NDRS
NATIONAL DISEASE REGISTRATION SERVICE

NHS England

Reporting congenital conditions

Guidance for notifiers

About the NDRS

The National Disease Registration Service (NDRS) is part of NHS England. Its purpose is to collect, collate and analyse data on patients with cancer, congenital anomalies, and rare diseases. It provides robust surveillance to monitor and detect changes in health and disease in the population. NDRS is a vital resource that helps researchers, healthcare professionals and policy makers make decisions about NHS services and the treatments people receive.

The NDRS includes:

- the National Cancer Registration and Analysis Service (NCRAS) and
- the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Healthcare professionals, researchers and policy makers use data to better understand population health and disease. The data is provided by patients and collected by the NHS as part of their care and support. The NDRS uses the data to help:

- understand cancer, rare diseases, and congenital anomalies
- improve diagnosis
- plan NHS services
- improve treatment
- evaluate policy
- improve genetic counselling

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NHS England

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Introduction

We collect information for cases booked in England for all pregnancy outcomes, for example pregnancy losses (all gestations), terminations of pregnancy (TOPS), stillbirths and live births. There is no limit on gestation or age.

NDRS uses a comprehensive, multi-source approach to data collection to ensure that congenital conditions are identified as accurately and completely as possible. By bringing together information from a range of healthcare settings and data systems, we are able to build a robust national picture of these conditions and their outcomes. When NHS teams suspect a physical condition, they share all scan reports with NDRS. This includes the initial scan report and any follow up fetal medicine scan reports with the outcome, including where the suspected condition is confirmed, changed or not present.

Congenital conditions we register

Congenital condition information we collect includes:

- congenital conditions, (suspected or confirmed) – structural (excluding normal variants), genetic and chromosomal conditions and metabolic/biochemical disorders
- enhanced data collection on NHS FASP physical conditions and trisomy 13, 18 & 21

For a full list of inclusions please refer to our inclusion list in the downloads section below. If in doubt, please contact NCARDRS for advice or notify us. If a notification should be excluded, or is a duplicate, it will be deleted. The common antenatal and postnatal exclusions are listed below.
These are NCARDRS exclusions which may still need to be referred clinically as per local guidelines. Please refer to the Fetal Anomaly Screening Programme Handbook for more information.

Common prenatal exclusions (when isolated)

Enlarged nuchals (NTs or nuchal folds) of any size and cases of twin-to-twin transfusion without suspicion of further registerable condition.

Normal variants seen on ultrasound:

- choroid plexus cysts
- dilated cisterna magna
- echogenic foci in the heart
- two vessel cord
- echogenic bowel
- short femurs
- renal pelvic dilation (RPD) if <10mm; (please notify RPD ≥ 10mm)
- ventriculomegaly if < 10mm (please notify ventriculomegaly ≥ 10mm

Common postnatal exclusions (when isolated)

- patent ductus arteriosus (PDA) or persistent foramen ovale (PFO) in preterm infants
- right sided aortic arch
- positional talipes
- heart murmurs
- clicky hips unless USS at 6 weeks confirms congenital hip dysplasia
- Undescended testes
- birth marks
- accessory nipples
- tongue tie
- pyloric stenosis
- sacral dimples - spina bifida occulta

General notification guidance

Please use this form for reporting suspected or confirmed congenital conditions (structural, chromosomal or biochemical). This form should be used when congenital conditions are suspected or have been identified antenatally, during delivery or postnatally.

Please do not wait until final confirmation before sending this form. For suspected conditions, we may receive confirmation from another source, or we will obtain follow up information at a later stage.

We depend on multiple reporting mechanisms to achieve high case ascertainment so do not rely on someone else notifying us. If in doubt always complete a form and send it through to us. For pregnancies/births with multiple fetuses/babies with congenital conditions, please make sure it's clear which fetus/baby the information relates to and complete one form per fetus/baby.

Please send us as much information as you have available, don't worry if you can't complete all the data fields. Please attach copies of any of the following to save time:

- relevant scans
- clinic letters
- laboratory reports
- postmortem reports

If you are attaching any reports, you do not need to complete the results in the form as well. You need to have access to Adobe Acrobat Reader 9 or above. You can download it for free (you might need to ask for help from your IT department).

Save a blank copy of the form and use this each time you complete a new form (you can save a copy to your desktop). You can tab or mouse click through the fields to enter the information you have. After completion save a copy of it on a secure network directory for your information (you might want to label the file with the local Patient Identifiable (PID) number.

Provider level guidance

When a physical condition is suspected, scan reports must be sent to NCARDRS in the following situations:

Table 1: District general hospitals

Data Type	Request
Electronic downloads covering all types of USS	If your site is notifying USS electronically no further spontaneous submissions required – any follow up data will be requested
USS: First trimester; dating; screening; growth or well-being scans	Mandatory in the following situations: strong suspicion or diagnosis of any congenital condition not referred to FM (e.g. Anencephaly; IUD; TOPFA)
USS: 20-week screen scan; Fetal Anomaly Scan	Mandatory in the following situations: all with suspicion/diagnosis of inclusion condition 11 FASP auditable conditions (including all suspicion of cardiac condition) and/or strong suspicion or diagnosis of any anomaly not referred to FM (e.g. Anencephaly; IUD; TOPFA
Telemed scans	Mandatory in the following situations: strong suspicion or diagnosis of any congenital condition as not included in FM data
NDRS Congenital Conditions Data collection form	Can be used for all cases with suspicion/diagnosis of inclusion condition; if used instead of submitting scan reports (not advised) then full information (date and report) must be filled out on form
NIPE notification	All suspicion or diagnosis of congenital condition not admitted to NICU
Postnatal; renal clinical; CRANE or referral letters	All suspicion or diagnosis of congenital condition not admitted to NICU
Postmortems	Where available in case of congenital condition
Private provider data suspicion/diagnostic (trisomy)	Suspicion/diagnostic for FASP conditions and trisomies
NDRS Congenital Conditions Data collection form	Can be used for all cases with suspicion/diagnosis of inclusion condition; if used instead of submitting scan reports (not advised) then full information (date and report) must be filled out on form
NIPE notification	All suspicion or diagnosis of congenital condition not admitted to NICU
Postnatal; renal clinical; CRANE or referral letters	All suspicion or diagnosis of congenital condition not admitted to NICU
Postmortems	Where available in case of congenital condition
Private provider data suspicion/diagnostic (trisomy)	Suspicion/diagnostic for FASP conditions and trisomies

Table 2: Referral centres, fetal medicine units, tertiary centres

Data Type	Request
Fetal medicine scan; echocardiographic scan; MRI scans where these are included in electronic downloads	If your site is notifying USS electronically no further spontaneous submissions required – any follow up data will be requested
Fetal medicine scan; echocardiographic scan; MRI scans	Mandatory in the following situations: All cases with suspicion/diagnosis of inclusion condition including initial consultation scan and final diagnostic scan
NIPE notification	All suspicion or diagnosis of congenital condition not admitted to NICU
Postnatal; renal clinical; CRANE or referral letters	All suspicion or diagnosis of congenital condition not admitted to NICU
Postmortems	Where available in case of congenital condition
Private provider data suspicion/diagnostic (trisomy)	Suspicion/diagnostic for FASP conditions and trisomies

Submitting notifications to NDRS

Notification checklist

Below are guidelines to support those completing NCARDRS notifications:

- Send notifications before final confirmation or outcome.
- Send all 20-week screening scan reports with a suspected or unconfirmed finding for FASP auditable conditions or suspected/confirmed conditions where there is no referral to fetal medicine.
- For twins/triplets, make sure it is clear which fetus has the condition.
- If you have a clinical report, such as an ultrasound scan report or a post-mortem, that contain the information you have you can send us a copy and you do not need to transcribe that information onto a notification form.
- If you prefer to use a notification form, please download this from our guidance page.

How to submit notifications

Where possible NCARDRS prefers to receive case notification in electronic data downloads. All notifications must be electronic and secure.

NCARDRS data collection portal

The secure NCARDRS data collection portal can be used - this contains a notification form and allows you to add six attachments per submission.

If you are currently sending in PDFs/Excel files and would like to switch to bulk downloads or using the portal, please contact your regional NCARDRS office on the emails linked below.

The regular Ultrasound Scan feed (USS), exported from Viewpoint or Astraia, can be submitted via the NCARDRS data collection portal. You can upload data for specific data feeds once your Trust has an account. Please contact the Data Liaison Manager, Helen Luff, if you require further information.

Sending notifications and supporting documents via email

PDF notifications & reports and Excel files can be emailed to your NCARDRS regional office.

Please ensure PDF notifications are in a format where text can be copied - ideally as electronic PDFs, not image files. We recommend that you request delivery and read receipts. We will confirm receipt within three working days, via email.

Opting out of disease registration

Patients can opt out of disease registration if they do not want us to hold or use their data.

Find out how patients can request to opt out of the disease registration process.

Further information

Please send any feedback or queries to ndrsenquiries@nhs.net or contact your NCARDRS regional office.