

## Fetal Anomalies

<b>Classification :</b>	Guideline		
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<b>Departments/Group this Document applies to:</b>	Maternity, Paediatrics, Sonography		
<b>Approval Group:</b> Women's Guideline Review Group, Women's Health CIG	<b>Date of Approval:</b>	07/10/2020	
	<b>Last Review:</b>	09/2020	
	<b>Review Date:</b>	01/10/2023	
<b>Unique Identifier:</b> MIDW/GL/146	<b>Status:</b> Approved	<b>Version No:</b> 5	
<b>Guideline to be followed by (target staff):</b> Sonographers, ANNB Screening Midwives, Paediatricians, Advanced Neonatal Practitioners (ANNP), Midwives			
<b>To be read in conjunction with the following documents:</b>			
<ul style="list-style-type: none"> <li>• Screening in Pregnancy guideline</li> <li>• Screening for Down's, Edwards' and Patau's Syndromes guideline</li> <li>• Intrauterine Death, Termination of Pregnancy, Miscarriage and Neonatal Death before 24/40 Gestation</li> <li>• Intrauterine Death, Termination of Pregnancy, Stillbirth and Neonatal Death after 24/40 Gestation</li> </ul>			
<b>CQC Fundamental standards:</b>			
Regulation 9 – person centred care			
Regulation 10 – dignity and respect			
Regulation 11 – Need for consent			
Regulation 12 – Safe care and treatment			

### Disclaimer –

Since every patient's history is different, and even the most exhaustive sources of information cannot cover every possible eventuality, you should be aware that all information is provided in this document on the basis that the healthcare professionals responsible for patient care will retain full and sole responsibility for decisions relating to patient care; the document is intended to supplement, not substitute

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for, the expertise and judgment of physicians, pharmacists or other healthcare professionals and should not be taken as an indication of suitability of a particular treatment for a particular individual.

The ultimate responsibility for the use of the guideline, dosage of drugs and correct following of instructions as well as the interpretation of the published material **lies solely with you** as the medical practitioner.

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### Abbreviations:

PHE – Public Health England

MKUH – Milton Keynes University Hospital

OUH – Oxford University Hospital

ANNB – Antenatal & Newborn

Fetal Medicine Unit - FMU

MDT – Multi-disciplinary Team

USS – Ultrasound Scan

CVS – Chorionic Villus Sampling

NCARDRS – National Congenital Anomaly and Rare Disease Registration Service

## Guideline Statement

The aim of this guideline is to standardise the process for referral and management of women who attend for their dating/nuchal, routine fetal anomaly or any subsequent obstetric ultrasound scans, when a fetal anomaly is suspected or confirmed.

### Objectives:

- To ensure correct pathways are followed when a fetal anomaly is suspected/confirmed
- To ensure appropriate and timely referrals are made
- To ensure correct information is provided to the woman and her family

## Executive Summary

- Antenatal screening tests are offered during pregnancy to try to find any health problems that could affect the woman or fetus.
- All pregnant women are offered the opportunity to have ultrasound scans as a screening tool for fetal anomalies.
- To provide early detection of fetal anomalies to facilitate decisions on care in pregnancy and the most appropriate place for birth.
- To provide early detection of fetal abnormalities this will enable women and their families to make an informed decision on whether or not they wish to continue with the pregnancy.

### 1.0 Roles and Responsibilities:

All practitioners to be fully conversant of their roles and responsibilities as outlined in the main body of this guideline.

### 2.0 Implementation and dissemination of document

Dissemination at maternity, sonography and paediatric team meetings, via 'The Grapevine' newsletter and this guideline is available on the Trust intranet.

### 3.0 Processes and procedures

#### 3.1 Sonographers

- Inform parents of their findings and offer immediate referral and discussion with a member of the ANNB Screening Team.
- The majority of abnormal findings on ultrasound scan (USS) will be structural, but an isolated finding such as oligohydramnios should be considered as a warning sign and also referred to the ANNB Screening Team or Fetal Medicine Team.
- To contact ANNB Screening on ext. 85236 or bleep 1169 to inform when an anomaly is suspected. If not available to contact the Obstetric Consultant on-call via bleep 1323.

## 3.2 The role of the Antenatal and Newborn (ANNB) Screening Team

**N.B.** The ANNB Screening Team comprises of the ANNB Screening Co-ordinator, Deputy ANNB Screening Midwife, Failsafe Officer and Lead Consultant Obstetrician.

- On being informed by the Sonographer that a fetal anomaly is suspected, to attend the ultrasound department to see the woman and her family, to explain findings and possible causes/outcomes together with offering support.
- Offer referral to a fetal medicine consultant for further review and confirmation/diagnosis.
- As per Fetal anomaly screening programme standards 8a and 8b, there should be timely referral (local and tertiary as clinically appropriate) when an anomaly is suspected or confirmed.
  - Standard 8a: local referral (MKUH) seen within 3 working days of the fetal anomaly scan
  - Standard 8b: tertiary referral (OUH) seen within 5 working days of the fetal anomaly scan
- Commence screening record sheet (see Appendix 7) and complete NCARDS antenatal data collection form
- Discuss and offer further tests; additional blood tests and diagnostic tests if appropriate; chorionic villus sampling (CVS), Amniocentesis.
- Provide Public Health England (PHE) (2020) NHS Fetal Anomaly Screening Programme: chorionic villus sampling (CVS) and amniocentesis: information for parents leaflet or sign-post to online version.  
Available at:  
<https://www.gov.uk/government/publications/cvs-and-amniocentesis-diagnostic-tests-description-in-brief>
- If a local fetal medicine consultant appointment is unavailable within the timeframe as per standard 8a, the ANNB Screening Team will make a referral to a tertiary unit.
- If referral to a tertiary unit is required, use the appropriate referral form for the relevant hospital: MKUH have a local pathway to refer to Oxford University Hospital (OUH) fetal medicine unit:
  - Complete OUH referral form (see appendices 8) and e-mail via generic email [mkg-tr.mkscreeningmidwives@nhs.net](mailto:mkg-tr.mkscreeningmidwives@nhs.net) to [fetalmedicine.pnd@nhs.net](mailto:fetalmedicine.pnd@nhs.net) who will then contact the woman direct with an appointment when sending a referral ensure to include blood results: blood group, infectious diseases screen, 1<sup>st</sup> or 2<sup>nd</sup> trimester screening results and any relevant ultrasound reports
- The ANNB Screening Team will receive the results of diagnostic testing via their generic email, and will communicate these to the woman and ensure any follow-up care and support is provided as required.

If diagnostic testing is performed at the tertiary unit, they will inform the woman of the result and arrange any follow-up appointments as required. The results will be forwarded to the MKUH ANNB screening team via [mkg-tr.mkscreeningmidwives@nhs.net](mailto:mkg-tr.mkscreeningmidwives@nhs.net) account.

The MKUH ANNB will arrange any local follow-up appointments or further testing if required.

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- The ANNB Screening Team will notify the patient's General Practitioner (GP) and community midwife of the results/findings and document all communication in the woman's electronic maternity records (e-Care).
- If the woman requests termination of pregnancy the ANNB Screening Team will make the necessary arrangements for the procedure in liaison with the relevant fetal medicine consultant and inform the bereavement midwife.
- The ANNB Screening Co-ordinator will monitor and audit the programme and produce both quarterly and annual reports.

### 3.3 Anomaly confirmed and pregnancy continuing

- The ANNB screening midwives ensure a baby alert (Appendix 3) is completed and sent to the consultant paediatricians via email. A baby alert sticker is placed on the woman's handheld notes and a clinical note is completed in the woman's electronic maternity record alerting staff.
- The consultant paediatrician prints a copy and completes a management plan for each individual case. A copy of this is placed in the baby alert folders, on labour ward and in the neonatal unit, for staff to access when a woman is admitted.

The baby alert will be paired with the delivery/postnatal National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) data collection form for completion at delivery by the labour ward midwife; completed forms to be placed in the ANNB tray in the Labour Ward manager's office.

- A monthly multi-disciplinary team (MDT) fetal anomaly meeting is held to review current cases and update individual management plans as required.
  - The MDT consists of: Fetal Medicine Consultant, Consultant Paediatrician, Superintendent Sonographer, ANNB screening midwives, Bereavement Midwife
  - Any undiagnosed cases are also reviewed and discussed at this meeting
- Parents to be kept informed of any changes to the plan of care and provided with support and condition specific information. Along with contact details for appropriate support groups.
- Cases are also presented at the Perinatal mortality meetings

### 3.4 National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

The National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) record those people with congenital abnormalities and rare diseases across the whole of England. This registration service:

- provides a resource for clinicians to support high quality clinical practice
- supports and empowers patients and their carers, by providing information relevant to their disease or disorder
- provides epidemiology and monitoring of the frequency, nature, cause and outcomes of these disorders

- supports all research into congenital anomalies, rare diseases and precision medicine including basic science, cause, prevention, diagnostics, treatment and management
- informs the planning and commissioning of public health and health and social care provision
- provides a resource to monitor, evaluate and audit health and social care services, including the efficacy and outcomes of screening programmes

Public Health England (PHE) has expanded congenital anomaly and rare disease registration to cover the whole population of England, to meet national requirements for high quality public health disease surveillance identified by the Chief Medical Officer. The creation of the NCARDRS is part of the [UK Rare Disease Strategy](#) and the Department of Health 2020 Vision on Rare Diseases.

NCARDRS forms can be found online at:

Antenatal: <https://www.gov.uk/government/publications/ncardrs-antenatal-data-collection>

Delivery/Postnatal: <https://www.gov.uk/government/publications/ncardrs-delivery-data-collection>

Postnatal: <https://www.gov.uk/government/publications/ncardrs-postnatal-data-collection>

Paper copies can also be found on Labour Ward, ANNB Screening office and in the Ultrasound department

***Please see Standard Operating Procedure (SOP): Process for Reporting to the NCARDRS***

### 3.5 Future pregnancies

Where a fetal abnormality or genetic problem has been identified in a previous pregnancy, then an early referral to ANNB should be offered.

### 4.0 Statement of evidence/references

#### References:

Public Health England (PHE) (2018) NHS Fetal Anomaly Screening Programme Handbook: valid from august 2018. London: PHE

Available from <https://www.gov.uk/government/publications/fetal-anomaly-screening-programme-handbook>

Public Health England (PHE) (2020) Fetal Anomaly Screening Programme Standards: valid for data collected from 1<sup>st</sup> April 2020. London: PHE

Available from <https://www.gov.uk/government/publications/fetal-anomaly-screening-programme-standards>

Public Health England (PHE) (2020) 'Screening Tests for you and your Baby' information booklet available in 12 languages and as easy read guides.

Available from: <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief>

#### External weblink references:

Please note that although Milton Keynes University Hospital NHS Foundation Trust may include links to external websites, the Trust is not responsible for the accuracy or content therein.

## 5.0 Governance

### 5.1 Document review history

Version number	Review date	Reviewed by	Changes made
4	July 2017	Women & Children's Health	Reviewed and updated
5	July 2020	Anita Males Antenatal & Newborn Screening Co-ordinator	Reviewed and updated

### 5.2 Consultation History

Stakeholders Name/Board	Area of Expertise	Date Sent	Date Received	Comments	Endorsed Yes/No
Anita Males	ANNB Screening Co-ordinator			Reviewed and updated	
Caroline Midgeley	Quality Assurance Adviser	November 2019	29.06.20	Acknowledged and included	
Julie Cooper	Head of Midwifery	September 2020	28.09.2020	Acknowledged and included	

### 5.3 Audit and monitoring

Audit Criteria	Tool	Audit Lead	Frequency of Audit	Responsible Committee	How changes will be implemented	Responsibility for Actions
a) Compliance with the standards of the process outlined in this guideline. b) Referrals to tertiary units c) Timeliness of referral	a) Audit of notes b) 'Referral log' c) 'Baby alert' forms	Screening Co-ordinator	Annually	a) NHS England Screening Board b) Women's Health CIG	Action plan to be completed	Screening Co-ordinator

## 5.4 Equality Impact Assessment

As part of its development this Guideline and its impact on equality has been reviewed. The purpose of the assessment is to minimise and if possible remove any disproportionate impact on the grounds of race, gender, disability, age, sexual orientation, religion or belief, pregnancy and maternity, gender reassignment or marriage and civil partnership. No detriment was identified. Equality Impact assessments will show any future actions required to overcome any identified barriers or discriminatory practice.

Equality Impact Assessment			
Division	Women & Children's	Department	Maternity
Person completing the EqIA	Anita Males	Contact No.	01908 995236
Others involved:		Date of assessment:	04.09.2020
Existing policy/service		New policy/service	
Will patients, carers, the public or staff be affected by the policy/service?		Yes	
If staff, how many/which groups will be affected?			
Protected characteristic	Any impact?	Comments	
Age	NO	Positive impact as the policy aims to recognise diversity, promote inclusion and fair treatment for patients and staff	
Disability	NO		
Gender reassignment	NO		
Marriage and civil partnership	NO		
Pregnancy and maternity	NO		
Race	NO		
Religion or belief	NO		
Sex	NO		
Sexual orientation	NO		
What consultation method(s) have you carried out?			
<i>For example: focus groups, face-to-face meetings, PRG, etc</i>			
How are the changes/amendments to the policies/services communicated?			
<i>email, community midwife meetings, intranet post</i>			
What future actions need to be taken to overcome any barriers or discrimination?			
What?	Who will lead this?	Date of completion	Resources needed
Review date of EqIA			



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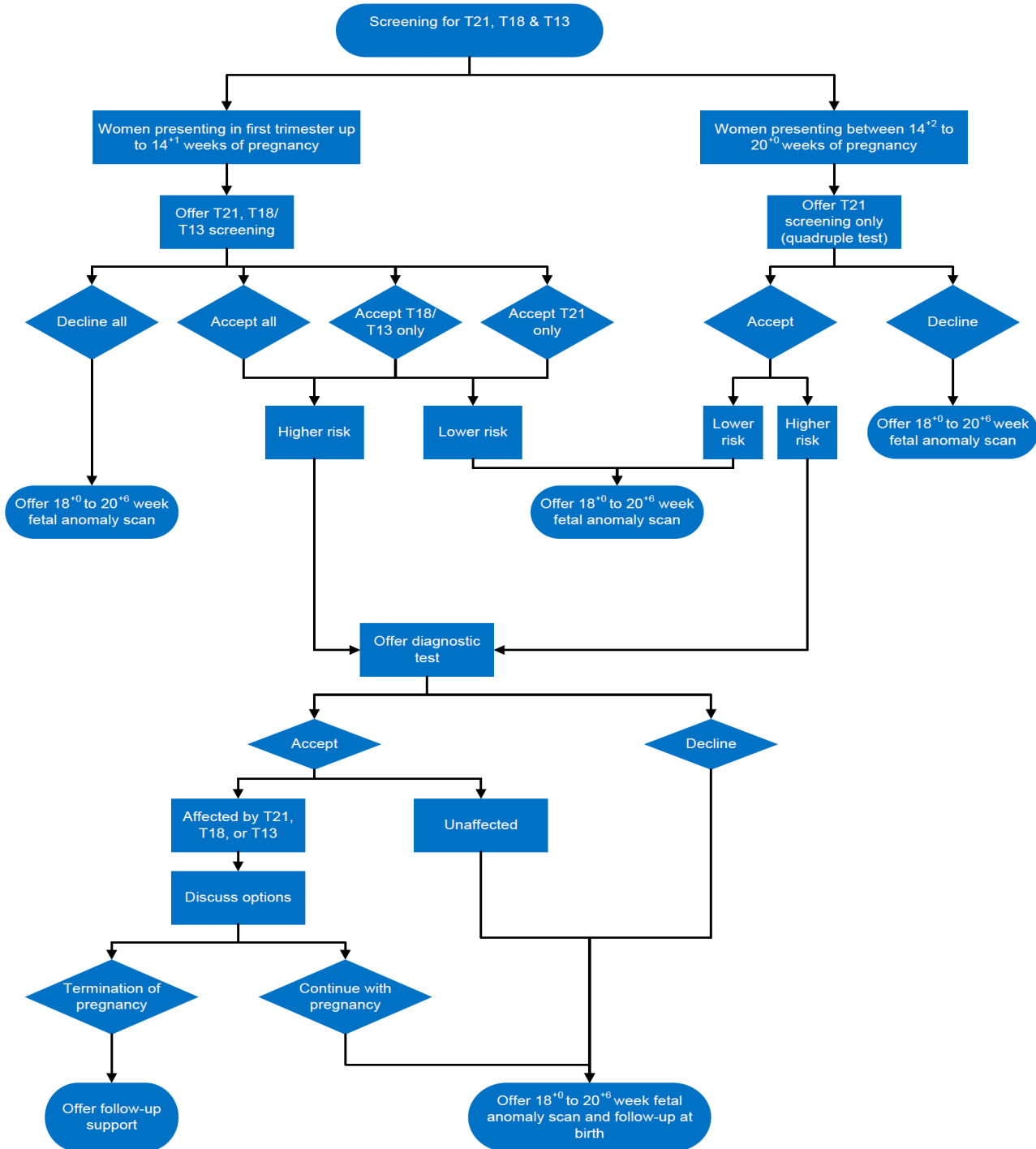
# Appendix 1: Fetal Anomaly Screening Programme Pathway: Down's T21, Edwards' (T18) and Patau's (T13)



Public Health  
England



NHS Fetal Anomaly Screening Programme care pathway: Down's (T21), Edwards' (T18) and Patau's (T13)



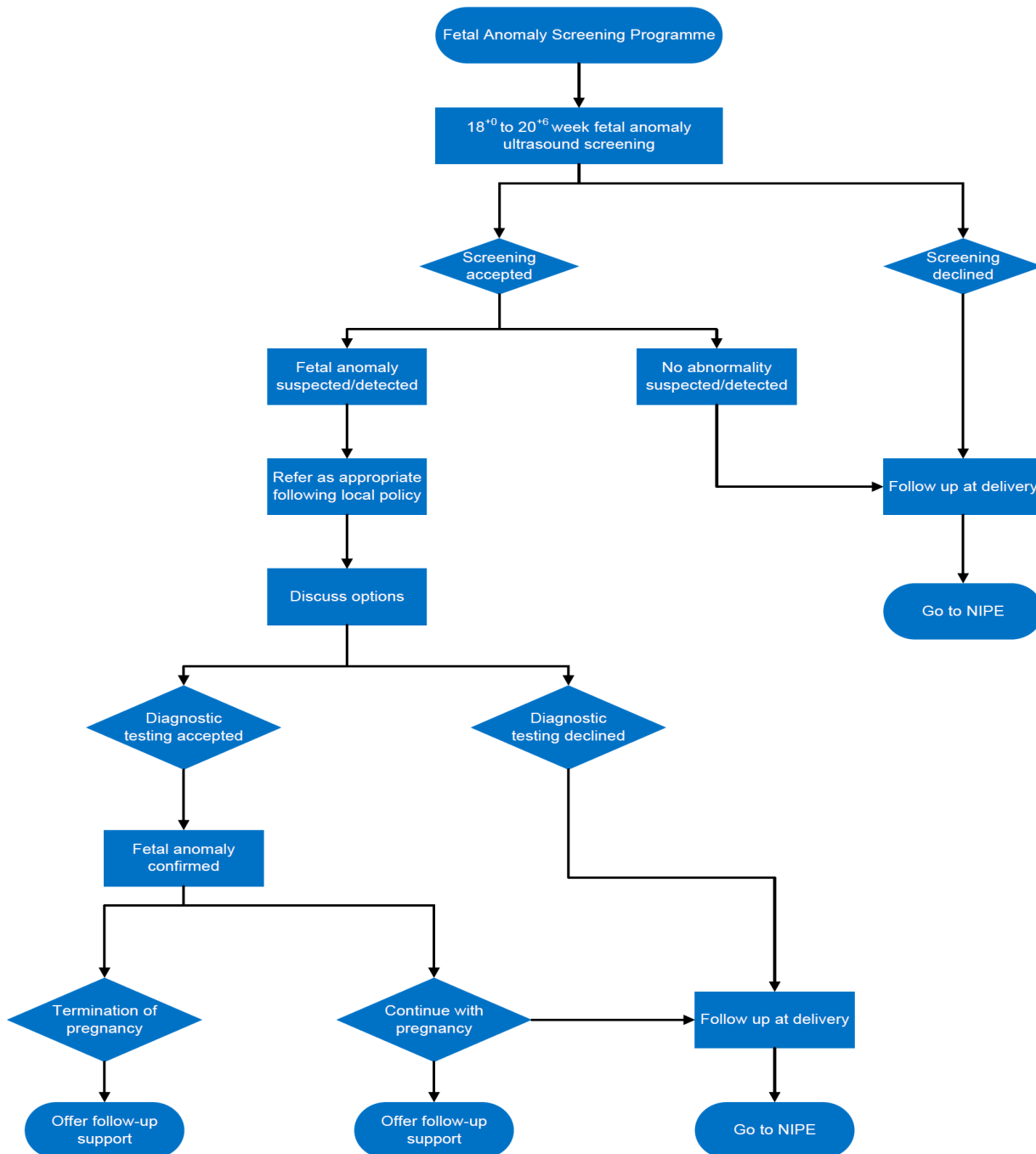
## Appendix 2: Fetal anomaly Screening Programme pathway: 18+0 to 20+6 week fetal anomaly ultrasounds scan



Public Health  
England



NHS Fetal Anomaly Screening Programme care pathway: 18<sup>+0</sup> to 20<sup>+6</sup> week fetal anomaly ultrasound scan



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## Appendix 3: Baby Alert Form

# BABY ALERT


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Please complete all boxes. A copy to be put in the labour ward baby alert folder and another copy to go to the neonatal team

Obstetric Consultant	EDD	Surname Forename DOB Hospital No. Or affix patient sticker
Community Midwife	Parity	
Mother's Phone number	GP	
<p><b>Risk factor identified:</b> (please give as much detail and use reverse side if required)</p> <ul style="list-style-type: none"> <li>- If previous baby with associated condition name and DOB of that baby</li> <li>- If on any medications then names and doses, details of relevant investigations</li> <li>- Next scan and consultant appointments</li> </ul>		
<p><b>Neonatal plan:</b> All babies should have a personalised care plan. Please give as much detail as possible for delivery details and postnatal period, use reverse side if required</p>		
<p><b>When to alert paediatricians</b> (circle as appropriate, paediatric team to complete):</p> <ol style="list-style-type: none"> <li>1. Whenever the mother is admitted to labour ward</li> <li>2. Shortly before birth</li> <li>3. As soon as the baby is born</li> <li>4. Within 12 hours of delivery</li> </ol>		<p><b>Who to alert</b> Paed SHO (Bleep 1630) Paed Registrar (Bleep 1631) Paed Consultant NNU</p>
Signed	Name	Date

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## Appendix 4: NCARDS Data Collection Form – Antenatal

National Congenital Anomaly and Rare Disease Registration Service (NCARDS)		For office use only
 Public Health England	<h3>Data collection form – Antenatal</h3> <p style="font-size: x-small;">Please notify any suspected or confirmed anomaly identified antenatally – structural, chromosomal or biochemical. <b>DO NOT WAIT</b> until final confirmation before sending this form.</p> <p style="font-size: x-small;">Authorised under Section 251 of the NHS Act 2006 to collect information without patient consent (CAG 10-02(d)2015)</p>	
MOTHER'S DETAILS		
(Sticky label, if available)		
Surname: <input style="width: 100%;" type="text"/>		
Forename: <input style="width: 100%;" type="text"/>		
Hosp. no: <input style="width: 100%;" type="text"/>		
NHS no: <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/>		
Address at booking: <input style="width: 100%;" type="text"/>		
Postcode: <input style="width: 20%;" type="text"/> <input style="width: 20%;" type="text"/> <input style="width: 20%;" type="text"/> <input style="width: 20%;" type="text"/> <input style="width: 20%;" type="text"/> <input style="width: 20%;" type="text"/>		
Date of birth: <input style="width: 30%;" type="text"/>		
Ethnic category: <input type="radio"/> White <input type="radio"/> Mixed <input type="radio"/> Indian <input type="radio"/> Pakistani		
<input type="radio"/> Bangladeshi <input type="radio"/> Other Asian* <input type="radio"/> Black Caribbean <input type="radio"/> Black African		
<input type="radio"/> Other Black* <input type="radio"/> Chinese <input type="radio"/> Other* <input type="radio"/> Not known		
*If other, please state: <input style="width: 100%;" type="text"/>		
Occupation: <input style="width: 100%;" type="text"/>		
BOOKING DETAILS		
Date of 1st booking appointment: <input style="width: 30%;" type="text"/>		
Booking hospital: <input style="width: 100%;" type="text"/>		
EDD: <input style="width: 30%;" type="text"/>		
Height: <input style="width: 10%;" type="text"/> cm Weight: <input style="width: 10%;" type="text"/> kg BMI: <input style="width: 10%;" type="text"/>		
Smoking status: <input type="radio"/> Current <input type="radio"/> Ex <input type="radio"/> Non <input type="radio"/> Never <input type="radio"/> Not known		
Weekly alcohol units at booking: <input style="width: 10%;" type="text"/>		
Substance use at booking: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not known		
If yes, substance: <input style="width: 100%;" type="text"/>		
Prescription drugs (1st trimester) inc. dose: <input style="width: 100%;" type="text"/>		
Maternal illnesses: <input style="width: 100%;" type="text"/>		
Folic acid: <input type="radio"/> Pre and post conception <input type="radio"/> Post conception only		
<input type="radio"/> Taken, timing unknown <input type="radio"/> Not taken <input type="radio"/> Not known		
If taken, dose: <input type="radio"/> Standard 400mcg <input type="radio"/> High 5mg		
Assisted conception: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not known		
If yes, type: <input type="radio"/> Ovulation induction <input type="radio"/> IVF <input type="radio"/> ICSI <input type="radio"/> Not known		
Number of previous live births: <input style="width: 10%;" type="text"/>		
Number of previous stillbirths (24+ weeks, incl. TOPs): <input style="width: 10%;" type="text"/>		
Number of previous losses (<24 weeks, incl. TOPs): <input style="width: 10%;" type="text"/>		
Number of previous neonatal deaths: <input style="width: 10%;" type="text"/>		
Previous congenital anomalies: <input style="width: 100%;" type="text"/>		
Father's age at booking: <input style="width: 10%;" type="text"/> years		
Family history of anomalies: <input style="width: 100%;" type="text"/>		
Maternal: <input style="width: 100%;" type="text"/>		
Paternal: <input style="width: 100%;" type="text"/>		
Consanguinity: <input type="radio"/> No <input type="radio"/> Yes, 1st cousin <input type="radio"/> Yes, 2nd cousin		
<input type="radio"/> Yes, other <input type="radio"/> Yes, relation nk <input type="radio"/> Not known		
PREGNANCY DETAILS		
Number of fetuses: <input style="width: 10%;" type="text"/>		
Twin type/chorionicity: <input style="width: 100%;" type="text"/>		
<p><b>Please attach copies of any relevant scans/clinic letters/laboratory or post mortem reports.</b></p> <p style="font-size: x-small;">Return forms to: NCARDS Thames Valley Regional Office, Public Health England, Second Floor, 4150 Chancellor Court, Oxford Business Park South, Oxford, OX4 2GX (using secure pre-paid return envelope) or email phe.tvcar@nhs.net</p>		
ANEUPLOIDY SCREENING DETAILS		
Date (specimen) <input style="width: 20%;" type="text"/>	Test <input type="radio"/> Combined <input type="radio"/> Quad <input type="radio"/> NIPT	Result <input type="radio"/> Accepted <input type="radio"/> Declined <input type="radio"/> Not offered <input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> Inconclusive
T21 risk: 1 in <input style="width: 20%;" type="text"/>		T13/18 risk: 1 in <input style="width: 20%;" type="text"/>
Reason: <input style="width: 100%;" type="text"/>		Risk: 1 in <input style="width: 20%;" type="text"/>
DIAGNOSTIC TEST DETAILS		
Date (procedure) <input style="width: 20%;" type="text"/>	Sample <input type="radio"/> CVS <input type="radio"/> Amnio <input type="radio"/> Fetal blood	Result <input type="radio"/> Normal <input type="radio"/> Abnormal <input type="radio"/> Declined <input type="radio"/> Offered <input type="radio"/> Not offered
Reason: <input style="width: 100%;" type="text"/>		Other, specify: <input style="width: 100%;" type="text"/>
Karyotype/microarray: <input style="width: 100%;" type="text"/>		
ANTENATAL SCAN DETAILS		
1st trimester (dating) scan:		
Date <input style="width: 20%;" type="text"/>	USS findings (attach report) <input type="radio"/> Normal <input type="radio"/> Abnormal <input type="radio"/> Incomplete	
NT measurement <input style="width: 20%;" type="text"/> mm		
Fetal anomaly (18 <sup>+</sup> – 20 <sup>+</sup> ) scan:		
1st attempt		
Date <input style="width: 20%;" type="text"/>	USS findings (attach report) <input type="radio"/> Normal <input type="radio"/> Abnormal <input type="radio"/> Incomplete <input type="radio"/> Not known	
Not done, give details: <input style="width: 100%;" type="text"/>		
2nd attempt		
Date <input style="width: 20%;" type="text"/>	USS findings (attach report) <input type="radio"/> Normal <input type="radio"/> Abnormal <input type="radio"/> Incomplete	
Not done, give details: <input style="width: 100%;" type="text"/>		
Echo/MRI/Other:		
Date <input style="width: 20%;" type="text"/>	Findings (attach report) <input style="width: 100%;" type="text"/>	
REFERRAL DETAILS		
Department/Hospital: <input style="width: 100%;" type="text"/>		
Consultant: <input style="width: 100%;" type="text"/>		
ADDITIONAL DETAILS		
Use this box/back of the form to extend answers or include any extra information you think is relevant		
NOTIFIER DETAILS		
Name: <input style="width: 100%;" type="text"/>		
Hospital: <input style="width: 100%;" type="text"/>		
Department: <input style="width: 100%;" type="text"/>		
Email: <input style="width: 100%;" type="text"/>		
Tel: <input style="width: 60%;" type="text"/>		Date: <input style="width: 20%;" type="text"/>

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## Appendix 5: NCARDS Data Collection Form – Delivery/Postnatal

National Congenital Anomaly and Rare Disease Registration Service (NCARDS)		For office use only																										
<b>Public Health England</b>																												
<b>Data collection form – Delivery/Postnatal</b> <small>Please notify any suspected or confirmed anomaly – structural, chromosomal or biochemical.  <b>DO NOT WAIT</b> until final confirmation before sending this form.                      One form per affected fetus (inc. live births, stillbirths, miscarriages and TOPs)                      Authorised under Section 251 of the NHS Act 2006 to collect information without patient consent (CAG 10-02(d)2015)</small>																												
<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">MOTHER'S DETAILS</div> <small>(Sticky label, if available)</small> Surname: <input style="width: 100%;" type="text"/> Forename: <input style="width: 100%;" type="text"/> Hosp. no: <input style="width: 100%;" type="text"/> NHS no: <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> Address at booking: <input style="width: 100%;" type="text"/> Postcode: <input style="width: 20%;" type="text"/> <input style="width: 20%;" type="text"/> Date of birth: <input style="width: 40%;" type="text"/> Ethnic category: <input type="radio"/> White <input type="radio"/> Mixed <input type="radio"/> Indian <input type="radio"/> Pakistani <input type="radio"/> Bangladeshi <input type="radio"/> Other Asian* <input type="radio"/> Black Caribbean <input type="radio"/> Black African <input type="radio"/> Other Black* <input type="radio"/> Chinese <input type="radio"/> Other* <input type="radio"/> Not known *If other, please state: <input style="width: 100%;" type="text"/> Occupation: <input style="width: 100%;" type="text"/>	<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">ANOMALY DETAILS – LIST ALL</div> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 40%;">Anomaly</th> <th style="width: 20%;">Suspected prenatally</th> <th style="width: 40%;">How confirmed? E.g. cytogenetics, x-ray, PM</th> </tr> </thead> <tbody> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input type="radio"/> Yes <input type="radio"/> No</td> <td><input style="width: 100%; height: 40px;" type="text"/> Date confirmed: <input style="width: 60%;" type="text"/></td> </tr> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input type="radio"/> Yes <input type="radio"/> No</td> <td><input style="width: 100%; height: 40px;" type="text"/> Date confirmed: <input style="width: 60%;" type="text"/></td> </tr> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input type="radio"/> Yes <input type="radio"/> No</td> <td><input style="width: 100%; height: 40px;" type="text"/> Date confirmed: <input style="width: 60%;" type="text"/></td> </tr> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input type="radio"/> Yes <input type="radio"/> No</td> <td><input style="width: 100%; height: 40px;" type="text"/> Date confirmed: <input style="width: 60%;" type="text"/></td> </tr> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input type="radio"/> Yes <input type="radio"/> No</td> <td><input style="width: 100%; height: 40px;" type="text"/> Date confirmed: <input style="width: 60%;" type="text"/></td> </tr> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input type="radio"/> Yes <input type="radio"/> No</td> <td><input style="width: 100%; height: 40px;" type="text"/> Date confirmed: <input style="width: 60%;" type="text"/></td> </tr> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input type="radio"/> Yes <input type="radio"/> No</td> <td><input style="width: 100%; height: 40px;" type="text"/> Date confirmed: <input style="width: 60%;" type="text"/></td> </tr> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input type="radio"/> Yes <input type="radio"/> No</td> <td><input style="width: 100%; height: 40px;" type="text"/> Date confirmed: <input style="width: 60%;" type="text"/></td> </tr> </tbody> </table>		Anomaly	Suspected prenatally	How confirmed? 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<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">BABY'S DETAILS</div> <small>(Sticky label, if available)</small> Surname: <input style="width: 100%;" type="text"/> Forename(s): <input style="width: 100%;" type="text"/> Hosp. no: <input style="width: 100%;" type="text"/> NHS no: <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> Address at birth: <input style="width: 100%;" type="text"/> Postcode: <input style="width: 20%;" type="text"/> <input style="width: 20%;" type="text"/> Date of birth: <input style="width: 40%;" type="text"/> Sex: <input type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Indeterminate <input type="radio"/> Not known																												
<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">BIRTH DETAILS</div> Place of delivery: <input style="width: 100%;" type="text"/> Type of delivery: <input type="radio"/> Spont. vertex <input type="radio"/> Spont. other <input type="radio"/> Low forceps <input type="radio"/> Other forceps <input type="radio"/> Ventouse <input type="radio"/> Breech <input type="radio"/> Breech extraction <input type="radio"/> Elective CS <input type="radio"/> Emergency CS <input type="radio"/> Other, specify <input style="width: 50%;" type="text"/> <input type="radio"/> Not known Birth weight: <input style="width: 30%;" type="text"/> g Birth order: <input style="width: 10%;" type="text"/> of <input style="width: 10%;" type="text"/>																												
<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">OUTCOME DETAILS</div> Outcome: <input type="radio"/> Live birth <input type="radio"/> Stillbirth (24+ weeks) <input type="radio"/> Fetal loss (<24 weeks) <input type="radio"/> Termination of preg. (<24 weeks) <input type="radio"/> Not known Termination of pregnancy: <input type="radio"/> Medical TOP <input type="radio"/> Surgical TOP <input type="radio"/> Yes – unknown method <input type="radio"/> No <input type="radio"/> Not known Feticide: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Not known If yes, date: <input style="width: 60%;" type="text"/>																												
<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">DEATH DETAILS (if applicable)</div> Date of death: <input style="width: 60%;" type="text"/> Post mortem: <input type="radio"/> Yes <input type="radio"/> Not requested <input type="radio"/> Not permitted <input type="radio"/> Requested but not performed <input type="radio"/> Not known																												
<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">NOTIFIER DETAILS</div> Name: <input style="width: 100%;" type="text"/> Hospital: <input style="width: 100%;" type="text"/> Department: <input style="width: 100%;" type="text"/> Email: <input style="width: 100%;" type="text"/> Tel: <input style="width: 30%;" type="text"/> Date: <input style="width: 30%;" type="text"/>																												
	<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">PROCEDURE DETAILS (if applicable)</div> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 30%;">Date/age performed/expected</th> <th style="width: 20%;">Department/Doctor</th> <th style="width: 50%;">Procedure</th> </tr> </thead> <tbody> <tr> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input style="width: 100%; height: 40px;" type="text"/></td> <td><input style="width: 100%; height: 40px;" type="text"/></td> </tr> </tbody> </table>	Date/age performed/expected	Department/Doctor	Procedure	<input style="width: 100%; height: 40px;" type="text"/>	<input style="width: 100%; height: 40px;" type="text"/>	<input style="width: 100%; height: 40px;" type="text"/>																					
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	<div style="background-color: #4b4b4b; color: white; padding: 2px; text-align: center; font-weight: bold;">BABY'S REFERRAL DETAILS</div> Department/Hospital: <input style="width: 100%;" type="text"/> Consultant: <input style="width: 100%;" type="text"/>																											

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### BOOKING DETAILS

Date of 1st booking appointment:

Booking hospital:

EDD:

Height:  cm Weight:  kg BMI:

Smoking status:  Current  Ex  Non  Never  Not known

Weekly alcohol units at booking:

Substance use at booking:  Yes  No  Not known

If yes, substance:

Prescription drugs (1st trimester) inc. dose:

Maternal illnesses:

Folic acid:  Pre and post conception  Post conception only  
 Taken, timing unknown  Not taken  Not known

If taken, dose:  Standard 400mcg  High 5mg

Assisted conception:  Yes  No  Not known

If yes, type:  Ovulation induction  IVF  ICSI  Not known

Number of previous live births:

Number of previous stillbirths (24+ weeks, incl. TOPs):

Number of previous losses (<24 weeks, incl. TOPs):

Number of previous neonatal deaths:

Previous congenital anomalies:

Father's age at booking:  years

Family history of anomalies:

Maternal:

Paternal:

Consanguinity:  No  Yes, 1st cousin  Yes, 2nd cousin  
 Yes, other  Yes, relation nk  Not known

### PREGNANCY DETAILS

Number of fetuses:

Twin type/chorionicity:

### ADDITIONAL DETAILS

Use this box to extend answers or include any extra information you think is relevant

### ANEUPLOIDY SCREENING DETAILS

Date (specimen)	Test	Result
<input type="text"/>	<input type="radio"/> Combined	<input type="radio"/> Accepted T21 risk: 1 in <input type="text"/> T13/18 risk: 1 in <input type="text"/>
	<input type="radio"/> Quad	<input type="radio"/> Declined <input type="radio"/> Not offered Reason <input type="text"/>
<input type="text"/>	<input type="radio"/> NIPT	<input type="radio"/> Positive <input type="radio"/> Negative <input type="radio"/> Inconclusive Risk: 1 in <input type="text"/>

### DIAGNOSTIC TEST DETAILS

Date (procedure)	Sample	Result
<input type="text"/>	<input type="radio"/> CVS	<input type="radio"/> Normal <input type="radio"/> Abnormal <input type="radio"/> Declined
	<input type="radio"/> Amnio	<input type="radio"/> Offered <input type="radio"/> Not offered Reason <input type="text"/>
	<input type="radio"/> Fetal blood	<input type="radio"/> Other, specify: <input type="text"/>

Karyotype/microarray:

### ANTENATAL SCAN DETAILS

1st trimester (dating) scan:

Date  USS findings (*attach report*)  
 Normal  Abnormal  Incomplete

NT measurement  mm

Fetal anomaly (18<sup>+0</sup> – 20<sup>+6</sup>) scan:

1st attempt

Date  USS findings (*attach report*)  
 Normal  Abnormal  Incomplete  Not known

2nd attempt

Date  USS findings (*attach report*)  
 Normal  Abnormal  Incomplete

Not done, give details:

Echo/MRI/Other:


Date  Findings (*attach report*)

Please attach copies of any relevant scans/clinic letters/laboratory or post mortem reports.

Return forms to:  
NCARDRS Thames Valley Regional Office, Public Health England, Second Floor, 4150 Chancellor Court, Oxford Business Park South, Oxford, OX4 2GX  
(using secure pre-paid return envelope) or email phe.tvcar@nhs.net

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## Appendix 6: NCARDS Data Collection Form – Postnatal

National Congenital Anomaly and Rare Disease Registration Service (NCARDS)		For office use only
 <b>Public Health England</b>	<b>Data collection form – Postnatal</b> <small>Please notify any confirmed anomaly – structural, chromosomal or biochemical. One form per affected baby</small> <small>Authorised under Section 251 of the NHS Act 2006 to collect information without patient consent (CAG 10-02(d)2015)</small>	
BABY'S DETAILS		
(Sticky label, if available)		
Surname:	<input style="width: 100%;" type="text"/>	
Forename(s):	<input style="width: 100%;" type="text"/>	
Hosp. no:	<input style="width: 100%;" type="text"/>	
NHS no:	<input style="width: 100%;" type="text"/>	
Address at birth:	<input style="width: 100%;" type="text"/>	
Postcode:	<input style="width: 100%;" type="text"/>	
Date of birth:	<input style="width: 100%;" type="text"/>	
Sex:	<input type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Indeterminate <input type="radio"/> Not known	
BIRTH DETAILS		
Place of delivery:	<input style="width: 100%;" type="text"/>	
Type of delivery:	<input type="radio"/> Spont. vertex <input type="radio"/> Spont. other <input type="radio"/> Low forceps <input type="radio"/> Other forceps <input type="radio"/> Ventouse <input type="radio"/> Breech <input type="radio"/> Breech extraction <input type="radio"/> Elective CS <input type="radio"/> Emergency CS <input type="radio"/> Other, specify <input style="width: 50px;" type="text"/> <input type="radio"/> Not known	
Birth weight:	<input style="width: 50px;" type="text"/> g	Birth order: <input style="width: 20px;" type="text"/> of <input style="width: 20px;" type="text"/>
Gestation at delivery:	<input style="width: 50px;" type="text"/> weeks + <input style="width: 20px;" type="text"/> days	
MOTHER'S DETAILS (if known)		
(Sticky label, if available)		
Surname:	<input style="width: 100%;" type="text"/>	
Forename:	<input style="width: 100%;" type="text"/>	
Hosp. no:	<input style="width: 100%;" type="text"/>	
NHS no:	<input style="width: 100%;" type="text"/>	
Address at booking:	<input style="width: 100%;" type="text"/>	
Postcode:	<input style="width: 100%;" type="text"/>	
Date of birth:	<input style="width: 100%;" type="text"/>	
Booking hospital:	<input style="width: 100%;" type="text"/>	
BABY'S DEATH DETAILS (if applicable)		
Date of death:	<input style="width: 100%;" type="text"/>	
Post mortem:	<input type="radio"/> Yes <input type="radio"/> Not requested <input type="radio"/> Not permitted <input type="radio"/> Requested but not performed <input type="radio"/> Not known	
BABY'S PROCEDURE DETAILS (if applicable)		
Date/age performed/expected	Department/Doctor	Procedure
<input style="width: 100%;" type="text"/>	<input style="width: 100%;" type="text"/>	<input style="width: 100%;" type="text"/>
NOTIFIER DETAILS		
Name:	<input style="width: 100%;" type="text"/>	
Hospital:	<input style="width: 100%;" type="text"/>	
Department:	<input style="width: 100%;" type="text"/>	
Email:	<input style="width: 100%;" type="text"/>	
Tel:	<input style="width: 100%;" type="text"/>	Date: <input style="width: 100%;" type="text"/>
ANOMALY DETAILS – LIST ALL		
Anomaly	Suspected prenatally	How confirmed? E.g. cytogenetics, x-ray, PM
<input style="width: 100%; height: 40px;" type="text"/>	<input type="radio"/> Yes <input type="radio"/> No	<input style="width: 100%; height: 40px;" type="text"/>
<input style="width: 100%; height: 40px;" type="text"/>	<input type="radio"/> Yes <input type="radio"/> No	Date confirmed: <input style="width: 100%;" type="text"/>
<input style="width: 100%; height: 40px;" type="text"/>	<input type="radio"/> Yes <input type="radio"/> No	Date confirmed: <input style="width: 100%;" type="text"/>
<input style="width: 100%; height: 40px;" type="text"/>	<input type="radio"/> Yes <input type="radio"/> No	Date confirmed: <input style="width: 100%;" type="text"/>
<input style="width: 100%; height: 40px;" type="text"/>	<input type="radio"/> Yes <input type="radio"/> No	Date confirmed: <input style="width: 100%;" type="text"/>
<input style="width: 100%; height: 40px;" type="text"/>	<input type="radio"/> Yes <input type="radio"/> No	Date confirmed: <input style="width: 100%;" type="text"/>
<input style="width: 100%; height: 40px;" type="text"/>	<input type="radio"/> Yes <input type="radio"/> No	Date confirmed: <input style="width: 100%;" type="text"/>
<input style="width: 100%; height: 40px;" type="text"/>	<input type="radio"/> Yes <input type="radio"/> No	Date confirmed: <input style="width: 100%;" type="text"/>
ADDITIONAL DETAILS		
Use this box/back of the form to extend answers or include any extra information you think is relevant (including future referrals and treatments)		
Please attach copies of any relevant scans/clinic letters/laboratory or post mortem reports.		
Return forms to: NCARDS Thames Valley Regional Office, Public Health England, Second Floor, 4150 Chancellor Court, Oxford Business Park South, Oxford, OX4 2GX (using secure pre-paid return envelope) or email phe.tvcar@nhs.net		

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## Appendix 7: Screening Record Sheet

Date of Pregnancy Booking \_\_\_\_\_ Gestation at Booking \_\_\_\_\_ **TEST YEAR** \_\_\_\_\_

**Pt Sticker**

LMP \_\_\_\_\_ EDD \_\_\_\_\_

Age at EDD \_\_\_\_\_

Maternal Weight \_\_\_\_\_

Ethnic Origin \_\_\_\_\_

Relevant Past Obstetric History \_\_\_\_\_

Phone number \_\_\_\_\_

Partners Name \_\_\_\_\_

GP Surgery \_\_\_\_\_

Midwife \_\_\_\_\_

BABY ALERT

NCARDS


**Dating Scan** \_\_\_\_\_

**Combined Test** \_\_\_\_\_ Gest \_\_\_\_\_

Screening Declined

CRL \_\_\_\_\_ Gestation \_\_\_\_\_

NT \_\_\_\_\_ mm \_\_\_\_\_ MoM

Twin 2 CRL \_\_\_\_\_

Twin 2 NT \_\_\_\_\_ mm \_\_\_\_\_ MoM

hCG \_\_\_\_\_ U/l \_\_\_\_\_ MoM

**Anomaly Scan** \_\_\_\_\_

PAPPA \_\_\_\_\_ mU/l \_\_\_\_\_ MoM

Comments:

T21 Chance 1: \_\_\_\_\_

T13 / T18 Chance 1: \_\_\_\_\_

Twin 2 T21 Chance 1: \_\_\_\_\_

Twin 2 T13 / T18 Chance \_\_\_\_\_

**PND** Accepted / Declined NIPT \_\_\_\_\_

MKUH / OUH Seen within timeframe Y / N

CVS / AMNIO Gest at Test \_\_\_\_\_

Blood Group \_\_\_\_\_ Anti D Y / N

Hep B Status \_\_\_\_\_ HIV Status \_\_\_\_\_

No of Insertions \_\_\_\_\_ Vol Obtained \_\_\_\_\_

Transplacental / Transamniotic

Liquor Quality: clear-yellow, water-clear, blood tinged, fresh blood stained, old blood stained

Fetal medicine Consultant performing test \_\_\_\_\_

PCR Y / N \_\_\_\_\_ Microarray Y / N \_\_\_\_\_ NIPT Results \_\_\_\_\_

**Outcome of Pregnancy** Date of delivery \_\_\_\_\_ / TOP \_\_\_\_\_

Gestation \_\_\_\_\_ Type of Birth: SVD / Assisted / ELLSCS / EMLSCS

Sex: Male / Female

Weight \_\_\_\_\_ Admission to NNU Y / N

Comments / PM / Pathology Results

Bereavement Follow up Y / N Date \_\_\_\_\_



Date of Pregnancy Booking \_\_\_\_\_ Gestation at Booking \_\_\_\_\_ **TEST YEAR** \_\_\_\_\_

**Pt Sticker**

LMP \_\_\_\_\_ EDD \_\_\_\_\_

Age at EDD \_\_\_\_\_

Maternal Weight \_\_\_\_\_

Ethnic Origin \_\_\_\_\_

Relevant Past Obstetric History \_\_\_\_\_

Phone number \_\_\_\_\_

Partners Name \_\_\_\_\_

GP Surgery \_\_\_\_\_

Midwife \_\_\_\_\_

BABY ALERT

NCARDS


**Dating Scan**

**Quadruple Test** Gest \_\_\_\_\_

Screening Declined

CRL \_\_\_\_\_ Gestation \_\_\_\_\_

AFP \_\_\_\_\_ U/mL \_\_\_\_\_ MoM

Twin 2 CRL \_\_\_\_\_

hCG \_\_\_\_\_ U/L \_\_\_\_\_ MoM

HC \_\_\_\_\_ Gestation \_\_\_\_\_

UE3 \_\_\_\_\_ nmol/l \_\_\_\_\_ MoM

Twin 2 HC \_\_\_\_\_

**Anomaly Scan**

Inhibin A \_\_\_\_\_ pg/ml \_\_\_\_\_ MoM

Comments:

T21 Chance 1: \_\_\_\_\_

Twin 2 T21 Chance 1: \_\_\_\_\_

**PND** Accepted / Declined NIPT \_\_\_\_\_

MKUH / OUH Seen within timeframe Y / N

CVS / AMNIO Gest at Test \_\_\_\_\_

Blood Group \_\_\_\_\_ Anti D Y / N

Hep B Status \_\_\_\_\_ HIV Status \_\_\_\_\_

No of Insertions \_\_\_\_\_ Vol Obtained \_\_\_\_\_

Transplacental / Transamniotic

Liquor Quality: clear-yellow, water-clear, blood tinged, fresh blood stained, old blood stained

Fetal medicine Consultant performing test \_\_\_\_\_

PCR Y / N \_\_\_\_\_ Microarray Y / N \_\_\_\_\_ NIPT Results \_\_\_\_\_

**Outcome of Pregnancy** Date of delivery \_\_\_\_\_ / TOP \_\_\_\_\_

Gestation \_\_\_\_\_ Type of Birth: SVD / Assisted / ELLSCS / EMLSCS

Sex: Male / Female

Weight \_\_\_\_\_ Admission to NNU Y / N

Comments / PM / Pathology Results

Bereavement Follow up Y / N Date \_\_\_\_\_

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## Appendix 8: Oxford University Hospital Fetal Medicine Referral Form



Oxford Fetal Medicine Unit  
Level 6, Women's Centre  
The John Radcliffe  
Headley Way  
Headington  
Oxford  
OX3 9DU

### Maternal Details

Name DOB NHS Address  Use addressograph label
--

Tel: 01865 221716  
Fax: 01865 221164  
Email: [fetalmedicine.pnd@nhs.net](mailto:fetalmedicine.pnd@nhs.net)

Hospital.....

Consultant.....

Referrer.....

Date of Referral.....

### Contact Numbers

Mobile.....

Landline.....

Email address.....

### GP details

Name.....

Practice.....

### Clinical Details

EDD..... Gestation.....

Blood Group.....

Has this woman been seen by Fetal Medicine Unit before?

Yes/No (if yes, state year )

If referring a woman for diagnostic testing following an increased risk from screening, please attach the screening result

If referring a woman for second opinion on scan, please attach a copy of your centre's scan report

Number of pages.....

### Referral Reason