

National Congenital Conditions and Rare Disease Registration Service (NCARDS)

Data collection form



Please notify any suspected or confirmed congenital conditions when identified – structural, chromosomal or biochemical. DO NOT WAIT until final confirmation before sending this form.

MOTHER'S DETAILS

Surname:

Forename(s):

NHS no:

Postcode:

Date of birth:

BABY'S DETAILS

Surname:

Forename(s):

NHS no:

Postcode:

Date of delivery or Gestation (weeks+days): +

Sex: Male Female
 Indeterminate Not known

BOOKING DETAILS

Booking hospital:

EDD (by scan):

Number of fetuses:

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

ANEUPLOIDY SCREENING DETAILS

Test completed: Yes No

Screening: Accepted Declined Not offered

Test type: Quad Combined

Date (specimen):

Result: High Low

REFERRAL DETAILS

Trust:

Department:

ANTENATAL SCAN DETAILS

1st abnormal scan:

Date:

Trust:

USS findings: (attach report)

Fetal anomaly (18+0 - 20+6) scan:

Date 1st attempt:

Trust:

USS findings: (attach report if a FASP anomaly)

Normal Abnormal Incomplete

Date 2nd attempt:

Trust:

USS findings: (attach report if a FASP anomaly)

Normal Abnormal Incomplete

Echo/MRI/Other:

Date:

Trust:

Findings (attach report):

First FM scan:

Date:

Trust:

Findings (attach report):

DIAGNOSTIC TEST RESULTS

Date (procedure):

Sample: CVS Fetal blood Amnio
 Blood Tissue/POC

Result: Normal Abnormal Other
 Declined Not offered

BIRTH DETAILS

Place of delivery:

Birth weight (g): (still/live births only)

Birth order: of

PREGNANCY OUTCOME DETAILS

Outcome: Live birth Stillbirth (24+ w) Fetal loss (<24 w)

Not known Termination of pregnancy (<24 w)

Termination of pregnancy: Medical Surgical No

Yes - unknown method Not known

Feticide: Yes No Not known

If yes, date:

CONDITION DETAILS

Condition description	Suspected antenatally? (Yes/No)	How confirmed? E.g. cytogenetics, x-ray, PM or clinically at delivery?
-----------------------	------------------------------------	--

<input type="text"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="text"/>
		Date confirmed: <input type="text"/>

<input type="text"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="text"/>
		Date confirmed: <input type="text"/>

<input type="text"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="text"/>
		Date confirmed: <input type="text"/>

<input type="text"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="text"/>
		Date confirmed: <input type="text"/>

<input type="text"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="text"/>
		Date confirmed: <input type="text"/>

<input type="text"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="text"/>
		Date confirmed: <input type="text"/>

DEATH DETAILS (if applicable)

Date of death or
Death diagnosed if
in utero

Postmortem: Yes No

ADDITIONAL DETAILS

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

NOTIFIER DETAILS

Name:

Hospital:

Department:

Email:

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

Please send by secure electronic transfer to your regional NCARDS office. **DO NOT POST.**

Details of each regional NCARDS office can be found at <https://digital.nhs.uk/ndrs/about/ncards-regional-offices>

The NDRS has legal permission to collect patient-level data and to use it to protect the health of the population, under The National Disease Registries Directions 2021 and section 254 of the Health and Social Care Act 2012.