Congenital anomalies in Scotland
2012 to 2017

An Official Statistics publication for Scotland

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About this release

This release by the Information Services Division is our first publication focused on congenital anomalies. The publication provides information on the project, started in 2018, to set up a national congenital anomaly register for Scotland. It also provides current best estimates of the number of babies affected by serious anomalies among pregnancies ending in Scotland in up to 2017.

Main Points

- In 2017, 1,640 babies affected by a serious congenital anomaly were identified among pregnancies ending in Scotland. This is 308.4 per 10,000 total (live and still) births.
- 1,321 (81%) of affected babies were live born. This is 249.5 per 10,000 live births. This means that around 1 in 40 babies born alive in Scotland in 2017 had a serious congenital anomaly.
- Overall, the commonest group of anomalies seen was congenital heart defects (448 babies affected; 84.3 per 10,000 total births).

Total birth prevalence of all major structural and chromosomal anomalies in Scotland, 2017

![Anomaly Group vs. Birth Prevalence](image-url)
Among the specific anomalies covered by the antenatal screening programme, the commonest anomaly seen was Down syndrome (84 babies affected; 15.8 per 10,000 total births).

Anomalies due to an underlying genetic problem were more common in babies of older mothers. Other anomalies were more common in babies of younger mothers.

Among live born babies, anomalies were more common in boys (796 boys affected; 292.3 per 10,000 live births) than girls (520 girls; 202.3/10,000); and in babies from a multiple pregnancy of twins or more (48 multiples; 307.5/10,000) than in singletons (1,273 singletons; 247.8/10,000), although the difference between multiples and singletons was not statistically significant.

**Background**

Congenital anomalies are abnormalities of body structure or function which are present from birth. They are the result of an abnormality in some aspect of the development of a baby in the womb. A baby’s anomaly (or anomalies) may be due to an underlying genetic problem, or exposure of the mother to factors that disrupt normal development. In many cases, no specific cause is found. Increasingly, anomalies can be detected during pregnancy through antenatal screening.

Scotland does not currently maintain a national register of babies affected by anomalies. This makes it difficult to monitor how many babies are affected and to plan services to meet their needs. In 2018, the Scottish Government asked ISD to set up a national congenital anomaly register. The register will be known as the Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS). We expect CARDRISS to be ready to register babies affected by anomalies from 2021 onwards.

Whilst we work to set up CARDRISS, we have used existing national records to produce the estimates of the number of babies affected by anomalies in recent years that are provided in this publication. Information is provided on the number of babies affected by a serious congenital anomaly such as a major structural anomaly or a chromosomal anomaly. Live born babies diagnosed before their first birthday; miscarriages and stillbirths from 20 weeks of pregnancy onwards; and terminations of pregnancy at any stage of pregnancy are all counted. We will update and publish these estimates every year until CARDRISS can be used as the source of national statistics on anomalies.

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**Further Information**

Find out more in the full report. Data from this publication is available to download from our web page along with a technical report detailing how the analyses were carried out.

The next release of this publication will be October 2020.

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**ISD and Official Statistics**

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