# **Briefing: Counting Miscarriages in the UK**

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Policy Unit

Sands &

Working together to save babies' lives

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## Key messages

Unlike stillbirths and neonatal deaths, the number of miscarriages which occur each year in the UK are not measured or reported. While there are no UK-wide data on miscarriage, some miscarriage-related data are collected across the four nations. However, data are often limited to the hospital setting and inconsistent records, definitions and digital systems makes collation challenging, even before integrating other areas of the health system, such as primary care.

Work is underway in each of the devolved nations to consider how to collect data on miscarriage going forward. This briefing note outlines what data are currently available in each nation and what improvement work is underway. Most progress has been made in recording miscarriages which occur after women and birthing people are booked onto maternity services. Work to collect data from primary care settings is at an earlier stage and may require a longer time horizon to achieve.

Going forward, collaboration between health systems will be critical to align approaches and enable meaningful comparison across the whole of the UK. As each nation decides how miscarriages will be coded in digital maternity systems, it will be critical to agree common coded values to enable UK-wide reporting

### Introduction

Unlike stillbirths and neonatal deaths, the number of miscarriages which occur each year in the UK are not measured or reported. A <u>systematic review</u> published in the Lancet in 2021 found a pooled miscarriage risk of 15.3% (95% confidence interval: 12.5% - 18.7%)¹. Applying this pooled miscarriage risk to <u>MBRRACE-UK total birth data</u> (including stillbirths² and live births), we estimate that there may have been approximately 120,000 miscarriages across the UK in 2022 (or a 95% confidence interval of between 96,500 and 155,500). Other risk estimates or approaches may be used to estimate the number and rate of miscarriages in the UK. While these may vary from the figures included above, this only emphasises the need for better data to understand the scale of the issue and monitor trends over time.

While there are no UK-wide data on miscarriage, some miscarriage-related data are collected across the four nations. Most existing data are limited to miscarriages resulting in hospital stay which excludes a potentially large proportion of miscarriages which are managed at home or through primary care, or which occur in women and birthing people who were not aware that they were pregnant. Some miscarriage data which are reported also lack the denominator (total deliveries or maternities for the same time period and geography) to create a miscarriage rate. Rates help to differentiate between annual changes in the number of pregnancies conceived, which subsequently affects the number of miscarriages, and changes in miscarriage trends.

<sup>1</sup> This estimate is based on pooled risk from international studies. The underlying studies use a mixture of self-reported miscarriage and miscarriages resulting in a hospital stay, which is likely to underestimate true risk. Recent data are also limited – studies include data from 1970s to early 2010s.

<sup>2</sup> Stillbirths which take place at 24 weeks' gestation or over.

In this briefing note, we will explain what data are currently available and what improvement work is underway.

# **England**

NHS England reports annual hospital admissions for miscarriage management in <a href="the NHS Maternity Statistics">the NHS Maternity Statistics</a>. The number of miscarriages resulting in a hospital stay are also reported across maternal age and area-level deprivation. However, only the total number of miscarriages and not the rate are report. As outlined above, this does not provide an accurate picture of the total number of miscarriage nor trends over time.

The NHS also states that the Maternity Service Data Set records when the <u>primary reason for</u> <u>discharge from maternity services</u> is due to miscarriage. This could provide a more complete picture of the number of pregnancies booked onto NHS maternity services result in a miscarriage. However, this metric is not routinely published in the Maternity statistics and NHS England has limited capacity to provide additional data.

The Pregnancy Loss Review, published in July 2023, recommended that NHS England or the National Institute for Health and Care research (NIHR) should undertake research into the feasibility of pre-12 week data collection and the Department for Health and Social Care (DHSC) should commission NHS England to collate and publish monthly data on all mid-trimester loss (12+0 to 23+6 weeks gestation). In answer to a written question in Parliament, the then Minister for Women, Maria Caulfield, stated that potential data for mid-trimester loss will be reviewed in early 2024 as part of the plan to update the Digital Maternity Record standard. The Digital Maternity Record Standard (DMRS) V2.0 which was published in July 2024 included a mandatory field for birth outcome. Version 2.0 allows for both coded values and free text to be used and it is not until the next iteration in July 2027 that the responses will be limited to coded values from SNOMED CT. This is to reflect that some digital systems have not yet implemented SNOMED codes as their value sets. However, the free text option creates challenges for data quality and reporting.

From V2.0 of the Standard, it does not appear that data collection for miscarriage has been a particular consideration, despite the Minister's statement in the autumn of 2023. By the time the coded values are in place it will be four years on from the publication of the Pregnancy Loss Review and will still require a national commitment to collate and analyse this data. The Digital Maternity Record Standard is also focused on records in maternity settings, with no further consideration of how data might be collected across other areas of the health system, such as primary care.

Priorities for action: Fast-track updates to the Digital Maternity Record Standard and digital systems. Commission the collation and publication of mid-trimester losses from digital maternity records

#### Northern Ireland

Miscarriage data are not reported on a national level by The Northern Ireland Statistics and Research Agency (NISRA) or Health and Social Care Northern Ireland (HSCNI) but in May 2024, the Minister of Health reported that consideration of the methods required to improve the collection of data across the health system is ongoing. Currently, anyone who has a booking appointment at a maternity unit will be added to the electronic health record and any miscarriage after this point is recorded on the system, although it is not reported. HSCNI has carried out a review of the miscarriage data recorded and found quality issues, including some instances of free text being used rather than coded variables. Data from outside of maternity services is limited and data from other hospital services, such as early pregnancy units, are not currently linked.

Trusts in Northern Ireland are in the process of moving to a new electronic health record system, Epic, which should be completed by June 2025. From this point all hospital services will be covered by Epic which should enable national reporting of miscarriages in a hospital setting. As these systems are

established there is an opportunity for collaboration across the four nations to agree coded values for recording miscarriages to enable UK-wide reporting. Primary care will still not be included in these data.

Priorities for action: Commit to reporting miscarriage data collected in the new maternity record system.

#### **Scotland**

Miscarriage data related to in-patient treatment has been recorded in Scotland since the 1970s<sup>3</sup>; however, from 2017 it was decided not to publish these data as it was deemed of low clinical value as an accurate assessment of the number of miscarriages that occur is not possible from hospital-based data only.

A <u>scoping review</u> took place in 2023 which included a review of miscarriage data that are currently collected in Scotland. The scoping review found variation in what is being recorded as a miscarriage both across and within Health Boards. Some sites record miscarriages based on reporting by patient, whereas others require confirmation from an NHS service. Miscarriage data are not collected in all sites of in all Health Boards, although some data is available for 11 of the 14 Health Boards. In some areas additional characteristics (including gestation, maternal age, ethnicity and area-level deprivation) are collected, although this is not uniform both within and across Health Board areas. Different IT systems are also used across Scotland to collect miscarriage data. This lack of consistency makes collation and analysis at the national, or even Health Board level, challenging.

Based on the scoping review Public Health Scotland (PHS) developed a Miscarriage (Early Pregnancy) dataset with a shortlist of 28 data points which include patient and demographic information and previous and current pregnancy information. The dataset has been reviewed by clinicians, digital midwives and PHS's public health consultant. PHS is currently reviewing the definitions used in the dataset and the technical possibility of gathering data from the two electronic health record systems used in Scotland (BadgerNet Maternity and Trak Maternity). PHS will request permission from NHS boards for one-off data files from the electronic health records to evaluate data completeness and that the data enables analysis of total number of miscarriages and miscarriage rates in different subpopulations. After any necessary amendments, PHS will seek to establish a routine data flow.

Miscarriage data from primary care settings is not in scope of the current phase of work led by PHS. Separate work is underway to secure access to data held in primary care for national analysis.

Priorities for action: Follow through on commitments to establish routine miscarriage data collection in the maternity setting and consider how to widen to include primary care.

#### Wales

On the 3 July 2024, in response to a written question on how the Welsh Government monitors the total number of miscarriages and the miscarriage rate in Wales, the then Cabinet Secretary for Health and Social Care, Eluned Morgan, stated that the Patient Episode Database Wales (PEDW) held by Digital Health and Care Wales (DHCW) includes data on when women have been admitted to hospital due to a miscarriage. The publicly available PEDW reports the number of finished consultant episodes for patients admitted to hospital in Wales when the primary diagnosis was coded as O021 - Missed abortion<sup>4</sup>. No other relevant codes are included in the public reporting, although looking at the numbers in the code sequence it appears that not all have been published.

In response to a Freedom of Information request from the Sands & Tommy's Joint Policy Unit in 2023, DHCW also reported holding data on the number of finished consultant episodes for patients admitted

<sup>3</sup> Through two main datasets: SMR01 Scottish Morbidity Records and SMR02 Maternity Inpatient and Day Records 4 A missed abortion is the definition used by PEDW and is when the pregnancy stops developing and the fetus is no longer alive, but the body does not recognise the pregnancy loss or expel the pregnancy tissue.

to the hospital in Wales when the reason for discharge was defined by DHCW as a spontaneous abortion<sup>5</sup>. However, this is not included in public reporting currently.

Overall, there is a lack of clarity over what data is held in Wales. In early 2023, the Welsh Government approved a five-year programme to create a new digital maternity system which will integrate with the core Welsh digital infrastructure and form part of the single clinical record for Wales. This is an opportunity for DHCW to define a central methodology for data collection related to miscarriage, ideally one that is aligned with the rest of the UK and integrate it into the new digital system.

Priorities for action: Ensure routine miscarriage data collection and reporting as part of the new digital maternity system.

#### Conclusion

There is need for improvement in the availability of miscarriage data across the UK. Variations in the data available across nations and Trusts / Health Boards means that it is challenging to get a picture of miscarriages across the UK. This is crucial to monitor any changes in miscarriage prevalence which may happen because of changes to population health or interventions aimed at reducing miscarriage.

Data are often limited to the hospital setting and inconsistent records, definitions and digital systems makes collation challenging, even before integrating other areas of the health system. While many of the digital maternity notes are focused on tailoring maternity care, better recording of miscarriage goes hand-in-hand with better care for individuals, as well as the importance of national analysis.

As each of the devolved nations consider how to collect data on miscarriage going forward, collaboration between health systems will be critical to monitor miscarriage across the whole of the UK and enable meaningful comparisons between areas and over time.

For any questions or feedback related to this briefing note - please contact Georgia.stevenson@sands.org.uk

<sup>5</sup> Pregnancy loss at less than 20 weeks' gestation in the absence of elective medical or surgical measures to terminate the pregnancy.