

# 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*<sup>1</sup>, 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 Strategic 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 December 2024; to receive these please contact [phs.matneodatahub@phs.scot](mailto:phs.matneodatahub@phs.scot)).

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### Official statistics

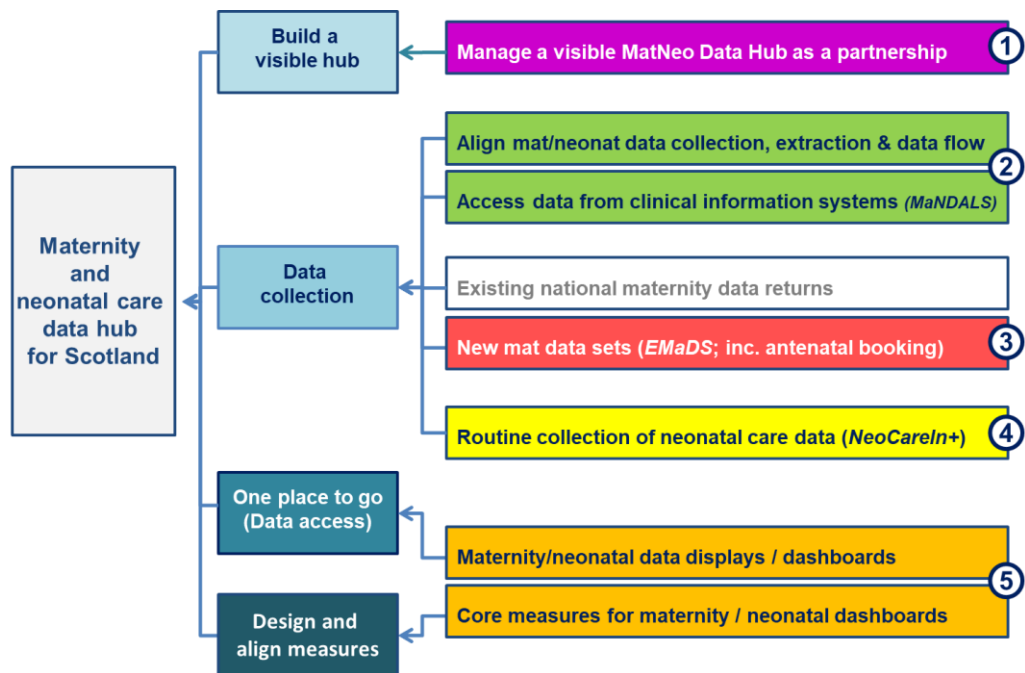
Our colleagues in Public Health Scotland publish a series of annual Official Statistics on pregnancy, childbirth and the early care of babies born in Scotland:

- [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](#).

<sup>1</sup> 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 (December 2024) on each work stream

### ① Manage a visible Maternity and Neonatal Data Hub for Scotland partnership

As well as managing the inter-dependencies among the projects described below, we convene a partnership involving collaboration among the five delivery partners (the [Scottish Perinatal Network](#), [Healthcare Improvement Scotland](#), [Scottish Government](#), [National Records of Scotland](#), and [Public Health 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 all five partners) 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 mid December 2024. 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 met again in mid-November 2024.

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.

To support this, and after a lengthy set of negotiations, we have signed a Data Services Agreement between PHS and System C. This agreement will facilitate access to maternity and neonatal data that System C hold on behalf of Scottish NHS boards, where boards ask System C to allow access.

### 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.

ABC data is used to maintain a **dynamic** pregnancy cohort for linkage studies (the Scottish Linked Pregnancy and Baby Dataset, SLiPBD). SLiPBD is described in a [data resource profile](#) published earlier this year. 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 to gather additional data on mothers, births and babies that is not included in SMR02. We plan to assess if ABC2 and MoBBa are fit-for-purpose by receiving one-off data transfers for each dataset. This has been delayed by us prioritising work to automate access to antenatal booking and neonatal care data. However, extraction scripts have now been prepared, we have developed an analytical plan and should receive data within the next couple of months.

We have continued to explore how we can capture data on **miscarriage** from 'early pregnancy' settings. A miscarriage (early pregnancy) dataset was previously reviewed by key contacts and Digital Midwives. Since most Health Boards use BadgerNet systems, we are exploring, with System C, how to access relevant data from BadgerNet Maternity and the BadgerNet Early Pregnancy and Gynaecology Unit (EPAGU) module. We intend to assess if the miscarriage (early pregnancy) dataset is fit-for-purpose by obtaining a one-off sample of the data. We are collecting permissions to do this and hope to receive the sample data within the next three months. We are also continuing to liaise with NHS Lothian to obtain required data items from Trak maternity.

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

PHS developed a neonatal care dataset some time ago. We have been working with NHS National Services Scotland and System C to make the content of this dataset routinely available via the secure, automated mechanism mentioned earlier in this briefing. We have now enabled this secure mechanism to access BadgerNet Neonatal data (for babies receiving care in neonatal units on, and/or after, 01 January 2018). We need to check that data loads as expected onto the data platform, assess data completeness and conduct initial analyses. So, we do not anticipate routine outputs (either public or for the neonatal network) will be available until mid-2025.

### 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 replaces: **Pregnancy** - number of pregnancies booked; average gestation at booking; number of terminations; average gestation at termination; and **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.

The [Health in the Early Years in Scotland](#) (HEYS) dashboard includes information on infant feeding. Data is refreshed quarterly (in January, April, July and October each year). 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](#).