with ongoing pregnancies that are likely to require paediatric surgical input are offered an appointment at the joint surgical clinic on at least one occasion during the pregnancy, to facilitate counselling from a member of the paediatric surgical team. Typically this is most appropriate during the early third trimester.

3.4.4 Joint Cardiac Clinic

Women with a suspected fetal cardiac anomaly are referred into one of the twice weekly cardiac fetal medicine clinics. These clinics facilitate input from Cardiac Liaison Nurses and Paediatrics. Subsequent follow up is individualised, and may be at the referring hospital, within the joint cardiac clinic or within a general fetal medicine clinic.

3.4.5 Joint renal clinic

Women with a suspected fetal renal anomaly will be offered a review in renal clinic at least one time during their pregnancy. At these clinics, a consultant from the paediatric renal team will offer individualised counselling following fetal ultrasound assessment and plan postnatal follow up.

3.5 Delivery Care Plan

Please see section 3.4.1 regarding generation of fetal care plans which cover initial post-delivery neonatal management.

If a planned delivery date is recommended, the Fetal Medicine Unit will inform the patient and, as appropriate: the neonatal team, paediatric surgeons (via secretary of Mr Lall Consultant paediatric surgeon), paediatric neurosurgeons (via secretary of Miss Nicholson, Consultant Neurosurgeon), paediatric cardiologists (via the secretary to Dr Magda Sajnach Menke) and/or other specialist teams involved. This communication will be documented in the maternal BadgerNet record.

If delivery is planned due to a significant measurable quantity of maternal antibodies, blood bank and blood transfusion reference lab will be informed of the planned date due to the risk of possible neonatal exchange transfusion. This will be reflected in the neonatal unit referral.

3.6 Unexpected abnormalities identified at birth

Some congenital abnormalities will go undetected and are only evident after birth. The parents should be kept informed of any concerns that are suspected and the neonatologist should be asked to review the baby as soon as appropriate. Support for the parents will be paramount. If an anomaly that might have been recognised antenatally is confirmed then a Datix form is completed to ensure that these missed abnormalities are reported.

4 Training, Implementation, Resource Implications

The 3 working day target from referral to review is regularly audited and information is provided to NHS England Specialist Quality Dashboard. If the FMU is unsuccessful in meeting appointment targets, clinic resources and staffing will be re-evaluated.

5 Monitoring compliance

Standard / process / issue	***Monitoring and audit***			
	Method	***By***	***Committee***	***Frequency***
1 Interval between referral with suspected anomaly and earliest offered FMU appointment. 90% within 3 working days from referral	Continuous monitoring by reception staff. Proportion of eligible new referrals offered appointment within 3 working days.	FM lead	Fetal Medicine Audit Group	Quarterly
2. Detection rates for the 11 NSC screening anomalies (annual dataset). Rates achieved in accordance with current (2013) NSC guidance	Reported by NCARDS annually, and triangulated with DATIX for 'missed' anomalies.	FM lead	Fetal Medicine Audit Group Antenatal Group	Annually (reported every 3 years due to small numbers)
3. Surgical cases reviewed in joint surgical clinic. One or more appointment offered in joint surgical clinic for ongoing pregnancies delivering at RVI (90%).	Snapshot audit of 10 sets of notes annually	FM lead	Fetal Medicine Audit Group	Annually*
4. Cardiac cases reviewed in joint cardiac clinic. One or more appointments offered for cardiac clinic for ongoing pregnancies delivering at RVI (90%).	Snapshot audit of 10 sets of notes annually	FM lead	Fetal Medicine Audit Group	Annually*
5. Liaison with all key professionals to inform them of the planned delivery date for conditions requiring paediatric or neonatal review. Documentation of key professionals informed where a planned delivery date is required.	Snapshot audit of 10 sets of notes annually	FM lead	Fetal Medicine Audit Group	Annually *
* Repeat within 6 months if standard not met.				

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Appendix 1.

Fetal medicine Unit referral criteria:

The intended purpose of this document is to standardise referrals that will be considered for review in the Fetal Medicine Unit, Newcastle upon Tyne. This is to be considered as guidance only.
NHS England Specialist Services Quality Dashboard suggest that mothers with the following should be seen within a defined period (3 working days).

1. Conditions which would be lethal, or likely to be associated with a significant handicap after birth
2. Conditions which may indicate a high risk of a genetic or chromosomal abnormality
3. Conditions that would need neonatal surgery or medical intervention

All queries regarding a family or pregnancy history that are genetic in nature should be submitted to the Clinical Genetics department via **nuth.fetalgenetics@nhs.net** . Suitable referrals will be screened and subsequently referred to the Fetal Medicine Unit via the genetics team.

Same day referral (please telephone 0191 2825837):

Inter-fetal transfusion, stage 2 or above
Fetal growth restriction with absent or reversed umbilical artery EDF
Suspected fetal anaemia
Fetal hydrops >16 weeks

3 day referrals (please complete e-referral form and email to tnu-tr.fetalmedicine-nuth@nhs.net):

“Increased chance” result detected at CT/Quad test/NIPT wanting diagnostic test For increased NT ≥3.5mm please see pathway
Cystic hygroma
Multiple structural anomalies
Severe small for gestation baby (EFW <3rd centile <24 weeks gestation)
Intracranial anomalies (for microcephaly please see the regional pathway)
Anencephaly/ exencephaly/ acrania (Referrals within RVI: follow acrania pathway. Referrals out with RVI: refer only if diagnostic uncertainty with attached imaging.)
Spina bifida
Encephalocele
Exomphalos
Gastroschisis
Suspected skeletal dysplasia: abnormal structure of long bones and/or long bones >3 SD below mean. (See short femur guidance.)
Megacystis
Congenital diaphragmatic hernia
Hydrops
CPAM with mediastinal shift
Suspected or confirmed Cardiac anomaly (structural and arrhythmia)
Intra-abdominal cyst/ “double bubble”/ dilated bowel (for dilated bowel see pathway)
Limb reduction defect

Radial ray anomaly
Multiple joint abnormalities (fetal akinesia appearance)
Body stalk anomaly
Cloacal anomaly
Inter-fetal transfusion Stage 1/ sub stage 1.
Sacrococcygeal teratoma
Bilateral renal agenesis
Bilateral multicystic kidneys
Micrognathia
Maternal antibodies (above a titre at risk of HDFN)
Suspected congenital infection
Severe oligohydramnios/ anhydramnios at extreme preterm gestation (<24 weeks)
Pleural effusion with **normal umbilical artery and MCA Doppler** (otherwise same day referral)
Ascites with **normal umbilical artery and MCA Doppler** (otherwise same day referral)
Midline or bilateral facial cleft

Suitable for referral (not considered necessary to see within 3 working day. Attempt to see within 1 week of referral):

Echogenic bowel
Unilateral facial cleft
Talipes
Duplex kidney
Unilateral multicystic kidney
Unilateral renal agenesis
Moderate to severe hydronephrosis (see regional pathway)
Placental abnormality
Growth discrepancy in monochorionic pregnancy >25%
MCMA twin pregnancy
Multiple pregnancy >twins
Small baby (less than 3rd centile) 24-28 weeks with normal umbilical artery Doppler
CPAM without mediastinal shift
Isolated polyhydramnios (DVP >12cm with normal maternal diabetes assessment)

Suitable clinic:

LLP with previous uterine surgery
Screening echocardiogram for family history (congenital heart disease [requiring intervention in the first year of life] in patient, partner or previous pregnancy/sibling) or patient with history of poorly controlled diabetes (HbA1c >68 mmol/mol at booking), maternal PKU, maternal anti ro/la antibodies
Invasive diagnostic test referred from **genetics** due to patient/ family history
Fetal anomaly in previous pregnancy
LLP at 32 weeks (RVI pathway only)