Scottish Perinatal and Infant Mortality and Morbidity Report: Background information

Sources of data

The National Records of Scotland (NRS) provides information on all registrations of stillbirths and infant deaths occurring up to the end of the first year of life.

The Scottish Stillbirth and Infant Death Survey (SSBIDS) collects additional information on stillbirths, neonatal deaths and late fetal deaths.

• Stillbirths and neonatal deaths: After receiving death registration data from NRS, a data collection form is sent from the NHS HIS administrative office to a local clinical co-ordinator in the hospital of birth for completion. Copies of relevant case summaries, postmortem reports, discharge letters and Perinatal Mortality Meeting reports are requested and sent to NHS HIS for processing and entering onto a database. Postmortem reports may also be sent directly to NHS HIS from pathology departments. This additional information is not available in all cases, and for some registered deaths only the NRS certificate and some additional information from SMR02 data is available.

• Late fetal deaths: These are not registered by NRS but SMR02 provides information on a proportion of cases. Co-ordinators are asked to complete forms for them, and for any other late fetal deaths known to them, in the same way as for stillbirths and neonatal deaths.

• Post-neonatal deaths: From 2011, survey forms have been completed for these deaths. Prior to this, the only information available for these deaths came from the NRS death certificate and SMR02.

Local hospital co-ordinators are obstetricians, paediatricians, midwives and supporting secretarial staff (Appendix 12.6 of SPIMMR 2012). The Survey could not continue without their help and co-operation.

The flow diagram shows organisational responsibility for the annual Scottish Stillbirth and Infant Death Survey.

The Scottish Morbidity Record 02 (SMR02) provides information on discharges from maternity hospitals.

Congenital Anomaly information is obtained from neonatal discharge summaries (SMR11) up to 2003 and from the Scottish Birth Record (SBR) from 2003; the annual SSBID survey; and from returns relating to acute hospital admissions in the first year of life (SMR01).
Much of the data relating to congenital anomalies are derived using record linkage techniques. These techniques link the data which relate to the same individual on different datasets.

ISD has been modifying the way that record linkage is performed and has recently implemented a technique which relies more heavily on the use of Community Health Index (CHI) numbers and less heavily on the previous approach of probability matching. Inevitably, this has changed the number of individuals identified with various conditions. We have used the new approach for all the years represented in the tables of this report but these numbers and rates are slightly different from those reported in previous editions for the same years.

**How complete is the information?**
The provision of information on all registered stillbirths and infant deaths by the National Records of Scotland means that the information on the number of these cases is complete. The number of unregistered stillbirths and infant deaths is likely to be extremely small. Notification of late fetal deaths is less certain. SMR02 records from maternity units are very helpful but some cases may occur in other units. Thus the numbers of late fetal deaths are likely to be less than complete.

**Diagnostic classification and coding**
Coding from 2011:
As discussed in the 2010 SPIMMR report, there is a new data collection form ([2012 version available by clicking this link](#)) and classification system for deaths which occurred in 2011. This new system was devised by a multidisciplinary working group, facilitated by Healthcare Improvement Scotland in response to the report on perinatal mortality over 30 years.

Pre-2011 diagnostic coding:
Each case of stillbirth or neonatal death was classified twice:

- first, for the main obstetric factor leading to the death
- second, for the pathology in the infant causing the death

This double classification uses the Scottish Obstetric and Paediatric classification last modified in 1987. The NHS HIS Clinical Advisor assigned the diagnostic classifications using the clinical information provided by local co-ordinators and pathologists. Consistency in the diagnostic categorisation is ensured as all cases were classified by a single individual. The accuracy of the classification depends on the amount of information available and this may be variable, as described above. Post-neonatal deaths were classified by the NHS HIS Clinical Advisor into one of eight categories based on information available from the death certificate and SMR02 only (no survey forms are completed for these deaths). The classification used is that devised by the International Collaborative Effort (ICE) in 1989.
Conventions/abbreviations
The following symbols and abbreviations have been used:

.. not available
- nil
0.0 negligible
* values that have been suppressed due to potential risk of disclosure
\( \chi^2 \) shorthand for chi-squared, the name given to tests using chi-squared distribution
AP Antepartum
APH Antepartum haemorrhage
CMACE Centre for Maternal and Child Enquiries
CNS Central nervous system
CVS Cardiovascular system
END Early neonatal death
FIGO International Federation of Gynaecology and Obstetrics
HMD Hyaline membrane disease
HPD Histological placental dysfunction
ICE International Collaborative Effort
IP Intrapartum
ISD Information Services Division
IUD Intrauterine death
IUGR Intrauterine growth restriction
IVH Intraventricular haemorrhage
LFD Late fetal death
LND Late neonatal death
NND Neonatal death
NRS National Records of Scotland
PM Postmortem
PNND Post-neonatal death
RHP Reproductive Health Programme
SB Stillbirth
SGA Small for gestational age
SMR02 Scottish Morbidity Record (maternity dataset)
SPIMMR Scottish Perinatal and Infant Mortality and Morbidity Report
SSBIDS Scottish Stillbirth and Infant Death Survey
SUDI Sudden unexpected death in infancy
Definitions

Stillbirths: Section 56(1) of the Registration of Births, Deaths and Marriages (Scotland) Act 1965 defined a stillbirth as a child which had issued forth from its mother after the 28th week of pregnancy and which did not breathe or show any other sign of life. The Still-Birth (Definition) Act 1992, which came into effect on 1 October 1992, amended Section 56(1) of the 1965 Act (and other relevant UK legislation), replacing the reference to the 28th week with a reference to the 24th week.

Perinatal deaths refer to stillbirths and deaths in the first week of life.

Neonatal deaths refer to deaths in the first four weeks of life.

- Early neonatal deaths refer to deaths in the first week of life.
- Late neonatal deaths refer to deaths in weeks two to four of life.

Post-neonatal deaths refer to deaths after the first four weeks but before the end of the first year.

Infant deaths refer to all deaths in the first year of life.

Late fetal deaths refer to infants born dead at 20-23 weeks of pregnancy or earlier in pregnancy if the birthweight is 500g or more.

Rates
- Stillbirth and perinatal death rates are based on the total of live and stillbirths.
- Neonatal, post-neonatal and infant death rates are based on live births only.
- Late fetal death rates are based on the total of live and stillbirths and late fetal deaths.
Scottish Stillbirth and Infant Death Survey process

National Records Scotland (NRS) notify Healthcare Improvement Scotland (HIS) of all registrations of stillbirths and deaths (under 1 year).

Send monthly lists with details of stillbirths and neonatal deaths to hospital co-ordinators, requesting return of completed SSBID form.

Hospital Co-ordinators receive lists and then return completed SSBID forms and any other available information relating to these events to HIS.

Healthcare Improvement Scotland (HIS) receives death notifications, enters details into database.

NHS HIS match up completed forms from hospitals with relevant post-mortem reports, death registration certificates and update database. Clinical Advisor reviews and assigns a cause of death for all events.

Pathology Departments send any relevant postmortem reports to HIS.

Information Services (of National Services Scotland) are responsible for ensuring that forms have been returned for all events by comparing numbers with published NRS figures; raising/resolving errors/queries; producing analyses for annual report. This is then sent to HIS who produce the commentary for the report. ISD then publish the Scottish Perinatal Mortality and Morbidity Report under National Statistics guidelines.
Classification system for deaths

SECTION 10. ASSOCIATED FACTORS AND CAUSE OF DEATH

Please check ALL the maternal or fetal conditions that were present during the pregnancy or appeared to contribute to the death

Q10 (1) Major congenital anomaly and chromosomal defects: (please check all that apply)
- Central nervous system
- Gastro-intestinal system
- Chromosomal disorders
- Cardiovascular system
- Musculo-skeletal anomalies
- Metabolic diseases
- Respiratory system
- Multiple anomalies
- Urinary tract

Please specify diagnosis

Q10 (2) Hypertensive disorders of pregnancy: (please check all that apply)
- Pregnancy induced hypertension
- Pre-eclampsia
- HELLP syndrome
- Eclampsia

Q10 (3) Antepartum or intrapartum haemorrhage: (please check all that apply)
- Placenta praevia
- Placental abruption
- Other

If other, please specify

Q10 (4) Mechanical: (please check all that apply)

Cord compression:
- Prolapse cord
- Cord around neck
- Other cord entanglement or knot

Uterine rupture:
- Before labour
- During labour

Shoulder dystocia:

Mal-presentation:
- Breech
- Face
- Compound
- Transverse
- Other please specify

If other, please specify

Q10 (5) Maternal disorder: (please check all that apply)
- Pre-existing hypertensive disease
- Other endocrine conditions
- Drug misuse
- Pre-existing diabetes
- Thrombophilias
- Urinary anomalies
- Gestational diabetes
- Obstetric cholestasis

- Other please specify
Q10 (6) Infection: (please check all that apply)

**Maternal infection:**
- Bacterial
- Viral diseases
- Protozoal
- Other, specify

**Ascending infection:**
- Chorioamnionitis
- Other, please specify below

Q10 (7) Specific fetal conditions: (please check all that apply)
- Twin-twin transfusion
- Non immune hydrops
- Other
- Feto-maternal haemorrhage
- Iso-immunisation
- Other, please specify

Q10 (8) Specific placental conditions: (please check all that apply)
- Placental infarction
- Chronic villitis
- Massive perivillous fibrin deposition
- Chronic intervillitis
- Vasa praevia
- Fetal thrombotic vasculopathy
- Velamentous insertion
- Cord hypocoiling
- Deficient placental villus maturation
- Cord hypercoiling
- Cord length [ ] cm
- Other, specify

Q10 (9) Intra-uterine growth restriction:
- Was this diagnosis made? Yes No
- What was this based on? (please check all that apply)
- Suspected antenatally
- Observed at delivery
- Observed at post mortem
- What led you to your suspicion
Q10 (10) Associated obstetric factors: (please check all that apply)

**Birth trauma:**
- [ ] Intracranial haemorrhage
- [ ] Birth injury to scalp
- [ ] Fracture, specify _______
- [ ] Other, specify _______

**Intrapartum anoxia (evidence of significant hypoxia/anoxia during labour):**
- [ ]

**Other:**
- [ ] Polyhydramnios
- [ ] Premature rupture of membranes
- [ ] Oligohydramnios
- [ ] Spontaneous premature delivery
- [ ] Other, specify _______

Q10 (11) No antecedent or associated obstetric factors:
- [ ]

Q10 (12) Unable to classify because of lack of information:
- [ ]

Q10 (13) Which condition, indicated in questions Q10 (1) to Q10 (12) as being present, was the MAIN condition causing or associated with the death (NB “non-MAIN” conditions are best described as the “Other clinically relevant maternal or fetal conditions/factors that were associated with but not necessarily causing the death”. Please give the MAIN condition)
- [ ]

**SECTION 11. CAUSE OF DEATH - NEONATES ONLY**

Please check ALL the neonatal conditions that appeared to contribute to the death:

Q11 (1) Major congenital anomaly: (please check all that apply)
- [ ] Central nervous system
- [ ] Gastro-intestinal system
- [ ] Chromosomal disorders
- [ ] Cardiovascular system
- [ ] Musculo-skeletal anomalies
- [ ] Metabolic diseases
- [ ] Respiratory system
- [ ] Multiple anomalies
- [ ] Urinary tract

If other, please specify _______

Q11 (2) Immaturity:
- [ ] < 22 weeks gestation
- [ ] 22 to 24 weeks gestation
Q11 (3) Respiratory disorders: (please check all that apply)

☐ Severe pulmonary immaturity
☐ Surfactant deficiency lung disease
☐ Pulmonary hypoplasia
☐ Meconium aspiration syndrome
☐ Primary persistent pulmonary hypertension
☐ Chronic lung disease / Bronchopulmonary dysplasia (BPD)
☐ Other (for example, pulmonary haemorrhage, pneumonia, iatrogenic)

If other, please specify

Q11 (4) Gastro-intestinal disease:

☐ Necrotising enterocolitis (NEC)

If other, please specify

Q11 (5) Neurological disorder:

☐ Hypoxic-ischaemic encephalopathy (HIE)  ☐ Intraventricular / Periventricular haemorrhage

If other please specify

Q11 (6) Infection:

☐ Sepsis (generalised)  ☐ Pneumonia  ☐ Meningitis

Other, please specify

Please specify the organism (e.g. group B streptococcus)

Q11 (7) Injury / Trauma (including iatrogenic trauma) (post natal):

Was trauma a factor?  If yes, please specify

☐ Yes  ☐ No

Q11 (8) Other specific causes:

☐ Malignancies / tumours*  ☐ Specific conditions *

* please specify
Q11 (9) Sudden unexpected deaths:
☐ Sudden Unexpected Natural Death (includes SIDS)
☐ Neonatal death - cause unascertained

Q11 (10) Unable to classify because of lack of information:

☐

Q11 (11) Which condition, indicated in questions Q11 (1) to Q11 (10) as being present, was the MAIN condition causing or associated with the death (NB "non-MAIN" conditions are best described as the "Other clinically relevant maternal or fetal conditions/factors that were associated with but not necessarily causing the death". Please give the MAIN condition)
SECTION 11. CAUSE OF DEATH - NEONATES ONLY

Please check ALL the neonatal conditions that appeared to contribute to the death:

C11 (1) Major congenital anomaly:
- Central nervous system
- Gastro-intestinal system
- Chromosomal disorders
- Cardiovascular system
- Musculo-skeletal anomalies
- Metabolic diseases
- Respiratory system
- Multiple anomalies
- Urinary tract

If other, please specify:

C11 (2) Immaturity:
- < 22 weeks gestation
- 22 to 24 weeks gestation

C11 (3) Respiratory disorders:
- Severe pulmonary immaturity
- Surfactant deficiency / lung disease
- Pulmonary hypoplasia
- Meconium aspiration syndrome
- Primary persistent pulmonary hypertension
- Chronic lung disease / Bronchopulmonary dysplasia (BPD)
- Other (for example, pulmonary haemorrhage, pneumonia, iatrogenic)

If other, please specify:

C11 (4) Gastro-intestinal disease:
- Necrotising enterocolitis (NEC)

If other, please specify:

C11 (5) Neurological disorder:
- Hypoxic-ischaemic encephalopathy (HIE)
- Intraventricular / Periventricular haemorrhage

If other please specify:

C11 (6) Infection:
- Sepsis (generalised)
- Pneumonia
- Meningitis

Other, please specify:

Please specify the organism (eg group B streptococcus)

C11 (7) Injury / Trauma (including iatrogenic trauma) (post natal):
Was trauma a factor?
- Yes
- No

If yes, please specify:

C11 (8) Other specific causes:
- Malignancies / tumours*
- Specific conditions *

* please specify
Q11 (9) Sudden unexpected deaths:
☐ Sudden Unexpected Natural Death (includes SIDS)
☐ Neonatal death - cause unascertained

Q11 (10) Unable to classify because of lack of information:
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Q11 (11) Which condition, indicated in questions Q11 (1) to Q11 (10) as being present, was the MAIN condition causing or associated with the death (NB "non-MAIN" conditions are best described as the "Other clinically relevant maternal or fetal conditions/factors that were associated with but not necessarily causing the death. Please give the MAIN condition")