CARDRISS: Congenital Anomalies and Rare Diseases Registration & Information Service for Scotland
Congenital Anomalies Dataset

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Definitions & Recording Guidance
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INTRODUCTION

NHS National Services Scotland, Information Services Division (ISD) has been commissioned to establish a Scottish Congenital Anomaly Register. Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS) is part of a wider programme of work to improve information on individuals affected by rare diseases, and hence ultimately improve their outcomes.

The early stages of this project will involve an initial analysis of existing national datasets to inform decisions about how they will feed into the new register. This will involve linking together a number of ISD held datasets and will allow us to analyse how well existing data ascertains congenital anomaly cases and will help identify gaps in the data that we will aim to collect locally.

Datasets will be linked using mother and/or baby CHI.

DATASET

One of the main aims of the project was to minimise data collection by using existing data from internal NSS systems. NSS data sources will not contain all the data items included within the dataset, therefore the register will be managed by a team of highly trained staff of NHS National Services Scotland. The registry team will need to work with NHS Boards and their Maternity systems to complete records within the congenital anomaly register. Our data will be used to report to EUROCAT, a European network of population-based registries for the epidemiologic surveillance of congenital anomalies.

The definitions, codes and values have been aligned with the ISD Data Dictionary as far as possible, along with trying to be as close to EUROCAT coding as possible.

The dataset has been split into four sections.

- Section 1 – Mother Information
- Section 2 – Pregnancy Information
- Section 3 – Baby Information
- Section 4 – Anomaly Information

The project has adhered to Information Governance and Information Security safeguards.
SCOPE

The Scottish congenital anomaly register will capture information on all babies affected by a major structural or chromosomal anomaly or recognised syndrome. We will also seek to include babies affected by inherited endocrine, metabolic, and haematological conditions, in particular those covered by newborn screening. Affected live born babies diagnosed within the first year of life, stillbirths and fetal losses at ≥ 20 weeks of pregnancy, and pregnancies terminated at any gestation due to an anomaly would all be included. Over time we will aim to extend the register to cover congenital anomalies diagnosed after the first year of life and other rare diseases.

Internal NSS data systems will be used to flag a record for inclusion on the Congenital Anomalies register. The registry team will then look to complete missing data items and close the record.

Health Boards are not expected to make any IT changes to their current systems to accommodate this data request.

SUBMISSION

Submission details will be discussed as part of the IT build later in 2019/20. It is anticipated that the registry will work in a similar way to Cancer registry and ISD staff will be responsible for completing records in the registry.

Registry staff will use a range of data sources including NSS internal data, external maternity data and maternal notes.
SECTION 1: MOTHER INFORMATION

General Guidance for Section 1:
- The mother information data will be populated using internal NSS data sources.
- The mother CHI will be the identifier to link the internal NSS data sources.
- The CHI number should be returned for all patients. Where CHI is not available surname, forename, date of birth, postcode and gender must be provided to allow CHI seeding to take place.

1.1 MOTHER CHI NUMBER

Definition: The Community Health Index (CHI) is a population register which is used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index.


Format: Integer (10)

Recording Guidance:
- This is a mandatory field.
- This field will be populated from Internal NSS Sources.
- No Eurocat variable.

Supplementary Information:
The CHI number is a unique numeric identifier allocated to each patient on first registration with the health service in Scotland.

The CHI number is a 10-character code consisting of the 6-digit date of birth (DDMMYY), two digits, a 9th digit which is always even for females and odd for males and an arithmetical check digit.

1.2 MOTHER NHS NUMBER

Definition: The NHS number is the identifier allocated to an individual to enable unique identification within the UK for NHS health care purposes


Format: Alphanumeric (10)

Recording Guidance:
- This is an optional field.
- The NHS Number for Scottish residents is held by NRS. We can populate this from NRS Data.
This is the new NHS Number which was implemented by the NHS in England and Wales in April 1997 and will be required to be held by Scottish health care systems for English or Welsh patients.

No Eurocat variable.

### 1.3 MOTHER Surname

**Common Names:** Second Name; Family Name

**Definition:** The surname of a person represents that part of the name of a person which indicates the family group of which the person is part.


**Format:** Characters (20)

**Recording Guidance:**
- This is a **mandatory** field.
- This field will be populated from Internal NSS Sources.
- Double-barrelled surnames should be entered with a hyphen between the two parts of the surname. Example: DURHAM-JONES.
- No Eurocat variable.

### 1.4 MOTHER FIRST Forename

**Common Names:** First Name; Given Name.

**Definition:** The first forename of a person represents that part of the name of a person which after the surname is the principal identifier of a person.


**Format:** Characters (20)

**Recording Guidance:**
- This is a **mandatory** field.
- This field will be populated from Internal NSS Sources.
- Hyphens occurring within a forename should be entered as a separate character (but not as a first character). Example: ANNE-MARIE.
- No Eurocat variable.
1.5 MOTHER SECOND FORENAME

**Common Names:** Middle Name; Second Name

**Definition:** A second and/or middle name that some people have between their first name and surname.


**Format:** Character (20)

**Recording Guidance:**
- This is an optional field.
- This field will be populated from Internal NSS Sources.
- Hyphens occurring within a forename should be entered as a separate character (but not as a first character). Example: ANNE-MARIE.
- No Eurocat variable.

1.6 MOTHER PREVIOUS Surname

**Common Names:** Maiden Name; Birth Surname

**Definition:** This is any surname by which a person was previously known.


**Format:** Character (20)

**Recording Guidance:**
- This is an optional field.
- This field will be populated from Internal NSS Sources, where possible.
- It may be used for Maiden Surname for married females including those widowed, divorced or separated; or for Birth Name and Alternative name, where these are required.
- Double-barrelled surnames should be entered with a hyphen between the two parts of the surname. Example: DURHAM-JONES.
- No Eurocat variable.

1.7 MOTHER DATE OF BIRTH

**Definition:** The date on which a person was born or is officially deemed to have been born as recorded on their birth certificate.

**Format:** Date – DDMMCCYY

**Recording Guidance:**
- This is a **mandatory** field.
- This field will be populated from Internal NSS Sources.
- Date of birth should be entered thus: 9th February 1972.
  
  0 9 0 2 1 9 7 2
- Eurocat variable – Date of Birth of Mother (DATEMO – non-core variable).

### 1.8 MOTHER ETHNICITY

**Definition:** A statement made by the patient about their current ethnic group.


**Format:** Alphanumeric (2)

**Coding Guidance:**

1A = Scottish  
1B = Other British  
1C = Irish  
1K = Gypsy/Traveller  
1L = Polish  
1Z = Other white ethnic group  
2A = Any mixed or multiple ethnic groups  
3F = Pakistani, Pakistani Scottish or Pakistani British  
3G = Indian, Indian Scottish or Indian British  
3H = Bangladeshi, Bangladeshi Scottish or Bangladeshi British  
3J = Chinese, Chinese Scottish or Chinese British  
3Z = Other Asian, Asian Scottish or Asian British  
4D = African, African Scottish or African British  
4Y = Other African  
5C = Caribbean, Caribbean Scottish or Caribbean British  
5D = Black, Black Scottish or Black British  
5Y = Other Caribbean or Black  
6A = Arab, Arab Scottish or Arab British  
6Z = Other ethnic group  
98 = Refused/Not provided by patient  
99 = Not Known

**Recording Guidance:**
- This is a **mandatory** field.
- This field will be populated from Internal NSS Sources, if unknown registry staff will complete.
- Ethnicity not recorded should be coded as 99 – Not Known.
- No Eurocat variable.
SECTION 2: PREGNANCY INFORMATION

General Guidance for Section 2:
- The pregnancy information data will be populated using internal NSS data sources where possible.
- The mother CHI will be the identifier to link the internal NSS data sources.
- There can be multiple pregnancies that will be linked to Mother.

2.1 POSTCODE OF MOTHER AT END OF PREGNANCY

Definition: Postcode of mother. The postcode is a basic unit for identifying geographic locations. A postcode is associated with each address in the UK.


Format: Alphanumeric (8)

Recording Guidance:
- This is a mandatory field.
- This field will be populated from Internal NSS Sources.
- The postcode of the mother's usual address at end of pregnancy.
- A postcode has two component parts. Part one of the postcode is known as the outcode, and part two is known as the incode.
  - Outcode – The outcode identifies the postal area and the postal district. The postal area is represented by 1 or 2 alpha characters and the postal district is represented by 1 or 2 digits. Therefore, part 1 contains 2, 3 or 4 characters.
  - Incode – The incode is of length 3 characters. The postcode sector is represented by the outcode plus the first digit of the incode.
- Eurocat variable – Mother's Residence Code (RESIDMO – non-core variable).

2.2 FATHER DATE OF BIRTH

Definition: The date on which a person was born or is officially deemed to have been born as recorded on their birth certificate.


Format: Date – DDMMCCYY

Recording Guidance:
- This is an optional field.
- Date of birth should be entered thus: 5th December 1970
  0 5 1 2 1 9 7 0
- No Eurocat variable.
2.3 EXPECTED DATE OF DELIVERY

Definition: Expected date of delivery (based on first trimester ultrasound scan where possible).

Definition source: NEW Definition for CARDRISS, to be added to National Data Dictionary.

Format: Date – DDMMCCYY

Recording Guidance:
- This is a mandatory field.
- Expected Date of Delivery should be entered thus: 1\textsuperscript{st} April 2020
  0 1 0 4 2 0 2 0
- No Eurocat variable.

2.4 NUMBER OF FETUSES THIS PREGNANCY

Definition: The number of fetuses this pregnancy.


Format: Integer (1)

Coding Guidance:
1 = Singleton
2 = Twins
3 = Triplets
4 = Quadruplets
5 = Quintuplets
6 = Sextuplets or more
7 = Multiple birth, number of babies not known
8 = Singleton at time of delivery/termination, but known to have been a multiple pregnancy at an earlier stage in pregnancy
9 = Not known

Recording Guidance:
- This is a mandatory field.
- This field will be populated from Internal NSS Sources.
- Eurocat variable – Number of Babies/Fetuses Delivered (NBRBABY – core variable).

2.5 NUMBER OF FETUSES AFFECTED BY ANOMALY THIS PREGNANCY

Definition: The number of fetuses/babies affected by congenital anomaly in this pregnancy.

**Format:** Integer (1)

**Coding Guidance:**
1 = One  
2 = Two  
3 = Three  
4 = Four  
5 = Five  
6 = Six or more  
9 = Not known

**Recording Guidance:**
- This is a **conditional** field.  
- Only record for multiple birth deliveries.  
- Eurocat variable – Number of Malformed in Multiple Set (NBRMALS – core variable).

### 2.6 ASSISTED CONCEPTION

**Definition:** Have any assisted conception methods been used in this pregnancy.


**Format:** Integer (2)

**Coding Guidance:**
0 = No  
1 = Induced ovulation only  
2 = Artificial insemination  
3 = IVF (In vitro fertilization)  
4 = GIFT (Gamete intra fallopian transfer)  
5 = ICSI (Intracytoplasmic sperm injection)  
6 = Egg donation  
8 = Other  
9 = Not known  
10 = Assisted conception, type unknown

**Recording Guidance:**
- This is an **optional** field.  
- Eurocat variable – Assisted Conception (ASSCONCEPT – non-core variable).
2.7 MOTHER OCCUPATION CODE

**Definition**: Occupation code of mother coded in Standard Occupational Classification.

**Definition source**: [https://www.ons.gov.uk/methodology/classificationsandstandards](https://www.ons.gov.uk/methodology/classificationsandstandards)

**Format**: Integer (4)


**Recording Guidance**:
- This is an optional field.
- This field will be populated from Internal NSS Sources.
- Eurocat variable – Mother’s occupation at time of conception (OCCUPMO – non-core variable) – requires mapping from SOC codes to ISCO-08 codes (cannot determine if at conception).

2.8 ILLNESS BEFORE PREGNANCY ICD10 CODE

**Definition**: Pre-pregnancy illness in mother of affected baby.


**Format**: Alphanumeric (5)

**Recording Guidance**:
- This is an optional field.
- This field will be partially populated from Internal NSS Sources.
- Code according to ICD10 code for condition.
- ICD10 codes are 4 or 5 characters in length.
- Record any illness whether chronic or acute with onset before pregnancy and that may affect fetal development (e.g. childhood cancer, metabolic and endocrine disease, severe congenital anomaly).
- Include coding for harmful use of alcohol and drug misuse.
- Do not insert the decimal point in the code.
- Up to four illnesses can be recorded
- Eurocat variable – Maternal Pregestational Diabetes (MATDIAB – non-core) can be derived from this.
2.9 ILLNESS DURING PREGNANCY ICD10 CODE

**Definition:** Illness in mother of affected baby during pregnancy.


**Format:** Alphanumeric (5)

**Coding Guidance:**
- ICD10 code
  - 0 = No
  - 1 = Yes, but no information available
  - 9 = Not known

**Recording Guidance:**
- This is an optional field.
- ICD10 codes are 4 or 5 characters in length.
- Record any illness with chronic or acute onset during pregnancy including asymptomatic maternal infections.
- Include coding for harmful use of alcohol and drug misuse.
- Fetal infections and associated malformations should be coded under syndrome and anomalies.
- Up to four illnesses can be recorded.
- Eurocat variable – Illness During Pregnancy (ILLDUR1 – non-core variable) and Illness During Pregnancy 2 (ILLDUR2 – non-core variable) – we may not be able to derive if illness was during first 20 weeks of pregnancy.

2.10 MOTHER SIDE ANOMALY

**Definition:** Mother of affected baby, or member of mother’s family affected by congenital anomaly.


**Format:** Integer (1)

**Coding Guidance:**
- 1 = Same
- 2 = Other
- 3 = Same and Other
- 4 = No
- 9 = Not Known

**Recording Guidance:**
- This is an optional field.
• Include mother herself as well as mother’s family and restrict the Mother’s family to first, second and third degree biological relatives (mother, father, siblings, grandparents, aunts, uncles, half siblings, first cousins).
• If the aetiology is known, “same” means the same aetiology, even if the spectrum of malformations present is slightly different.
• If the aetiology is unknown or multifactorial, “same” is a matter of judgment by a qualified coder, but full specification of the anomaly should be given, whether other or the same.
• “Same and other” refers to two different relatives. If a relative has both the same and another anomaly, code “same”.
• Eurocat variable – Mother’s Family with Anomalies (MOANOM – non-core variable).

2.11 MOTHER SIDE ANOMALY DESCRIPTION

Definition: Description of congenital anomaly affecting mother, or member of mother’s family as recorded in variable 2.10.


Format: Character (200)

Recording Guidance:
• This is a conditional field.
• Only record if variable 2.10 is coded 1, 2 or 3.
• Eurocat variable – Specify Type of Anomaly and Describe Malformation (SP_MOANOM – non-core variable).

2.12 FATHER SIDE ANOMALY

Definition: Father of affected baby, or member of father’s family affected by congenital anomaly.


Format: Integer (1)

Coding Guidance:
1 = Same
2 = Other
3 = Same and Other
4 = No
9 = Not Known

Recording Guidance:
• This is an optional field.
• Include father himself as well as father’s family and restrict the family to first, second and third degree biological relatives (mother, father, siblings, grandparents, aunts, uncles, half siblings, first cousins).
• If the aetiology is known, “same” means the same aetiology, even if the spectrum of malformations present is slightly different.
• If the aetiology is unknown or multifactorial, “same” is a matter of judgment by a qualified coder, but full specification of the anomaly should be given, whether other or the same.
• “Same and other” refers to two different relatives. If a relative has both the same and another anomaly, code “same”.
• Eurocat variable – Father’s Family with Anomalies (FAANOM – non-core variable).

2.13 FATHER SIDE ANOMALY DESCRIPTION

Definition: Description of congenital anomaly affecting father, or member of father’s family as recorded in variable 2.12.


Format: Character (200)

Recording Guidance:
• This is a conditional field.
• Only record if variable 2.12 is coded 1, 2 or 3.
• Eurocat variable – Specify Type of Anomaly and Describe the Malformation (SP_FAANOM – non-core variable).

2.14 SIBLING ANOMALY

Definition: Sibling (including terminated, fetal loss, live birth) of affected baby affected by congenital anomaly.


Format: Integer (1)

Coding Guidance:
1 = Same
2 = Other
3 = Same and Other
4 = No
9 = Not Known

Recording Guidance:
• This is an optional field.
• Include siblings – terminated, fetal loss and live birth.
If one sibling has both the same anomaly and a different anomaly, code under “same”.
If one sibling has the same anomaly and another sibling has a different anomaly, code under “same and other”
Eurocat variable – Siblings with Anomalies (SIBANOM – non-core variable).

2.15 SIBLING ANOMALY DESCRIPTION

**Definition:** Description of congenital anomaly affecting sibling as recorded in variable 2.14.


**Format:** Character (200)

**Recording Guidance:**
- This is a conditional field.
- Only record if variable 2.14 is coded 1, 2 or 3
- Eurocat variable – Specify Type of Anomaly and Describe the Malformation (SP_SIBANOM – non-core variable).
SECTION 3: BABY INFORMATION

General Guidance for Section 3:
- The baby information data will be populated using internal NSS data sources where possible, shown in recording guidance.
- The mother or baby CHI will be the identifier to link the internal NSS data sources.
- There can be multiple babies linked to one pregnancy episode.

3.1 CARDRISS UNIQUE FETUS/BABY ID

Definition: Each fetus/baby has a unique identification. This number is a maximum of 10 characters long.

Definition source: NEW Definition for CARDRISS, to be added to National Data Dictionary.

Format: Integer (10)

Recording Guidance:
- This is a mandatory field.
- This field will be derived from baby’s CHI Number if this is available.
- Where no CHI exists, the CARDRISS system will generate a unique system number and will link to CHI when available.
- Eurocat variable – Local ID (NUMLOC – core variable. ID numbers should not repeat themselves in different years).

3.2 LOCAL FETUS ID NUMBER

Definition: Local fetus ID created before birth.

Definition source: NEW Definition for CARDRISS, to be added to National Data Dictionary.

Format: Integer (11)

Recording Guidance:
- This is an optional field.
- A local fetus ID is currently automatically created in the BadgerNet Maternity system – this is the mother’s CHI followed by an a/b/c depending on the number of babies she is pregnant with. This is then linked to that one pregnancy, but can link to the babies CHI at birth.
- This field will be populated from Internal NSS Sources when BadgerNet Maternity data becomes available or via registration staff in the interim.
- No Eurocat variable.
3.3 BABY CHI NUMBER

**Definition:** The Community Health Index (CHI) is a population register which is used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index.


**Format:** Integer (10)

**Recording Guidance:**
- This is an optional field.
- This field will be populated from Internal NSS Sources.
- No Eurocat variable.

**Supplementary Information:**
The CHI number is a unique numeric identifier allocated to each patient on first registration with the health service in Scotland.
The CHI number is a 10-character code consisting of the 6-digit date of birth (DDMMYY), two digits, a 9th digit which is always even for females and odd for males and an arithmetical check digit.

3.4 BABY NHS NUMBER

**Definition:** The NHS number is the identifier allocated to an individual to enable unique identification within the UK for NHS health care purposes.


**Format:** Alphanumeric (10)

**Recording Guidance:**
- This is an optional field.
- The NHS Number for Scottish residents is held by NRS. We can populate this from NRS Data.
- This is the new NHS Number which was implemented by the NHS in England and Wales in April 1997 and will be required to be held by Scottish health care systems for English or Welsh patients.
- No Eurocat variable.

3.5 NRS LIVE BIRTH OR STILLBIRTH RECORD AVAILABLE

**Definition:** Is there an NRS Live Birth or Stillbirth record available.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)
Coding Guidance:
1 = Live Birth Record
2 = Stillbirth Record
3 = No
9 = Not Known

Recording Guidance:
- This is a mandatory field.
- This field will be populated from Internal NSS Sources.
- Eurocat variable – Civil Registration Status (CIVREG – core variable).

3.6 NRS LIVE BIRTH / STILLBIRTH REGISTRATION DISTRICT

Definition: Registration districts are the areas used for recording births and stillbirths in Scotland. Today, there 32 Registration District boundaries and the boundaries are the same as the 32 Council Area boundaries.

Definition source: NEW Definition for CARDRISS, to be added to National Data Dictionary. Taken from NRS Glossary of Terms: https://www.nrscotland.gov.uk/glossary-of-terms#

Format: Integer (3)

Recording Guidance:
- This is a conditional field.
- Only record if variable 3.13 is coded 1 or 2.
- Each registration district has a unique reference number.
- This field will be populated from Internal NSS Sources.
- No Eurocat variable.

3.7 NRS LIVE BIRTH / STILLBIRTH YEAR OF REGISTRATION

Definition: Year of live birth / stillbirth registration with the National Records of Scotland.

Definition source: NEW Definition for CARDRISS, to be added to National Data Dictionary.

Format: Integer (4)

Recording Guidance:
- This is a conditional field.
- Only record if variable 3.13 is coded 1 or 2.
- This field will be populated from Internal NSS Sources.
- No Eurocat variable.
3.8 NRS LIVE BIRTH / STILLBIRTH ENTRY NUMBER

**Definition:** Entry number given at live birth / stillbirth registration with the National Records of Scotland.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (5)

**Recording Guidance:**
- This is a **conditional** field.
- Only record if variable 3.13 is coded 1 or 2.
- This field will be populated from Internal NSS Sources.
- No Eurocat variable.

3.9 BABY SURNAME

**Common Names:** Second Name; Family Name

**Definition:** The surname of a person represents that part of the name of a person which indicates the family group of which the person is part.


**Format:** Character (20)

**Recording Guidance:**
- This is a **conditional** field.
- Only record if variable 3.13 is coded 1 or 2.
- This field will be populated from Internal NSS Sources.
- Double-barrelled surnames should be entered with a hyphen between the two parts of the surname. Example: DURHAM-JONES.
- No Eurocat variable.

3.10 BABY FORENAME

**Common Names:** First Name; Given Name.

**Definition:** The first forename of a person represents that part of the name of a person which after the surname is the principal identifier of a person.


**Format:** Character (20)
Recording Guidance:
- This is a conditional field.
- Only record if variable 3.13 is coded 1 or 2.
- This field will be populated from Internal NSS Sources.
- Where only the initial letter of the first forename is available this should be entered in the first character space.
- In the very rare circumstances where the first forename is not known "X" should be entered in the first character space.
- Hyphens occurring within a forename should be entered as a separate character (but not as a first character). Example: ANNE-MARIE.
- No Eurocat variable.

3.11 BABY SECOND FORENAME

Common Names: Middle Name; Second Name

Definition: A second and/or middle name that some people have between their first name and surname.


Format: Character (20)

Recording Guidance:
- This is an optional field.
- This field will be populated from Internal NSS Sources.
- Hyphens occurring within a forename should be entered as a separate character (but not as a first character). Example: ANNE-MARIE.
- No Eurocat variable.

3.12 BABY PREVIOUS Surname

Common Names: Birth Surname.

Definition: This is any surname by which a person was previously known.


Format: Character (20)

Recording Guidance:
- This is an optional field.
- This field will be populated from Internal NSS Sources, where possible.
- This field may be used for birth name and alternative name
- This item also applies to any person who has changed their surname (e.g. by deed poll).
- This data item has been retained primarily for maternity and record linkage purposes until a unique identifier is available.
- Double-barrelled surnames should be entered with a hyphen between the two parts of the surname. Example: DURHAM-JONES.
- No Eurocat variable.

### 3.13 OUTCOME OF PREGNANCY

**Definition:** Outcome of pregnancy indicates whether the baby was live born, stillborn, spontaneously aborted or subject to termination of pregnancy due to fetal anomaly.


**Format:** Integer (1)

**Coding Guidance:**
- 1 = Live birth
- 2 = Stillbirth
- 3 = Spontaneous abortion
- 4 = TOPFA (Termination of Pregnancy due to Fetal Anomaly)
- 9 = Not known

**Points to Note:**
- Spontaneous Abortions (20-23 weeks)
- Stillbirths (>=24 weeks)

**Recording Guidance:**
- This is a mandatory field.
- This field will be partially populated from Internal NSS Sources, if unknown registry staff will complete.
- Terminations of pregnancy refer to cases where prenatal diagnosis was made of malformation in a live fetus and the pregnancy was then terminated.
- If the fetus died spontaneously in utero either before or after prenatal diagnosis of malformation then it should be coded as spontaneous abortion or stillbirth, not as termination of pregnancy.
- Stillbirths or perinatal deaths resulting from termination of pregnancy following prenatal diagnosis must be coded as terminations (value = 4), irrespective of civil registration status.
- For a non-natural fetal reduction in a multiple pregnancy where one fetus has an anomaly, code 4 (in that case gestlength = gestational age at reduction; date of birth = date of reduction; and code carefully all multiple birth variables).
- If a termination was performed for other reasons than malformation, the case should not be recorded on CARDRISS.
- Eurocat variable – Type of Birth (TYPE – core variable).
3.14 SEX

**Definition:** The state of being male or female.


**Format:** Integer (1)

**Coding Guidance:**
- 0 = Not Known (i.e. indeterminate sex, includes ‘Intersex’)
- 1 = Male
- 2 = Female
- 9 = Not Specified (includes not stated by patient, or not recorded)

**Recording Guidance:**
- This is a mandatory field.
- This field will be populated from Internal NSS Sources.
- Eurocat variable – Sex (Sex – core variable). Mapping required to Eurocat codes.

3.15 END OF PREGNANCY DATE

**Definition:** The date on which the pregnancy ended.
- For live births this will be date of birth,
- For still births (>24 weeks) this will be date of delivery,
- For spontaneous abortions (20-23 weeks) this will be date of abortion/delivery,
- For Termination of Pregnancy due to Fetal Anomaly (TOPFA) this will be date of Termination.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Date – DDMMCCYY

**Recording Guidance:**
- This is a mandatory field.
- This field will be populated from Internal NSS Sources.
- Date cannot be in the future.
- End of Pregnancy Date should be entered thus: 1st April 2020
  0 1 0 4 2 0 2 0
- Eurocat variable – Date of Birth (BIRTH_DATE – core variable).

3.16 DATE FETAL DEATH CONFIRMED

**Definition:** The first date on which a fetus is clinically confirmed to have died in utero.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.
**Format:** Date – DDMMCCYY

**Points to Note:** Fetal Death would usually be confirmed by absence of fetal heart activity on real time ultrasound. For early TOPFAs, if fetal status is not assessed prior to termination, the date fetal death is confirmed would be the same as the end of pregnancy date (i.e. the date that the termination is completed / products of conception are expelled). For later TOPFAs preceded by feticide, the date fetal death is confirmed would be the date that the feticide was performed.

**Recording Guidance:**
- This is a conditional field.
- Only record if variable 3.13 is coded 2, 3 or 4.
- Record for still births (>24 weeks), spontaneous abortions (20-23 weeks) and Termination of Pregnancy due to Fetal Anomaly (TOPFA).
- Date before or equal to 3.15.
- Date fetal death confirmed should be entered thus: 1st April 2020 01042020
- No Eurocat variable.

### 3.17 GESTATIONAL AGE AT END OF PREGNANCY

**Definition:** Length of gestation in completed weeks at delivery/end of pregnancy. Give best estimate based on first trimester ultrasound scan where possible.


**Format:** Integer (2)

**Coding Guidance:**
99 = Unknown

**Recording Guidance:**
- This is a mandatory field.
- This field will be derived from a rule.
  - Date of Birth – Expected Date of Delivery (based on first trimester ultrasound scan where possible).
- Eurocat variable – Length of Gestation in Completed Weeks (GESTLENGTH – core variable).

### 3.18 BIRTH WEIGHT

**Definition:** The weight of the baby at birth/end of pregnancy specified in grams.

**Format:** Integer (4)

**Recording Guidance:**
- This is a **mandatory** field.
- This field will be populated from Internal NSS Sources.
- Preceding zeros should be entered if the weight is less than 1000g.
- If the baby has not been weighed at birth, the birth weight should be recorded as 9999. This may happen if the baby needs immediate medical attention.
- This field should be recorded for all live births and still births.
- For Spontaneous Abortions and TOPFAs the weight of the fetus should be recorded if possible.
- Eurocat variable – Birth Weight (WEIGHT – core variable).

### 3.19 DATE OF DEATH PRIOR TO FIRST BIRTHDAY

**Definition:** The date of death of baby, after live birth.


**Format:** Date – DDMMCCYY

**Recording Guidance:**
- This is a **conditional** field.
- This field will be populated from Internal NSS Sources.
- Only to be recorded if variable 3.13 coded 1.
- The date must be equal to date of birth or up to 364 days.
- Date cannot be in the future.
- Date of death should be entered thus: 1\textsuperscript{st} April 2020
  
  0 1 0 4 2 0 2 0
- Eurocat variable – Date of Death (DEATH_DATE – non-core variable).

### 3.20 DATE FETUS/BABY FIRST SUSPECTED OF HAVING ANOMALY

**Definition:** Date at which the fetus/baby was first suspected of having an anomaly. Indicate date of examination rather than time when result known.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Date – DDMMCCYY

**Recording Guidance:**
- This is a **mandatory** field.
- This field will be based on the earliest anomaly recorded.
- Date cannot be in the future.
• Date Case First Suspected should be entered thus: 1\textsuperscript{st} April 2020
  0 1 0 4 2 0 2 0
• No Eurocat variable.

### 3.21 PERIOD FETUS/BABY FIRST SUSPECTED OF HAVING ANOMALY

**Definition:** When the fetus/baby was first suspected of having a congenital anomaly.


**Format:** Integer (2)

**Coding Guidance:**
- 1 = At delivery/birth
- 2 = Prenatal
- 3 = Postnatal
- 9 = Not Known

**Recording Guidance:**
- This is a **mandatory** field.
- All cases MUST have been confirmed as having a congenital anomaly

### 3.22 GESTATIONAL AGE FETUS FIRST SUSPECTED OF HAVING ANOMALY

**Definition:** Gestational age in completed weeks at which the fetus was first suspected to have an anomaly.


**Format:** Integer (2)

**Coding Guidance:**
- 99 = Not Known

**Recording Guidance:**
- This is a **conditional** field.
- Only record if variable 3.21 coded 2.
- This field will be derived from Date Case First Suspected and Expected Date of Delivery (based on first trimester ultrasound scan where possible).
- Exclude soft markers.
- Indicate time of examination rather than time when result known.
- If no prenatal diagnosis please leave blank.
• Eurocat variable – If Prenatally Diagnosed, Gestational Age at Discovery (AGEDISC – core variable).

### 3.23 CONDITION AT DISCOVERY

**Definition:** Condition of fetus or baby when anomaly was first suspected.


**Format:** Integer (1)

**Coding Guidance:**

1 = Alive  
2 = Dead  
9 = Not Known

**Recording Guidance:**

- This is a mandatory field.
- Eurocat variable – Condition at Discovery (CONDISC – non-core variable).

### 3.24 FIRST POSITIVE PRENATAL TEST OF ANOMALY

**Definition:** First prenatal test whether screening procedure or diagnostic test which indicated a possible congenital anomaly or need for further tests.


**Format:** Integer (2)

**Coding Guidance:**

1 = Ultrasound at GA < 14 weeks  
2 = Ultrasound at GA 14-21 weeks  
3 = Ultrasound at GA ≥ 22 weeks  
4 = Ultrasound GA not known  
5 = Serum/combined screening  
6 = Fetal karyotype on maternal blood  
7 = CVS or amniocentesis  
8 = Other test positive  
9 = Test(s) performed, result negative  
10 = No test performed  
11 = Not known

**Recording Guidance:**

- This is a mandatory field.
- For code 8 = other test, give information in text field (variable 3.25).
• If test performed and result negative, then the “Prenatal Diagnosis For Syndrome” variable cannot be coded 1 = Yes, syndrome was diagnosed prenatally.
• Ultrasound < 14 weeks means only ultrasound performed which may include a nuchal measurement.
• The serum/combined screening must involve a biochemical test
• Eurocat variable – First Positive Prenatal Test (FIRSTPRE – non-core variable). Mapping required to Eurocat codes.

3.25 DESCRIPTION OF 'OTHER' FIRST PRENATAL TEST

**Definition:** Details of other screening procedure or diagnostic test carried out showing positive test.


**Format:** Character (200)

**Recording Guidance:**
• This is a **conditional** field.
• Only complete if variable 3.24 coded 8.
• Eurocat variable – Specify First Prenatal Test in Text if Coded 7 (First Positive Prenatal Test of Anomaly coded 8) (SP_FIRSTPRE – non-core variable).

3.26 FIRST TRIMESTER COMBINED TEST CARRIED OUT

**Definition:** Has the first trimester combined test to assess trisomy chance been carried out in this pregnancy? This test usually takes place at gestation 11^{2} – 14^{1}.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = Yes
2 = No
9 = Not Known

**Recording Guidance:**
• This is a **mandatory** field.
• No Eurocat variable.

3.27 SECOND TRIMESTER SERUM SCREENING CARRIED OUT

**Definition:** Has the second trimester serum screening to assess trisomy chance been carried out this pregnancy? This screening usually takes place at gestation 14^{2} – 20^{1}.
**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = Yes  
2 = No  
9 = Not Known

**Recording Guidance:**
- This is a mandatory field.
- No Eurocat variable.

### 3.28 TRISOMY 21 CHANCE SCORE BASED ON FIRST LINE ANTENATAL SCREENING

**Definition:** What is the trisomy 21 chance score based on first line antenatal screening (i.e. either first trimester combined screening or second trimester serum screening).

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (6)

**Points to Note:** This is the result of first line antenatal screening (i.e. either first trimester combined screening or second trimester serum screening).

**Recording Guidance:**
- This is a conditional field.
- Only record if 3.26 or 3.27 are coded 1.
- Record the denominator number only, i.e. chance of 1 in X.
- X truncated to range from 5 to 100,000.
- No Eurocat variable.

### 3.29 TRISOMY 13/18 CHANCE SCORE BASED ON FIRST LINE ANTENATAL SCREENING

**Definition:** What is the trisomy 13/18 chance score based on first line antenatal screening (NB. first trimester combined screening only).

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (6)

**Recording Guidance:**
- This is a conditional field.
- Only record if 3.26 is coded 1.
- Record the denominator number only, i.e. chance of 1 in X.
- X truncated to range from 5 to 100,000.
• No Eurocat variable.

3.30 FETAL ANOMALY SCAN CARRIED OUT

**Definition:** Has the fetal anomaly scan been carried out? This screening usually takes place at $18^{+0} - 20^{+6}$.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = Yes  
2 = No  
9 = Not Known

**Recording Guidance:**
• This is a **mandatory** field.
• No Eurocat variable.

3.31 NIPT CARRIED OUT

**Definition:** Has Non Invasive Prenatal Testing (NIPT) on maternal blood to assess trisomy chance been carried out in this pregnancy?

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = Yes  
2 = No  
9 = Not Known

**Recording Guidance:**
• This is a **mandatory** field.
• No Eurocat variable.

3.32 TRISOMY 21 CHANCE BASED ON NIPT

**Definition:** What is the chance of trisomy 21 based on NIPT.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = High Chance
2 = Low Chance  
9 = No Result

**Recording Guidance:**
- This is a conditional field.
- Only record if 3.31 is coded 1.
- No Eurocat variable.

---

### 3.33 TRISOMY 13 CHANCE BASED ON NIPT

**Definition:** What is the chance of trisomy 13 based on NIPT.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
- 1 = High Chance  
- 2 = Low Chance  
- 9 = No Result

**Recording Guidance:**
- This is a conditional field.
- Only record if 3.31 is coded 1.
- No Eurocat variable.

---

### 3.34 TRISOMY 18 CHANCE BASED ON NIPT

**Definition:** What is the chance of trisomy 18 based on NIPT.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
- 1 = High Chance  
- 2 = Low Chance  
- 9 = No Result

**Recording Guidance:**
- This is a conditional field.
- Only record if 3.31 is coded 1.
- No Eurocat variable.

---

### 3.35 AMNIOCENTESIS CARRIED OUT

**Definition:** Has amniocentesis been carried out in this pregnancy?
**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = Yes  
2 = No  
9 = Not Known

**Recording Guidance:**
- This is a mandatory field.  
- No Eurocat variable.

### 3.36 CVS CARRIED OUT

**Definition:** Has chorionic villus sampling (CVS) been carried out in this pregnancy?

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = Yes  
2 = No  
9 = Not Known

**Recording Guidance:**
- This is a mandatory field.  
- No Eurocat variable.

### 3.37 KARYOTYPE TEST CARRIED OUT

**Definition:** Has a karyotype test been performed on this fetus/baby?


**Format:** Integer (1)

**Coding Guidance:**
1 = Performed, result known  
2 = Performed, results not known  
3 = Not performed  
8 = Failed  
9 = Not known

**Recording Guidance:**
- This is a mandatory field.
- A karyotype test is any diagnostic test examining chromosome number or structure.
- Do not include second line NIPT screening tests.
- “Failed” refers to a technical failure where a repeat examination could not be done and the test result is therefore unknown.

### 3.38 KARYOTYPE TEST SAMPLE TYPE

**Definition:** Type of clinical sample karyotype test performed on.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
- 1 = Chorionic villus
- 2 = Amniotic fluid
- 3 = Live infant specimen
- 4 = Post-mortem specimen
- 5 = Other
- 9 = Not known

**Recording Guidance:**
- This is a **conditional** field.
- Only record if variable 3.37 is coded 1, 2 or 8.
- Live infant specimen includes cord or infant blood samples, saliva samples, skin biopsy.
- Post-mortem specimen includes products of conception, post-mortem fetal and infant tissue.
- No Eurocat variable.

### 3.39 KARYOTYPE TEST TYPE

**Definition:** Type of karyotype test performed.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
- 1 = Standard karyotype
- 2 = Microarray-based comparative genomic hybridisation
- 3 = Quantitative-fluorescent polymerase chain reaction
- 4 = Fluorescence in-situ hybridization
- 8 = Other
- 9 = Not known
3.40 KARYOTYPE TEST RESULT

**Definition:** Result of Karyotype test.


**Format:** Character (200)

**Recording Guidance:**
- This is a **conditional** field.
- Only recordable if variable 3.37 is coded 1.
- Record according to the International System for Human Cytogenetic Nomenclature (ISCN) 2016 version.
- Only record likely or clearly pathogenic results.
- Eurocat variable – Specify Karyotype (SP_KARYO – non-core variable).

3.41 MOLECULAR GENETIC TEST CARRIED OUT

**Definition:** Has molecular genetic testing been performed on this fetus/baby?


**Format:** Integer (1)

**Coding Guidance:**
- 1 = Performed, result known
- 2 = Performed, results not known
- 3 = Not performed
- 8 = Failed
- 9 = Not Known

**Recording Guidance:**
- This is a **mandatory** field.
- If the test is performed but the result not yet known, please wait for the result before reporting.
- A molecular genetic test is any diagnostic test examining exact DNA sequence.
- Do not include second line NIPT screening tests.
- “Failed” refers to a technical failure where a repeat examination could not be done and the test result is therefore unknown.
• Eurocat variable – Genetic Test (GENTEST – non-core variable). Mapping required to Eurocat codes.

3.42 MOLECULAR GENETIC TEST SAMPLE TYPE

Definition: Type of clinical sample molecular genetic test performed on.

Definition source: NEW Definition for CARDRISS, to be added to National Data Dictionary.

Format: Integer (1)

Coding Guidance:
1 = Chorionic villus
2 = Amniotic fluid
3 = Live infant specimen
4 = Post-mortem specimen
5 = Other
9 = Not known

Recording Guidance:
• This is a conditional field.
• Only recordable if variable 3.41 is coded 1, 2 or 8.
• Live infant specimen includes cord or infant blood samples, saliva samples, skin biopsy.
• Post-mortem specimen includes products of conception, post-mortem fetal and infant tissue.
• No Eurocat variable.

3.43 MOLECULAR GENETIC TEST TYPE

Definition: Type of molecular genetic test performed.


Format: Integer (1)

Coding Guidance:
1 = Single gene sequencing
2 = Multiple gene panel sequencing
3 = Whole exome sequencing
4 = Whole genome sequencing
8 = Other
9 = Not known

Recording Guidance:
• This is a conditional field.
• Only record if variable 3.41 is coded 1, 2 or 8.
- Record all applicable responses.
- Eurocat variable – Specify Genetic Test (SP_GENTEST – non-core variable), free text.

### 3.44 MOLECULAR GENETIC TEST RESULT

**Definition:** Result of molecular genetic test.


**Format:** Character (200)

**Recording Guidance:**
- This is a **conditional** field.
- Only record if variable 3.41 is coded 1.
- Record according to the Human Genome Variation Society variant description nomenclature.
- Only record likely or clearly pathogenic results.
- Eurocat variable – Specify Genetic Test (SP_GENTEST – non-core variable), free text.

### 3.45 OTHER DIAGNOSTIC TEST TO CONFIRM ANOMALY CARRIED OUT

**Definition:** Has another diagnostic test been carried out to confirm anomaly.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
- 1 = Yes
- 2 = No
- 3 = Not Known

**Recording Guidance:**
- This is an **optional** field.
- No Eurocat variable.

### 3.46 DESCRIPTION OF ‘OTHER’ DIAGNOSTIC TEST TO CONFIRM ANOMALY

**Definition:** Description of ‘other’ diagnostic test carried out and result.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Character (200)

**Recording Guidance:**
- This is a **conditional** field.
- Only to be recorded if variable 3.45 is coded 1.
- No Eurocat variable.

### 3.47 POST MORTEM CARRIED OUT

**Definition:** Has a post mortem been carried out on this fetus/baby.


**Format:** Integer (1)

**Coding Guidance:**
- 1 = Performed, results known
- 2 = Performed, results not known
- 3 = Not performed
- 4 = Macerated fetus
- 9 = Not known

**Points to Note:**
- If performed record the anomaly(ies) discovered in section 4 Anomaly Information.

**Recording Guidance:**
- This is an **optional** field.
- “Results known” means that the autopsy record has been reviewed by the registration team.
- “Results not known” means that the autopsy record was not available to the registration team.
- “Macerated fetus” means that although a post mortem was performed, maceration of the fetus prevented a full protocol from being followed.
- Eurocat variable – Post Mortem Examination (PM – non-core variable).

### 3.48 SYNDROME ICD10 CODE

**Definition:** ICD10 Code for recognised syndrome or association if present. Code according to ICD10 code for syndrome as listed in the EUROCAT syndrome guide. A syndrome is defined as a recognisable pattern of anomalies which are known or thought to be related.


**Format:** Alphanumeric (5)

**Recording Guidance:**
- This is an **optional** field.
- ICD10 codes are 4 or 5 characters in length.
- Eurocat variable – Syndrome (SYNDROME – core variable).
3.49 SYNDROME DESCRIPTION

**Definition**: Written text description of the ICD10 code in variable 3.48


**Format**: Character (200)

**Recording Guidance**:
- This is a conditional field.
- Only to be recorded if ICD10 code in variable 3.48.
- Eurocat variable – Specify Syndrome (SP_SYNDROME – core variable).

3.50 PRENATAL DIAGNOSIS FOR SYNDROME

**Definition**: Was the syndrome diagnosed prenatally.


**Format**: Integer (1)

**Coding Guidance**:
- 1 = Yes, this syndrome was diagnosed prenatally
- 2 = No, this syndrome was diagnosed postnatally
- 3 = This syndrome partially prenatally diagnosed
- 9 = Not known

**Recording Guidance**:
- This is a conditional field.
- Only to be recorded if ICD10 code in variable 3.48.
- ‘Yes, this syndrome was diagnosed prenatally’, should be used when the prenatal finding is nearly 100% predictive of the congenital anomaly
- ‘Partially’ means that the prenatal finding is consistent with the postnatal anomaly but has a lesser predictive value, being suggestive of more than one type of anomaly, an example here would be increased nuchal translucency
- Eurocat variable – Prenatal Diagnosis for Syndrome (PRESYN – non-core variable).

3.51 SYNDROME ORPHA CODE

**Definition**: ORPHA code for the recorded syndrome.

**Definition source**: [https://www.orpha.net/consor/cgi-bin/Disease.php?lng=EN](https://www.orpha.net/consor/cgi-bin/Disease.php?lng=EN)

**Format**: Integer (9)

**Recording Guidance**:
- This is an **optional** field.
- Record if a specific ORPHA code for the recorded syndrome is available.
- Record the most specific code possible given the level of clinical and aetiological information available about the syndrome present (i.e. ideally code at subgroup level, then if not possible, code at disorder or group level).
- An ORPHA code at disease level will generally be available for syndromes meeting the ORPHAnet definition of rare disease (affecting <1 in 2,000 of the general European population).
- Full codes can be found on the ORPHA website.

### 3.52 SYNDROME OMIM CODE (NOT FOR INITIAL USE)

**Definition:** OMIM Code linked to the recorded recognised syndrome.


**Format:** Alphanumeric (12)

**Recording Guidance:**
- This is an **optional** field.
- Record if a specific OMIM code for the recorded syndrome is available.
- Record the most specific code possible given the level of clinical and aetiological information available about the syndrome present.
- This code is to be used for cases with single gene origin only.
- The first digit may be filled in without the rest of the code if the full OMIM code is not known.
- Full codes can be found on the OMIM website.

### 3.53 SYNDROME SNOMED CT CODE (NOT FOR INITIAL USE)

**Definition:** SNOMED CT Code linked to the recorded recognised syndrome.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (9)

**Recording Guidance:**
- This is an **optional** field.
- Record if a specific SNOMED CT code for the recorded syndrome is available.
- Record the most specific code possible given the level of clinical and aetiological information available about the syndrome present.
- No Eurocat variable.
3.54 HOSPITAL FETUS/BABY FIRST SUSPECTED OF HAVING ANOMALY

Definition: Hospital at which the fetus/baby was first suspected of having anomaly, code by ISD location code.

Definition source: https://www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/National-Reference-Files/

Format: Alphanumeric (5)

Recording Guidance:
- This is an optional field.
- No Eurocat variable.

3.55 HOSPITAL FETUS/BABY FIRST CONFIRMED AS HAVING ANOMALY

Definition: Hospital at which the fetus/baby was first confirmed as having anomaly, code by ISD location code.

Definition source: https://www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/National-Reference-Files/

Format: Alphanumeric (5)

Recording Guidance:
- This is an optional field.
- No Eurocat variable.

3.56 HOSPITAL OF DELIVERY

Definition: Hospital at which delivery took place, code by ISD location code.

Definition source: https://www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/National-Reference-Files/

Format: Alphanumeric (5)

Recording Guidance:
- This is a conditional field.
- Only to be recorded if variable 3.13 is coded 1.
- This field will be populated from Internal NSS Sources.
- Domestic and other codes available if delivery took place at home or elsewhere.
- No Eurocat variable.

3.57 NOTIFICATION TYPE

Definition: How case was first notified to the registry for inclusion and investigation.
**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = Routine Internal NSS data
2 = Notified by clinician
3 = Notified by family

**Recording Guidance:**
- This is a **mandatory** field.
- Up to **three** notification types can be recorded.
- No Eurocat variable.

### 3.58 ROLE OF NOTIFYING PERSON

**Definition:** The role of the person notifying the registry of case to be investigated, this will allow information to be gathered for completion of the record.

**Definition source:** NEW Definition for CARDRISS, to be added to National Data Dictionary.

**Format:** Integer (1)

**Coding Guidance:**
1 = Paediatrician
2 = Neonatal Nurse
3 = Obstetrician
4 = Surgeon
5 = Midwife
6 = Pathologist
7 = Geneticist
8 = Family Member
9 = Other

**Recording Guidance:**
- This is a **conditional** field.
- Only to be recorded if variable 3.57 is coded 2 and/or 3.
- Up to **two** roles can be recorded.
- No Eurocat variable.
SECTION 4: ANOMALY INFORMATION

General Guidance for Section 4:
- The anomaly information data will be populated using internal NSS data sources where possible, shown in recording guidance.
- The mother and/or baby CHI will be the identifier to link the internal NSS data sources.

4.1 ANOMALY ICD10 CODE

Definition: ICD10 code for specific anomaly present.


Format: Alphanumeric (5)

Recording Guidance:
- This is a mandatory field if 3.48 is left blank.
- ICD10 codes are 4 or 5 characters in length.
- Up to 8 anomalies can be recorded.
- Eurocat variables – Malformation (MALFO1 to MALFO8 – core variables).

4.2 ANOMALY DESCRIPTION

Definition: Written text description of the ICD10 code in variable 4.1


Format: Character (200)

Recording Guidance:
- This is a conditional field.
- Only to be recorded if anomaly coded in variable 4.1.
- Up to 8 anomalies can be recorded.
- Eurocat variables – Specify Malformation (SP_MALFO1 to SP_MALFO8 – core variables).

4.3 PRENATAL DIAGNOSIS FOR ANOMALY

Definition: Was the anomaly diagnosed prenatally.


Format: Integer (1)
Coding Guidance:
1 = Yes, this anomaly was diagnosed prenatally
2 = No, this anomaly was diagnosed postnatally
3 = This anomaly partially prenatally diagnosed
9 = Not known

Recording Guidance:
- This is a conditional field.
- Only to be recorded if anomaly coded in variable 4.1.
- Coding for up to 8 anomalies can be recorded.
- ‘Yes, prenatally diagnosed’, should be used when the prenatal finding is nearly 100% predictive of the congenital anomaly
- ‘Partially’ means that the prenatal finding is consistent with the postnatal anomaly but has a lesser predictive value, being suggestive of more than one type of anomaly, an example here would be increased nuchal translucency
- Eurocat variables – Prenatal Diagnosis for Malformation (PREMAL1 to PREMAL8 – non-core variable).

4.4 ANOMALY ORPHA CODE

Definition: ORPHA code for the recorded anomaly.

Definition source: https://www.orpha.net/consor/cgi-bin/Disease.php?lng=EN

Format: Integer (9)

Recording Guidance:
- This is an optional field.
- Only to be recorded if anomaly coded in variable 4.1.
- Coding for up to 8 anomalies can be recorded.
- Record if a specific ORPHA code for the recorded anomaly is available.
- Record the most specific code possible given the level of clinical and aetiological information available about the anomaly present (i.e. ideally code at subgroup level, then if not possible, code at disorder or group level).
- An ORPHA code at disease level will generally be available for anomalies meeting the ORPHAnet definition of rare disease (affecting <1 in 2,000 of the general European population).
- Full codes can be found on the ORPHA website.
- Eurocat variable – ORPHA Code (ORPHA – non-core variable) only if 3.48 is blank. Eurocat only looking for one code, so send syndrome in 3.48 or primary anomaly.

4.5 ANOMALY OMIM CODE (NOT FOR INITIAL USE)

Definition: OMIM Code linked to the recorded recognised anomaly.

Format: Alphanumeric (12)

Recording Guidance:
- This is an optional field.
- Only to be recorded if anomaly coded in variable 4.1.
- Coding for up to 8 anomalies can be recorded.
- Record if a specific OMIM code for the recorded anomaly is available.
- Record the most specific code possible given the level of clinical and aetiological information available about the anomaly present.
- This code is to be used for cases with single gene origin only.
- The first digit may be filled in without the rest of the code if the full OMIM code is not known.
- Full codes can be found on the OMIM website.
- Eurocat variable – OMIM Code / Type of Mendelian Inheritance (OMIM – non-core variable) only if 3.48 is blank. Eurocat only looking for one code, so send syndrome in 3.48 or primary anomaly.

4.6 ANOMALY SNOMED CT CODE (NOT FOR INITIAL USE)

Definition: SNOMED CT Code linked to the recorded recognised anomaly.

Definition source: NEW Definition for CARDRISS, to be added to National Data Dictionary.

Format: Integer (9)

Recording Guidance:
- This is an optional field.
- Only to be recorded if anomaly coded in variable 4.1.
- Coding for up to 8 anomalies can be recorded.
- Record if a specific SNOMED CT code for the recorded anomaly is available.
- Record the most specific code possible given the level of clinical and aetiological information available about the anomaly present.
- No Eurocat variable.