NHS England

# SCHEDULE 2 – THE SERVICES

## A. Service Specifications

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| **Service Specification No.** | **E12a** |
| **Service** | Specialised Fetal Medicine Services |
| **Commissioner Lead** | |
| **Provider Lead** | |
| **Period** | |
| **Date of Review** | |

## 1. Population Needs

### 1.1 National/local context and evidence base

Fetal medicine is the branch of medicine that provides care for the fetus (or fetuses) and mother. This includes the assessment of fetal growth and wellbeing and the diagnosis and management of fetal disorders (including fetal abnormalities) and counselling and support for parents.

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 specialist Fetal Medicine Centre is one (a) staffed by at least two subspecialist consultants (i.e. those who are accredited subspecialists in Maternal and Fetal Medicine having successfully completed a RCOG subspecialty training programme), (b) which provides a full range of prenatal diagnostic and fetal therapeutic services in collaboration (and co-located) with other specialist services (see below) and (c) which is approved by RCOG for subspecialty training in Maternal and Fetal Medicine. A few rare and complex therapies are only provided in a more limited number of centres (typically no more than five).

The rationale for these services being specialised is the complexity of the investigations and / or treatment involved requires a sufficient volume of cases to be concentrated in a specialist centre to maintain expertise e.g. management of a potentially correctable fetal malformation.

Once the diagnosis is confirmed (and it is not always possible to make a definitive diagnosis) a number of pregnancies will require joint management with other specialties including: medical genetics, radiology, virology, microbiology, neonatology, paediatric surgery, paediatric cardiology, paediatric nephrology/urology, paediatric neurology, facial

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cleft services and (specialist) gynaecology. Delivery or termination of pregnancy may be arranged at the woman's local hospital.

## 2. Outcomes

### 2.1 NHS Outcomes Framework Domains & Indicators

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|---|---|---|
| **Domain 1** | **Preventing people from dying prematurely** | |
| **Domain 2** | **Enhancing quality of life for people with long-term conditions** | |
| **Domain 3** | **Helping people to recover from episodes of ill-health or following injury** | |
| **Domain 4** | **Ensuring people have a positive experience of care** | √ |
| **Domain 5** | **Treating and caring for people in safe environment and protecting them from avoidable harm** | √ |

Provide a tertiary service to support women requiring specialist support before, during and after pregnancy.

Planned and mapped care for women with a fetal medicine problem.

Social, economic and psychological benefits for families.

The provider will ensure equity of access including:

- Vulnerable and hard to reach groups
- Disadvantaged groups, asylum seekers, refugees, gypsies and travelers
- Women with learning disabilities
- Women with physical disabilities
- Women with translation/interpretation/advocacy issues

Care and information should be appropriate and the woman's cultural practices should be taken into account. All information should be provided in a form that is accessible to women, their partners and families, taking into account any additional needs, such as physical, cognitive or sensory disabilities, and people who do not speak or read English.

Women and their families should always be treated with kindness, respect and dignity.

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The views, beliefs and values of the woman, her partner and her family in relation to her care and that of her baby should be sought and respected at all times.

**Accessibility/ Acceptability**

The service will be flexible and responsive, adapting to the individual needs of the baby and family.

The provider will provide a service that is based on the principle of equal access for all and one that is responsive to diverse needs and is free from stereotyping and discriminatory practices.

## 3. Scope

### 3.1 Aims and objectives of service

The aim of specialised Fetal Medicine services is to provide patient focused high quality evidence-based care to women with complex pregnancies or whose fetus (or fetuses) has a confirmed or suspected disorder. The ability to improve the outcome of some fetal disorders has developed because of advances in prenatal diagnosis and therapy. Fetal medicine is the specialty that focuses on fetal health and its consequences for women and their families.

**Objectives of the service:**

To provide a safe and effective care pathway for women and babies with a fetal abnormality or fetal disorder.

To provide social, economic and psychological benefits for the mother and fetus

To provide a high level of care and support to local maternity and obstetric services

To provide continuity of care.

### 3.2 Service description/care pathway

Specialised fetal medicine services include prenatal diagnosis and fetal therapy as well as pre and postnatal counselling about future risks and appropriate management strategies, where it takes place in a recognised Fetal Medicine Centre. There are less than 20 specialist Fetal Medicine centres in England, each specialist Fetal Medicine centre team works closely with obstetric and genetic services as well as neonatal and paediatric services.

Fetal medicine involves the assessment of the unborn fetus mainly by ultrasound. This may allow monitoring of certain conditions, the diagnosis of congenital disorders, in utero therapy, optimisation of time and place of delivery and optimisation of postnatal management. In some cases of serious or potentially serious underlying fetal conditions, termination of pregnancy will be discussed and can also be arranged.

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All aspects of advanced fetal medicine are practised in Fetal Medicine Centres. Services include all forms of invasive prenatal diagnosis (including chorionic villus sampling, amniocentesis and fetal blood and urine sampling), management of severely anaemic and thrombocytopaenic fetuses with in utero transfusions and insertion of shunts to allow drainage of over distended organs (e.g. the fetal bladder). A minority of fetal interventions (e.g. fetoscopic laser ablation of placental vessels for twin-twin transfusion syndrome) are available in a more limited number of Fetal Medicine Centres.

### 3.3 Population covered

The service outlined in this specification is for patients ordinarily resident in England*, or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

Note: for the purposes of commissioning health services, this excludes patients who, whilst resident in England, are registered with a GP Practice in Wales, but includes patients resident in Wales who are registered with a GP Practice in England.

Specifically, this service is for the following circumstances, which will generate a referral:

- Fetal abnormality suspected / detected during ultrasound screening (+/- biochemical screening).
- Pregnancy complicated by a genetic abnormality (suspected recurrence).
- Pregnancy complicated by possible fetal infection
- Severe fetal growth restriction (most commonly presenting before 32 weeks gestation)
- Twin pregnancy with complications
- Triplet and higher order multiple pregnancy

Entry to fetal medicine specialist services is by referral from an obstetrician, GP or midwife.

### Operational Delivery Network

Clear documented pathways for care will be in place between networked units. This will offer opportunities for co-commissioning with Clinical Commissioning Groups to improve service integration and patient care.

There will be an Operational Delivery Network (ODN) expected for this service area, subject to further definition. ODNs will ensure quality standards and networked patient pathways are in place. They will focus on an operational role, supporting the activity of provider trusts in service delivery, improvement and delivery of a commissioned pathway, with a key focus on the quality and equity of access to service provision. This will allow for more local determination, innovation and efficiency across the pathway. ODNs

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support the delivery of Right Care principles by incentivising a system to manage the right patient in the right place

### 3.4 Any acceptance and exclusion criteria and thresholds

#### Acceptance

Fetal Medicine Services include all care provided by Fetal Medicine Centres including out-reach when delivered as part of a provider network. Centres will also provide care for other non-specialised cases which are beyond the scope of this specification - such cases will form part of the contract with the Clinical Commissioning Groups and would be paid through the maternity pathway payment.

It is also acknowledged that smaller fetal medicine units (staffed by specialists in fetal medicine) may provide elements of specialised care. Where a Trust provides specialised fetal medicine services, as described in this specification, this will only be commissioned by the NHS ENGLAND where the service is compliant with this specification or derogation plans have been discussed and agreed.

If required expertise is not available through the provider network or if the problem is complex then the woman is referred to a specialist Fetal Medicine Centre for a fetal medicine assessment.

**Exclusions:**

- Routine screening for fetal abnormalities (including trisomy 21) and fetal diseases (such as rhesus isoimmunisation), as well as routine assessment of fetal wellbeing, is undertaken by most maternity units and is not a specialised service.

- Chorion Villus Sampling (CHORIONIC VILLUS that takes place in a non specialist centre is not a specialised fetal medicine service).

- After the initial screening, if a fetal problem is suspected, further assessment will be required. In some cases, e.g. common fetal abnormalities with a clear prognosis such as anencephaly, assessment typically involving ultrasound scanning will be performed by an obstetrician with a special interest in fetal medicine (Advanced Training Skills Module in Fetal Medicine) at the woman's local hospital.

The same obstetrician may also manage the pregnancy, this not a specialised service.

### 3.5 Interdependencies with other services/providers

#### Whole System Relationships/ Interdependencies

Centres that provide this service will also need defined links to other services within the specialised services definition sets.

Medical genetic services (all ages) - laboratory testing for Down's syndrome, other pre-pregnancy and antenatal genetic problems and pre-implantation genetic diagnosis services.

Complex child and adolescent gynaecology, neonatal care, paediatric cardiology, paediatric surgery, paediatric endocrinology and paediatric urology/nephrology services.

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The provider will facilitate and develop robust two-way mechanisms for women who require onward referral to other services where required. The provider will also ensure important information is communicated across services (in line with governance policy), including maintaining patient records efficiently.

It is essential that there is a robust relationship with community provider services to ensure effective two way communication and efficient handover to the general obstetric teams and midwifery teams. It is important that the community provider services are fully aware of the details and individual circumstances for every woman and baby who resides in their community.

The provider will be expected to liaise with neighbouring Fetal Medicine teams to facilitate repatriation to local services

**Multidisciplinary assessments / imaging / counselling**:

Joint working with other specialties e.g. neonatologists, paediatric surgeons, clinical geneticists, paediatric cardiologists, paediatric urologists/nephrologists, paediatric neurologists, radiologists, virologists, microbiologists.

**Relevant Networks/ Programmes**

The provider will need to participate actively in a range of appropriate networks and screening programmes including the following:

- Maternity and Newborn Networks
- Neonatal Networks
- Newborn screening programme
- Genetic Networks

## 4. Applicable Service Standards

### 4.1 Applicable national standards e.g. NICE

- *Maternity Matters: Choice, access and continuity of care in a safe service*, Department of Health, 2007 sets out the Government's commitment for modern NHS maternity services and provides a national framework for local delivery.

- Specialised Services National Definition Set, Definition No.4, Specialised Services for Women's Health (3rd edition)

- The NHS Fetal Anomaly Screening Programme has produced a number of standards and policies in collaboration with the UK National Screening Committee, which recommend the best working practice for health

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professionals to work towards within Down's syndrome and Fetal Anomaly screening.

- *Antenatal and Postnatal Mental Health: Clinical Management and Service Guidance*, National Institute of Clinical Excellence, clinical guideline 45, 2007
- NHS Operating Framework, Department of Health, 2008
- *NHS 2010–2015: from good to great. Preventative, people-centred, productive*, Department of Health, 2009
- *You're Welcome quality criteria; Making health services young people friendly*, Department of Health, 2007
- *Getting maternity services right for pregnant teenagers and young fathers*, Department of Children Schools and Families and Department of Health, 2008

**4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)**

Other national guidance is as follows:

- The code: Standards of conduct, performance and ethics for nurses and midwives, Nursing and Midwifery Council. The Code, 2008
- Safer Childbirth: Minimum Standards for the Organisation, Delivery of Care in Labour, Royal College of Obstetricians and Gynaecologists (RCOG), 2007)
- Standards for Maternity Care, RCOG, 2008
- Standards for Hospitals Providing Neonatal Intensive and High Dependency Care, British Association of Perinatal Medicine (BAPM), 2001
- Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales, RCOG, 2010
- Amniocentesis and Chorionic Villus Sampling, Policy, Standards and Protocols, Fetal Abnormality Screening Programme, 2008
- NHS Fetal Anomaly Screening Programme Standards for Screening (2010)
- Small-for-Gestational-Age Fetus, Investigation and Management (Green-top Guideline 31), RCOG 2014.
- Red Cell Antibodies during Pregnancy, The Management of Women with (Green-top Guideline 65), RCOG 2014
- Thalassaemia in Pregnancy, Management of Beta (Green-top Guideline No.66), RCOG 2014
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**Report of a working party**

- Management of monochorionic twin pregnancy, (Green-top Guideline 51), RCOG, 2008
- Amniocentesis and chorionic villus sampling (Green-top Guideline 8), RCOG 2005
- Ultrasound screening for fetal abnormalities, report of the RCOG

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| Working Party (1997) and Supplement (2000), ROCG 1997 & 2000 |
| **5. Applicable quality requirements and CQUIN goals** |
| **5.1 Applicable quality requirements (See Schedule 4 Parts A-D)**<br>These are in the process of being developed and will be updated once agreed.<br>**5.2 Applicable CQUIN goals (See Schedule 4 Part E)**<br>These are in the process of being developed and will be updated once agreed. |
| **6. Location of Provider Premises** |
| N/A |
| **7. Individual Service User Placement** |
| N/A |

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## Appendix Two

**Quality standards specific to the service using the following template:**

| Quality Requirement | Threshold | Method of Measurement | Consequence of breach |
|---|---|---|---|
| **Domain 1: Preventing people dying prematurely** | | | |
| Insert text | | | |
| **Domain 2: Enhancing the quality of life of people with long-term conditions** | | | |
| Insert text | | | |
| **Domain 3: Helping people to recover from episodes of ill-health or following injury** | | | |
| Insert text | | | |
| **Domain 4: Ensuring that people have a positive experience of care** | | | |
| Referred women should have a good understanding of | All women referred should receive a questionnaire | Dashboard returns<br><br>Questionnaire (6 | Audit and benchmarking |

| Quality Requirement | Threshold | Method of Measurement | Consequence of breach |
|---|---|---|---|
| their baby's problem and the proposed management and should be involved in decisions about their management. (1=strongly agree; 5= strongly disagree)) | | questions scored 1-5 | |
| **Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm** | | | |
| The outcome of invasive diagnostic procedures (amniocentesis) should be determined to identify the frequency of fetal loss (excluding termination of pregnancy). | Total fetal loss rate within 14 days after any invasive diagnostic sampling procedure (amniocentesis) to be recorded and reported | Dashboard | Audit and benchmarking |

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