©Milton Keynes University Hospital NHS Foundation Trust

Fetal Anomalies

Classification :	Guideline
Authors Name:	Anita Males Monica Wilson
Authors Job Title:	Antenatal & Newborn (ANNB) Screening Co-ordinator Deputy Antenatal & Newborn (ANNB) Screening Midwife
Authors Division:	Women & Children's
Departments/Group this Document applies to:	Maternity, Paediatrics, Sonography

Approval Group: Women's Guideline Review Group, Women's Health CIG	**Date of Approval:**	07/10/2020
	Last Review:	09/2020
	Review Date:	01/04/2024

Unique Identifier: MIDW/GL/146	**Status:** Approved	**Version No:** 5

Guideline to be followed by (target staff): Sonographers, ANNB Screening Midwives, Paediatricians, Advanced Neonatal Practitioners (ANNP), Midwives

To be read in conjunction with the following documents:

- Screening in Pregnancy guideline
- Screening for Down's, Edwards' and Patau's Syndromes guideline
- Intrauterine Death, Termination of Pregnancy, Miscarriage and Neonatal Death before 24/40 Gestation
- Intrauterine Death, Termination of Pregnancy, Stillbirth and Neonatal Death after 24/40 Gestation

CQC Fundamental standards:
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

©Milton Keynes University Hospital NHS Foundation Trust

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.

Index

Abbreviations: 2
PHE – Public Health England....2
Guideline Statement....3
Executive Summary 3
1.0 Roles and Responsibilities: 3
2.0 Implementation and dissemination of document....3
3.0 Processes and procedures....3
3.1 Sonographers....3
3.2 The role of the Antenatal and Newborn (ANNB) Screening Team 4
3.3 Anomaly confirmed and pregnancy continuing 5
3.4 National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) 5
3.5 Future pregnancies 6
4.0 Statement of evidence/references 6
References:....6
5.0 Governance....7
5.1 Document review history 7
5.2 Consultation History 7
5.3 Audit and monitoring 7
5.4 Equality Impact Assessment 9
Appendix 1: Fetal Anomaly Screening Programme Pathway: Down's T21, Edwards' (T18) and Patau's (T13) 10
Appendix 3: Baby Alert Form....12
Appendix 4: NCARDRS Data Collection Form – Antenatal....12
Appendix 7: Screening Record Sheet....17
Appendix 8: Oxford University Hospital Fetal Medicine Referral Form 19

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

©Milton Keynes University Hospital NHS Foundation Trust

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.

©Milton Keynes University Hospital NHS Foundation Trust

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 NCARDRS 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 to 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, 1st or 2nd 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 account.

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

©Milton Keynes University Hospital NHS Foundation Trust

- 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

©Milton Keynes University Hospital NHS Foundation Trust

- 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 1st 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.

©Milton Keynes University Hospital NHS Foundation Trust

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-odinator	Reviewed and updated
5.1	October 2023	Maternity Assurance Group	Review date extended by 6 months as agreed to maternity assurance group, as guideline lead midwife position vacant.

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

©Milton Keynes University Hospital NHS Foundation Trust

©Milton Keynes University Hospital NHS Foundation Trust

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?
For example: focus groups, face-to-face meetings, PRG, etc
How are the changes/amendments to the policies/services communicated?
email, community midwife meetings, intranet post
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			

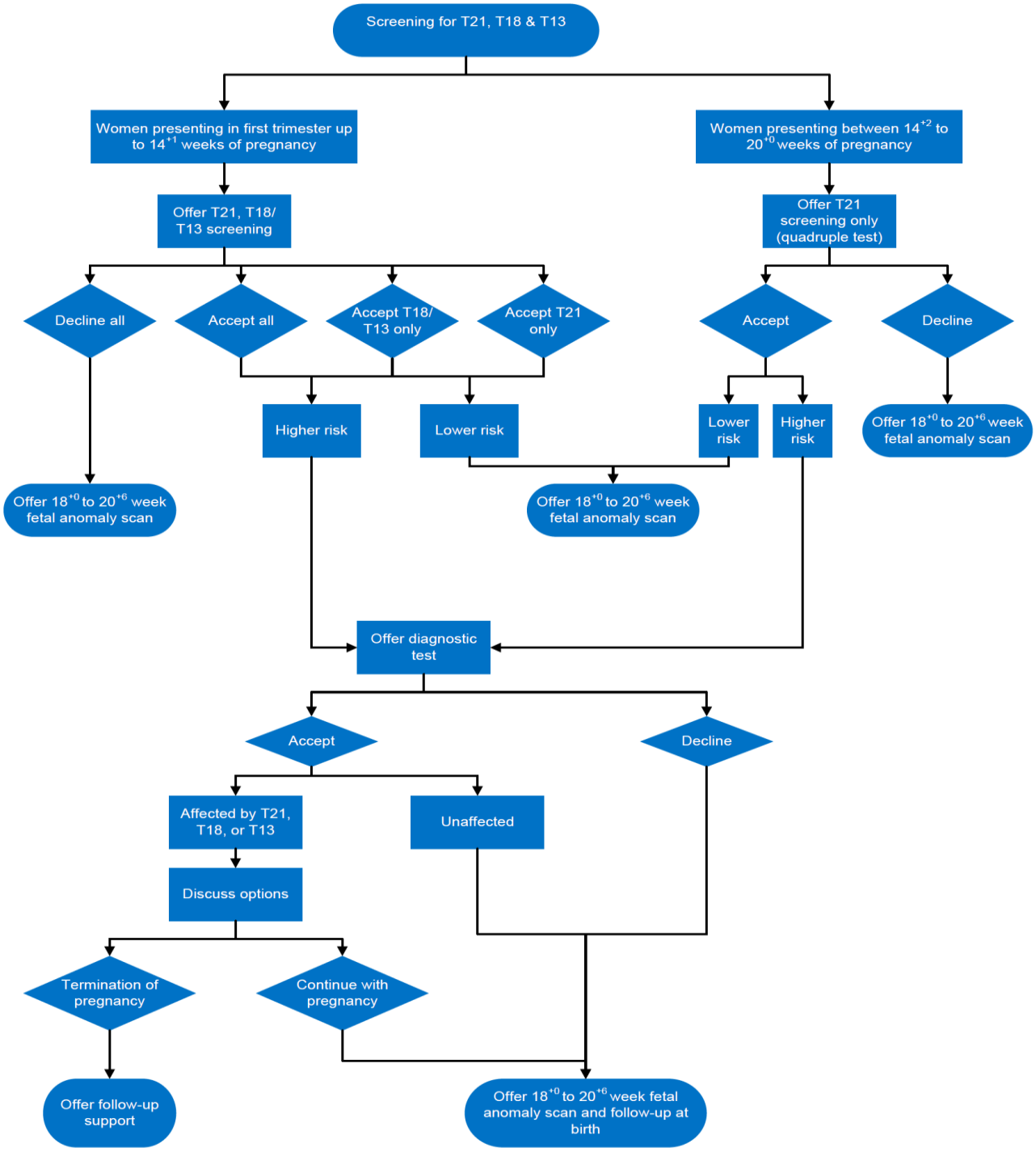
©Milton Keynes University Hospital NHS Foundation Trust

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

Public Health England

NHS

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



Public Health England leads the NHS Screening Programmes

Version 1.1

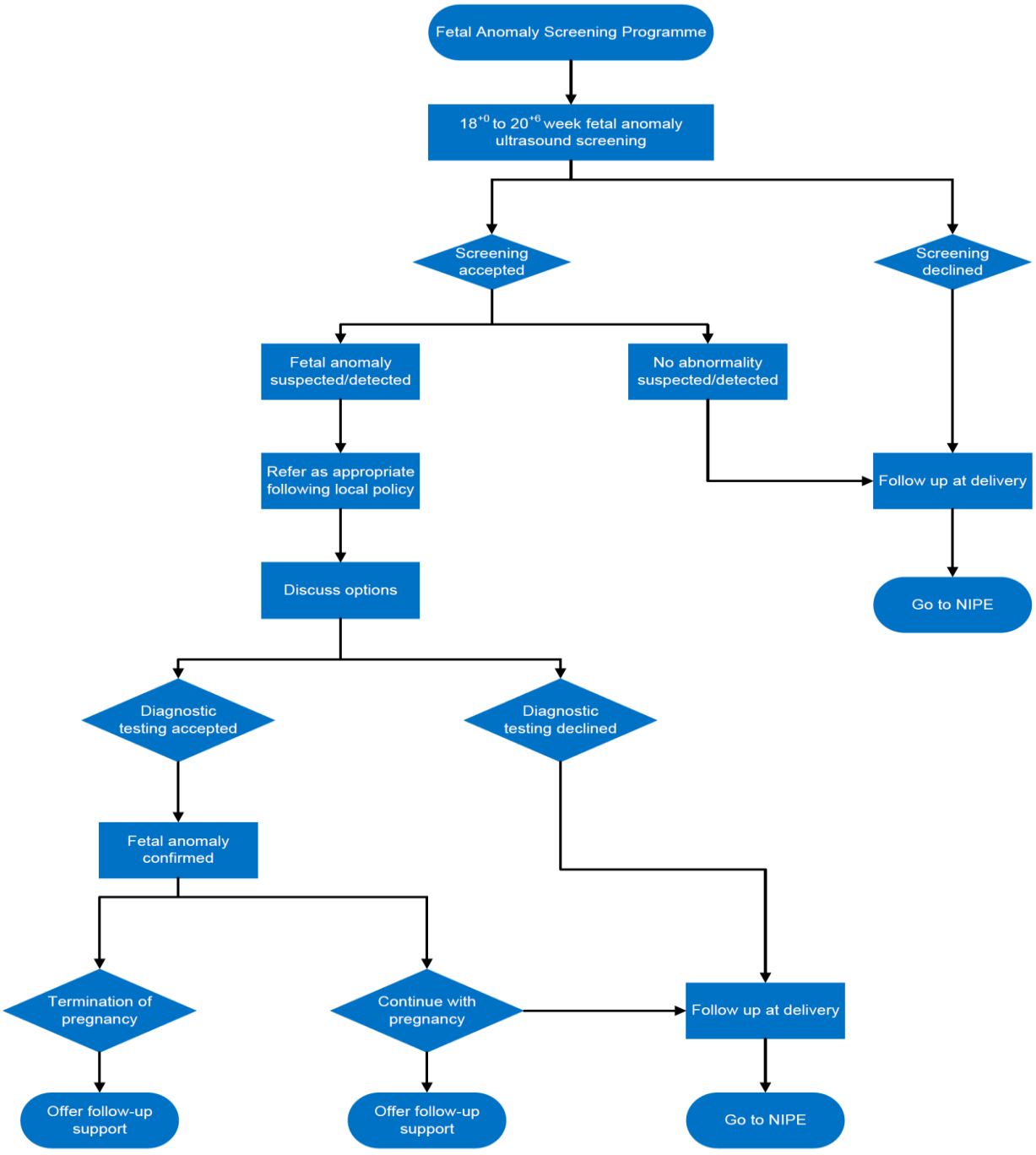
©Milton Keynes University Hospital NHS Foundation Trust

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

Public Health England

NHS

NHS Fetal Anomaly Screening Programme care pathway: 18^{+0} to 20^{+6} week fetal anomaly ultrasound scan



Public Health England leads the NHS Screening Programmes

Version 1.2

This document is uncontrolled once printed. Please check on the Trust's Intranet site for the most up to date version.
©Milton Keynes University Hospital NHS Foundation Trust

Appendix 3: Baby Alert Form

BABY ALERT

Milton Keynes Hospital NHS
NHS Foundation Trust

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**	

Risk factor identified: *(please give as much detail and use reverse side if required)*
- If previous baby with associated condition name and DOB of that baby
- If on any medications then names and doses, details of relevant investigations
- Next scan and consultant appointments

Neonatal plan: *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*

When to alert paediatricians *(circle as appropriate, paediatric team to complete):* 1. Whenever the mother is admitted to labour ward 2. Shortly before birth 3. As soon as the baby is born 4. Within 12 hours of delivery	***Who to alert*** Paed SHO (Bleep 1630) Paed Registrar (Bleep 1631) Paed Consultant NNU

Signed	**Name**	**Date**

WeCARE Visit NHS Choices and leave your feedback www.nhs.uk
Chairman: Baroness Wall of New Barnet
Chief Executive: Joe Harrison

©Milton Keynes University Hospital NHS Foundation Trust

Appendix 4: NCARDRS Data Collection Form – Antenatal

Public Health England

National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Data collection form – **Antenatal**

For office use only

Please notify any suspected or confirmed anomaly identified antenatally – structural, chromosomal or biochemical.
DO NOT WAIT until final confirmation before sending this form.
Authorised under Section 251 of the NHS Act 2006 to collect information without patient consent (CAG 10-02(d)2015)

MOTHER'S DETAILS

(Sticky label, if available)

Surname:
Forename:
Hosp. no:
NHS no:
Address at booking:
Postcode: Date of birth:
Ethnic category: ○ White ○ Mixed ○ Indian ○ Pakistani ○ Bangladeshi ○ Other Asian* ○ Black Caribbean ○ Black African ○ Other Black* ○ Chinese ○ Other* ○ Not known
*If other, please state:
Occupation:

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:

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

ANEUPLOIDY SCREENING DETAILS

Date (specimen) Test: ○ Combined ○ Quad ○ NIPT
Result: ○ Accepted T21 risk:1 in T13/18 risk: 1 in ○ Declined ○ Not offered Reason ○ Positive ○ Negative ○ Inconclusive Risk: 1 in

DIAGNOSTIC TEST DETAILS

Date (procedure) Sample: ○ CVS ○ Amnio ○ Fetal blood
Result: ○ Normal ○ Abnormal ○ Declined ○ Offered ○ Not offered Reason ○ Other, specify:
Karyotype/microarray:

ANTENATAL SCAN DETAILS

1st trimester (dating) scan:
Date
USS findings *(attach report)* ○ Normal ○ Abnormal ○ Incomplete
NT measurement mm

Fetal anomaly (18^{+0} – 20^{+6}) scan:
1st attempt
Date
USS findings *(attach report)* ○ Normal ○ Abnormal ○ Incomplete ○ Not known
○ Not done, give details:
2nd attempt
Date
USS findings *(attach report)* ○ Normal ○ Abnormal ○ Incomplete
○ Not done, give details:

Echo/MRI/Other:
Date
Findings *(attach report)*

REFERRAL DETAILS

Department/Hospital:
Consultant:

ADDITIONAL DETAILS

Use this box/back of the form to extend answers or include any extra information you think is relevant

NOTIFIER DETAILS

Name:
Hospital:
Department:
Email:
Tel: Date:

©Milton Keynes University Hospital NHS Foundation Trust

Appendix 5: NCARDRS Data Collection Form – Delivery/Postnatal

Public Health England

National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Data collection form – Delivery/Postnatal

Please notify any suspected or confirmed anomaly – structural, chromosomal or biochemical.
DO NOT WAIT 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)

For office use only

MOTHER'S DETAILS

(Sticky label, if available)
Surname:
Forename:
Hosp. no:
NHS no:
Address at booking:
Postcode: Date of birth:
Ethnic category: White Mixed Indian Pakistani
Bangladeshi Other Asian* Black Caribbean Black African
Other Black* Chinese Other* Not known
*If other, please state:
Occupation:

BABY'S DETAILS

(Sticky label, if available)
Surname:
Forename(s):
Hosp. no:
NHS no:
Address at birth:
Postcode:
Date of birth:
Sex: Male Female Indeterminate Not known

BIRTH DETAILS

Place of delivery:
Type of delivery: Spont. vertex Spont. other Low forceps
Other forceps Ventouse Breech
Breech extraction Elective CS Emergency CS
Other, specify Not known
Birth weight: g Birth order: of

OUTCOME DETAILS

Outcome: Live birth Stillbirth (24+ weeks) Fetal loss (<24 weeks)
Termination of preg. (<24 weeks) Not known
Termination of pregnancy: Medical TOP Surgical TOP
Yes – unknown method No
Not known
Feticide: Yes No Not known
If yes, date:

DEATH DETAILS (if applicable)

Date of death:
Post mortem: Yes Not requested Not permitted
Requested but not performed Not known

NOTIFIER DETAILS

Name:
Hospital:
Department:
Email:
Tel: Date:

ANOMALY DETAILS – LIST ALL

Anomaly	Suspected prenatally	How confirmed? E.g. cytogenetics, x-ray, PM
	Yes / No	Date confirmed
	Yes / No	Date confirmed
	Yes / No	Date confirmed
	Yes / No	Date confirmed
	Yes / No	Date confirmed
	Yes / No	Date confirmed
	Yes / No	Date confirmed
	Yes / No	Date confirmed

PROCEDURE DETAILS (if applicable)

Date/age performed/ expected	Department/ Doctor	Procedure

BABY'S REFERRAL DETAILS

Department/Hospital:
Consultant:

Page 1 of 2

Form continues on next page

This document is uncontrolled once printed. Please check on the Trust's Intranet site for the most up to date version.
©Milton Keynes University Hospital NHS Foundation Trust

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
	○ Combined	○ Accepted; T21 risk: 1 in; T13/18 risk: 1 in
	○ Quad	○ Declined ○ Not offered Reason
	○ NIPT	○ Positive ○ Negative ○ Inconclusive; Risk: 1 in

DIAGNOSTIC TEST DETAILS

Date (procedure)	Sample	Result
	○ CVS	○ Normal ○ Abnormal ○ Declined
	○ Amnio	○ Offered ○ Not offered Reason
	○ Fetal blood	○ Other, specify:

Karyotype/microarray:

ANTENATAL SCAN DETAILS

1st trimester (dating) scan:
Date
USS findings *(attach report)*
○ Normal ○ Abnormal ○ Incomplete
NT measurement mm

Fetal anomaly (18⁺⁰ – 20⁺⁶) scan:
1st attempt
Date
USS findings *(attach report)*
○ Normal ○ Abnormal ○ Incomplete ○ Not known
○ Not done, give details:

2nd attempt
Date
USS findings *(attach report)*
○ Normal ○ Abnormal ○ Incomplete
○ Not done, give details:

Echo/MRI/Other:
Date
Findings *(attach report)*

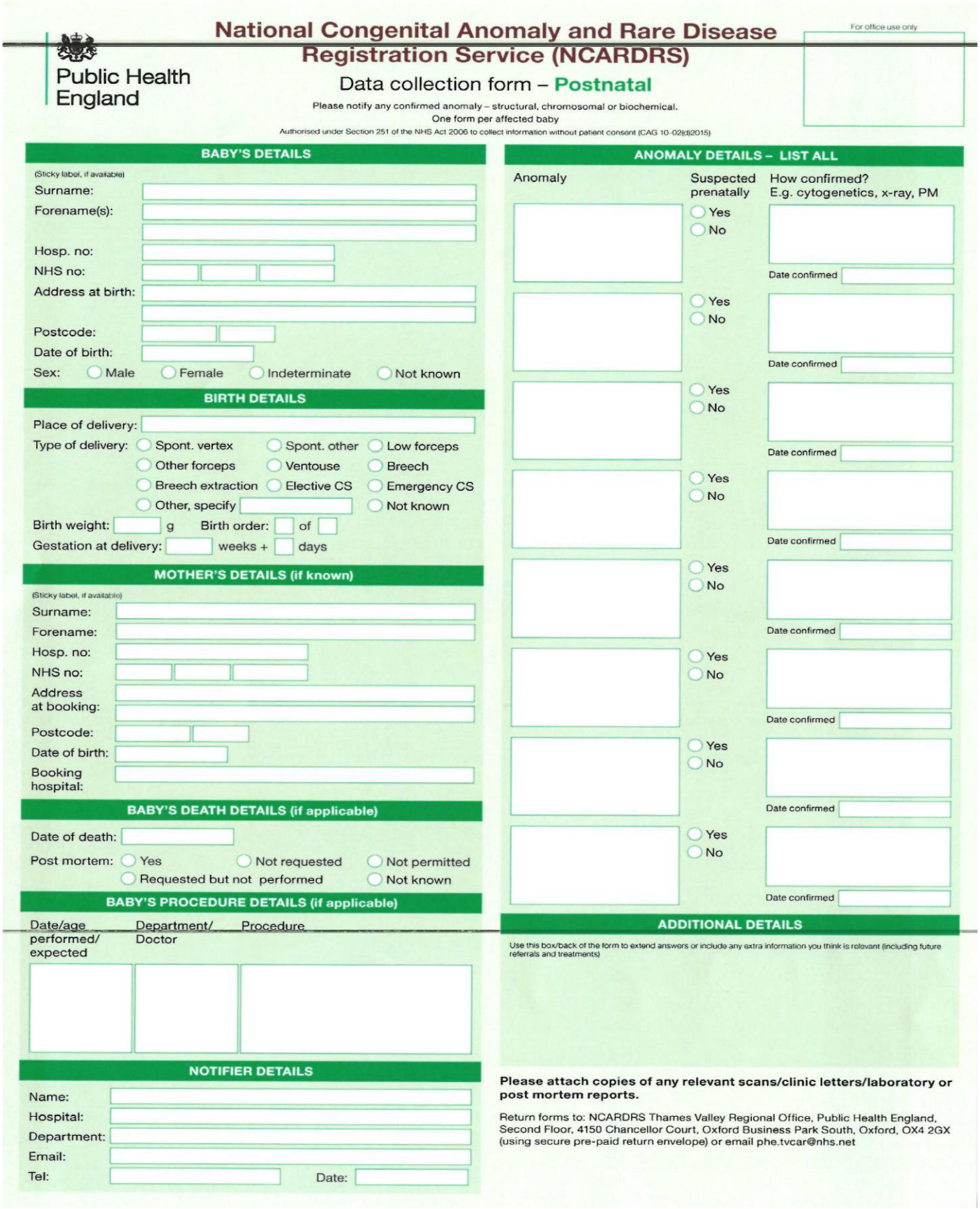
Please attach copies of any relevant scans/clinic letters/laboratory or post mortem reports.

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

©Milton Keynes University Hospital NHS Foundation Trust

Appendix 6: NCARDRS Data Collection Form – Postnatal



National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Public Health England

For office use only

Data collection form – Postnatal

Please notify any confirmed anomaly – structural, chromosomal or biochemical.
One form per affected baby

Authorised under Section 251 of the NHS Act 2006 to collect information without patient consent (CAG 10-02(d)2015)

BABY'S DETAILS

(Sticky label, if available)

Surname:
Forename(s):
Hosp. no:
NHS no:
Address at birth:
Postcode:
Date of birth:
Sex: ○ Male ○ Female ○ Indeterminate ○ Not known

BIRTH DETAILS

Place of delivery:
Type of delivery: ○ Spont. vertex ○ Spont. other ○ Low forceps ○ Other forceps ○ Ventouse ○ Breech ○ Breech extraction ○ Elective CS ○ Emergency CS ○ Other, specify ○ Not known
Birth weight: g Birth order: of
Gestation at delivery: weeks + days

MOTHER'S DETAILS (if known)

(Sticky label, if available)

Surname:
Forename:
Hosp. no:
NHS no:
Address at booking:
Postcode:
Date of birth:
Booking hospital:

BABY'S DEATH DETAILS (if applicable)

Date of death:
Post mortem: ○ Yes ○ Not requested ○ Not permitted ○ Requested but not performed ○ Not known

BABY'S PROCEDURE DETAILS (if applicable)

Date/age performed/ expected	Department/ Doctor	Procedure

NOTIFIER DETAILS

Name:
Hospital:
Department:
Email:
Tel: Date:

ANOMALY DETAILS – LIST ALL

Anomaly	Suspected prenatally	How confirmed? E.g. cytogenetics, x-ray, PM
	○ Yes ○ No	Date confirmed
	○ Yes ○ No	Date confirmed
	○ Yes ○ No	Date confirmed
	○ Yes ○ No	Date confirmed
	○ Yes ○ No	Date confirmed
	○ Yes ○ No	Date confirmed
	○ Yes ○ No	Date confirmed
	○ Yes ○ No	Date confirmed

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: 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

©Milton Keynes University Hospital NHS Foundation Trust

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_____

BABY ALERT ☐

NCARDRS ☐

Midwife_____

Dating Scan_____

CRL_____ Gestation_____

Twin 2 CRL_____

Anomoly Scan_____

Comments:

Combined Test_____ Gest_____

Screening Declined ☐

NT_____mm_____MoM

Twin 2 NT_____mm_____MoM

hCG_____U/l_____MoM

PAPPA_____mU/l_____MoM

T21 Chance 1:_____

T13 / T18 Chance 1:_____

Twin 2 T21 Chance 1:_____

Twin 2 T13 / T18 Chance_____

PND Accepted / Declined NIPT_____

CVS / AMNIO Gest at Test_____

MKUH / OUH Seen within timeframe Y / N

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_____

This document is uncontrolled once printed. Please check on the Trust's Intranet site for the most up to date version.
©Milton Keynes University Hospital NHS Foundation Trust

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_____ BABY ALERT ☐

GP Surgery_____ NCARDRS ☐

Midwife_____

Dating Scan_____

CRL_____ Gestation_____

Twin 2 CRL_____

HC_____ Gestation_____

Twin 2 HC_____

Anomoly Scan_____

Comments:

Quadruple Test_____Gest_____

Screening Declined ☐

AFP_____U/mL_____MoM

hCG_____U/L_____MoM

UE3_____nmol/l_____MoM

Inhibin A_____pg/ml_____MoM

T21 Chance 1:_____

Twin 2 T21 Chance 1:_____

PND Accepted / Declined NIPT_____

CVS / AMNIO Gest at Test_____

No of Insertions_____ Vol Obtained_____

MKUH / OUH Seen within timeframe Y / N

Blood Group_____Anti D Y / N

Hep B Status_____HIV Status_____

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_____

©Milton Keynes University Hospital NHS Foundation Trust

Appendix 8: Oxford University Hospital Fetal Medicine Referral Form

Oxford Fetal Medicine Unit

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

Tel: 01865 221716
Fax: 01865 221164
Email: fetalmedicine.pnd@nhs.net

Maternal Details

Name
DOB
NHS
Address

Use addressograph label

Contact Numbers

Mobile.....

Landline.....

Email address.....

Clinical Details

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

Blood Group.....

Has this woman been seen by Fetal Medicine Unit before?

Yes/No (if yes, state year)

Referral Reason

Hospital.....

Consultant.....

Referrer.....

Date of Referral.....

GP details

Name.....

Practice.....

.....

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.....