

# 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, and to develop the following vision statement for the MatNeo Data Hub:

*To ensure the Best Start for mothers and babies in Scotland, a maternity and neonatal data hub should be established to: coordinate collection and verification of all Scottish related neonatal and maternity data; streamline data collection; reduce duplication of data entry; ensure access to relevant data, and support data use to commission, operate and improve services.*

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 August 2024; to receive these please contact [phs.matneodatahub@phs.scot](mailto:phs.matneodatahub@phs.scot)).

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### Official statistics

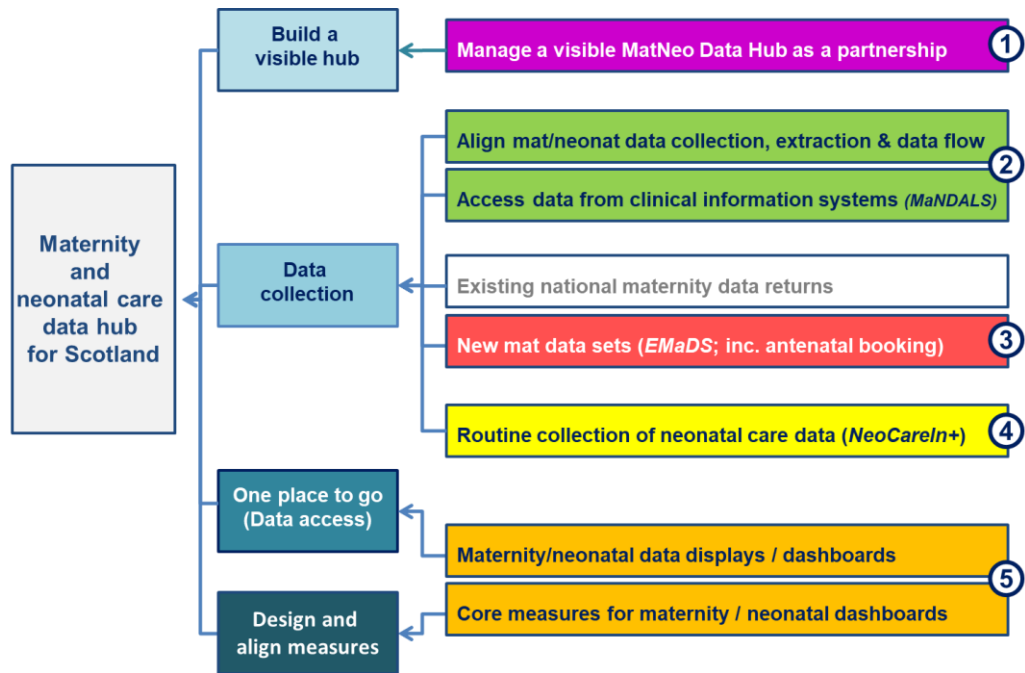
Our colleagues in Public Health Scotland publish a series of annual Official Statistics on pregnancy, childbirth and the early care of babies born in Scotland:

- **[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).

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 (August 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 at the end of August 2024. With the assistance of the [Scottish Perinatal Network](#) (one of the five delivery partners) we have established a web presence at <https://www.perinatalnetwork.scot/data>. Each of the hub's workstreams is described, and links are provided to the resources that the hub has already 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 mid November 2024.

After frustrating delays due to IT-development-capacity constraints, we are close to implementing an automated way to routinely bring nationally-consistent maternity and neonatal data from clinical systems into Public Health Scotland (PHS). We are working intensively on this with colleagues in National Services Scotland Digital and Security (NSS: DaS), with colleagues in NHS Boards, and with System C (who [acquired Clevermed](#) in February 2023 and who provide the BadgerNet systems). We will confirm soon when the new automated data flow (initially for the current antenatal booking collection dataset) will start.

To support this, and after a lengthy set of negotiations, we are also close to concluding 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)

At the onset of the COVID-19 pandemic we refocused our [Enhanced Maternity Dataset for Scotland \(EMaDS\)](#) work to capture close-to-real-time data on aspects of antenatal booking. We established weekly reporting for antenatal booking data, and received historic data back to April 2019, so we could report on all women pregnant in March 20 (and thereafter).

The Antenatal Booking Collection (ABC) is now a routine and enduring all-Scotland data collection. 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 recently published [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 will be deployed alongside the existing SMR02 to gather additional data on mothers, births and babies that is not included in SMR02. We have continued to work on finalising data mapping and data definitions for ABC2 and MoBBa with System C and with NHS Lothian. We still plan to assess if ABC2 and MoBBa are fit-for-purpose by obtaining one-off data transfers for each dataset. This has been delayed by us prioritising other work but should happen by December 2024.

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 discussing, with clinical and reporting specialists in System C, how to access relevant data from BadgerNet Maternity and the BadgerNet Early Pregnancy and Gynaecology Unit (EPAGU) module. We are also continuing to liaise with NHS Lothian to obtain required data items from Trak maternity. We are completing a detailed item-by-item review of data items, definitions and potential mappings to BadgerNet and Trak maternity fields. The miscarriage dataset now aligns with the ABC and MoBBa datasets.

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

We are working to establish routine collection of a new national (all-Scotland) minimum dataset on specialist neonatal care. In November 2019 we received a one-off extract of data from BadgerNet Neonatal and we analysed this to see what we could learn. We now have a dataset suitable for routine submission. We are working with System C (and NHS National Services Scotland) to make this dataset routinely available via the same automated route described earlier in this briefing.

### 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](#) and [PHS websites](#).