Briefing paper

Maternity & neonatal care data hub for Scotland

Background

The Best Start – A Five Year Forward Plan for Maternity and Neonatal Care in Scotland[1], published in January 2017, reports the findings of the Scottish Government's Review of Maternity and Neonatal Services in Scotland. Recommendation 70 of *The Best Start* is to develop a ***national maternity and neonatal care data hub*** and recommendation 67 is "…*national level maternity and neonatal dashboards should be developed to facilitate benchmarking and reduce variations in care*".

Engagement in 2018 with the maternity and neonatal services community allowed us to agree what a data hub should include. The hub was established in 2019 as a collaboration involving five delivery partners (Public Health Scotland, the Scottish Perinatal Network, Healthcare Improvement Scotland, Scottish Government, and National Records of Scotland), with close links to UK-wide audits and IT system suppliers.

Scottish Government funded a programme with five work streams:

1. **Manage a visible Maternity and Neonatal Data Hub for Scotland partnership**
2. **Align Maternity and Neonatal data collection, extraction, and data flow**
3. **Establish new all-Scotland maternity data sets**
4. **Routine collection of data on specialist neonatal care**
5. **Data displays showing maternity and neonatal CORE measures**

Further information on each programme work stream is included on the following pages.

Staying informed

We provide regular updates to stakeholders to keep you informed on progress. This includes short briefings like this, a 'one-place-to-go' web presence (at https://www.perinatalnetwork.scot/data/) and e-mails (most recent April 2025; to receive these please contact phs.matneodatahub@phs.scot)**.**

For **further information** please contact: Alastair Philp, Programme Lead (Alastair.Philp2@phs.scot)

Official statistics

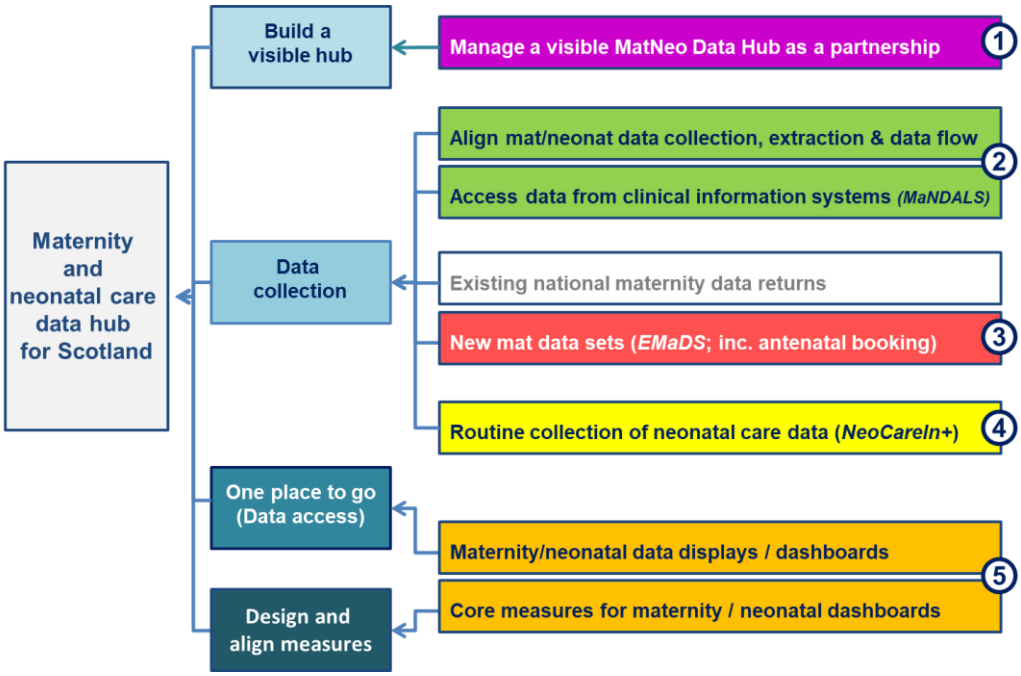
Our colleagues in Public Health Scotland publish a series of annual Official Statistics on pregnancy, childbirth and the early care of babies born in Scotland:

- Births in Scotland: data on mother's age, ethnicity, deprivation, BMI, maternal diabetes, method of birth, gestation at birth and birthweight.
- Antenatal Booking in Scotland: data on numbers of pregnancies booked, gestation at booking, and smoking status (by mother's age, deprivation and ethnicity, for all three topics).
- Termination of pregnancy: information on age, gestation, method of termination, deprivation, ethnicity, previous terminations, and grounds for termination.
- Teenage pregnancies: information is provided on age group (<16, <18, <20), deprivation, and whether the pregnancy was terminated or led to a birth.
- Congenital Conditions in Scotland: current best estimates of the number of babies with serious congenital conditions
- Infant feeding: information on exclusive breastfeeding, mixed, and formula feeding (initiation; first visit; 6-8 week; 13 to 15 month; maternal age; deprivation, ethnicity; looked-after status; maternal smoking status).
- Pregnancy Screening for Down's Syndrome, Edward's Syndrome, and Patau's Syndrome in Scotland: information on the coverage of screening (including by maternal age group, deprivation quintile and ethnic group), screening results and laboratory activity for financial years 2019/2020 to 2021/22

These are all included in the MatNeo Data Hub Topics Index.

[1] See **http://www.gov.scot/Topics/People/Young-People/child-maternal-health/neonatal-maternity-review**

Components of the *MatNeo data hub* programme



Quick progress update (April 2025) on each work stream

1 Manage a visible Maternity and Neonatal Data Hub for Scotland

As well as managing the inter-dependencies among the projects described below, we continue to work closely with the Scottish Perinatal Network, Healthcare Improvement Scotland, Scottish Government and National Records of Scotland). We are also maintaining links to colleagues undertaking similar national work in England, Wales, and Northern Ireland (via twice-yearly meetings of a 4-nation maternal data group we established).

Until June 2024 a Programme Board (with representation from the delivery partners mentioned above) met quarterly to discuss progress. The PHS-based MatNeo Data Hub team are now part of the PHS cross-organisational Early Years and Young People (EY&YP) Programme. So the governance of the MatNeo Data Hub has shifted to run through the PHS EY&YP programme too.

We circulated a quarterly e-mail update on hub activities in early April 2025. With the assistance of the Scottish Perinatal Network we maintain a web presence that includes links to the resources that the hub has developed. These include data dashboards and a Topics Index showing where maternity and neonatal data is already available.

2 Align Maternity and Neonatal data collection, extraction, and data flow

The Maternity and Neonatal Data Access Liaison Group for Scotland (MaNDALS) was established to share updates from multiple parallel conversations involving organisations who require all-Scotland-consistent data for national purposes from clinical information systems (mainly BadgerNet), and to align these conversations. The group will meet again in May 2025.

PHS signed a Data Services Agreement with System C in December 2024. This agreement facilitates access to maternity and neonatal data that System C hold on behalf of Scottish NHS boards, where boards ask System C to allow access. We will shortly be meeting with System C to discuss how to deal better with changes they make to the BadgerNet systems and how to add additional data items, in future, to PHS MatNeo datasets.

We have developed a **secure, automated mechanism** to routinely transfer nationally-consistent maternity and neonatal data from BadgerNet systems into Public Health Scotland (PHS). We worked on this with colleagues in National Services Scotland Digital and Security (NSS DaS) and with System C who provide the BadgerNet systems. The first data to be accessed in this way is antenatal booking and neonatal care data.

NSS DaS have now built a **MatNeo Data Platform** to hold data and make it available for analysis. This Data Platform will also be used to support the Congenital Conditions and Rare Diseases Registration and Information Service for Scotland (CARDRISS) and further expanded to include the additional maternity datasets we are developing that are described below.

③ Establish new all-Scotland maternity data sets (Enhanced Maternity Dataset for Scotland - EMaDS)

During 2020 PHS established a new routine **antenatal booking** data collection (ABC). Numbers of pregnancies booked, and gestation at booking, based on ABC data are presented on the Scottish Pregnancy, Births and Neonatal Data (SPBAND) Dashboard. Official Statistics on numbers of pregnancies booked, gestation at booking, and smoking status, sourced from the Antenatal Booking Collection, are also published annually in the Antenatal Booking in Scotland publication (most recently in March 2025).

ABC data is used to maintain a **dynamic pregnancy cohort** for linkage studies (the Scottish Linked Pregnancy and Baby Dataset, SLiPBD). More details on SLiPBD are given in a data resource profile. A similar dynamic pregnancy cohort was used (in the COVID-19 in Pregnancy in Scotland (COPS) study) to monitor COVID vaccine uptake in pregnant women and investigate the effect of COVID-19 infection (and COVID-19 vaccination) on outcomes for mothers and babies. SLiPBD is now allowing PHS to do studies on medicines use in pregnancy. SLiPBD data also allows us to estimate how many people were pregnant at a point in time and therefore eligible for antenatal screening and immunisations.

PHS have created an expanded version 2 of the **Antenatal Booking Collection** (ABC2). We have also developed a **Mother, Birth and Baby** (MoBBa) dataset. MoBBa is intended to be deployed alongside the existing SMR02 dataset to gather additional data on mothers, births and babies that is not included in SMR02.

We are establishing if ABC2 and MoBBa are fit for the purpose of allowing national reporting by analysing one-off data transfers for each dataset. We received BadgerNet Maternity data related to thirteen boards in January and will shortly receive data from NHS Lothian. We are checking completeness for each data item and conducting initial analyses to see with what frequency different options appear for each of the data items. This will allow us to decide if individual data items are available and suitable for national reporting. We will then revise the two datasets and prepare to introduce the revised versions as routine data flows. This will require us to obtain refreshed information governance permissions from territorial boards. We will also work with NSS DaS to complete technical (IT) and data specifications so DaS can add ABC2 data items and the additional MoBBa dataset to the MatNeo Data Platform already developed for ABC and NeoCareIn+. Our aim is to introduce ABC2 and MoBBa as routine data flows in spring 2026.

We have continued to explore how we can capture data on **miscarriage** from 'early pregnancy' settings. A miscarriage dataset has been developed in collaboration with Scottish Government, clinicians and digital midwives. We are taking a similar approach, to that described above for ABC2 and MoBBa, to testing whether this miscarriage dataset is collectable and useful. One-off data transfers have been received from System C (containing data from BadgerNet Maternity and the BadgerNet Early Pregnancy and Gynaecology Unit (EPAGU) module) and from NHS Lothian (containing Trak Maternity data). We are doing the same assessments as described above for ABC2 and MoBBa and will follow the same steps to prepare revised proposals for a routine miscarriage data flow, which we are working towards also having in spring 2026.

④ Routine collection of data on specialist neonatal care (NeoCareIn+)

PHS developed a **neonatal care dataset** (NeoCareIn+) in 2018 and 2019, and analysed a one-off extract of those data items, derived from the BadgerNet Neonatal system, in 2020. Since then, we have been working to make the content of the NeoCareIn+ dataset routinely available for analysis via the secure, automated data transfer mechanism mentioned earlier in this update. This has been in partnership with colleagues in National Services Scotland Digital and Security (NSS DaS) and System C. NSS: DaS recently completed intensive work with us to specify and build a neonatal component of our **MatNeo Data Platform**. We have accessed BadgerNet Neonatal data held by System C and loaded NeoCareIn+ data onto the MatNeo Data Platform.

We hope that routine outputs (both public and for the neonatal network) using this new neonatal data flow will be available in mid-2025. However, ongoing testing of analytical access to neonatal data on the data platform, intensive assessment of data completeness, and conducting initial analyses, is taking a little longer than we wanted so there may be a short delay to availability of NeoCareIn+ data outputs.

⑤ Data displays showing maternity and neonatal CORE measures

In 2019 we developed **CORE maternity measures** for incorporation into maternity dashboards. This supports Commitment 67 in Best Start: "*National level maternity and neonatal dashboards should be developed to facilitate benchmarking and reduce variations in care*". Such measures, using all-Scotland-comparable data, support individual services and regional collaborations to learn from each other's experience.

From 2020 many of the CORE maternity measures were presented on a **Wider Impacts** (of COVID) dashboard. **Pregnancy** and **Births and babies** sections of the Wider Impacts dashboard were updated each month until Sep 2023. Those two sections were replaced in October 2023 by a new Scottish Pregnancy, Births and Neonatal Data (SPBAND) Dashboard. Data on SPBAND is refreshed quarterly (in January, April, July and October each year).

SPBAND includes the same topics as those that featured in the two sections of the Wider Impacts dashboard it replaced:

- **Pregnancy**: number of pregnancies booked; average gestation at booking; number of terminations; average gestation at termination.
- **Births and Babies**: location of extremely pre-term births; induction of labour; type of birth; third- and fourth-degree perineal tears; pre- and post-term births; stillbirths and infant deaths; Apgar scores.

We are continuing to develop two additional neonatal measures to be included within SPBAND. These are:

- Median length of stay for babies born at 30^{+0} to 32^{+6} weeks, expressed as corrected gestational age at discharge.
- Percentage of live-born babies who are admitted to a neonatal unit, by BAPM level of care (shown separately for late pre-term - 34^{+0} to 36^{+6} weeks - and term/ post-term - 37^{+0} to 42^{+6} weeks).

We are discussing definitions for these neonatal measures with the National Neonatal Network Data Group. If our assessments of NeoCareIn+ data (see above) are positive, we plan to introduce these additional measures from either the July 2025 or October 2025 SPBAND refresh.

The Health in the Early Years in Scotland (HEYS) dashboard includes information on infant feeding. Data is refreshed quarterly. A link to data on HEYS is available from the **Infant feeding** menu item on SPBAND.

We are continuing to maintain a Topics Index. As well as containing a list of the CORE maternity measures, this catalogues individual maternity and neonatal measures already available, including those on the Scottish Pregnancy, Births and Neonatal Data (SPBAND) Dashboard, Health in the Early Years in Scotland, Discovery, NMPA, NNAP, National Records of Scotland, and PHS websites. If you cannot access the Google Sheets platform that hosts the Topics Index please contact us and we will share the latest index with you.