

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, 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 quarterly e-mails (most recent March 2024; to receive these please contact phs.matneodatahub@phs.scot).

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Official statistics

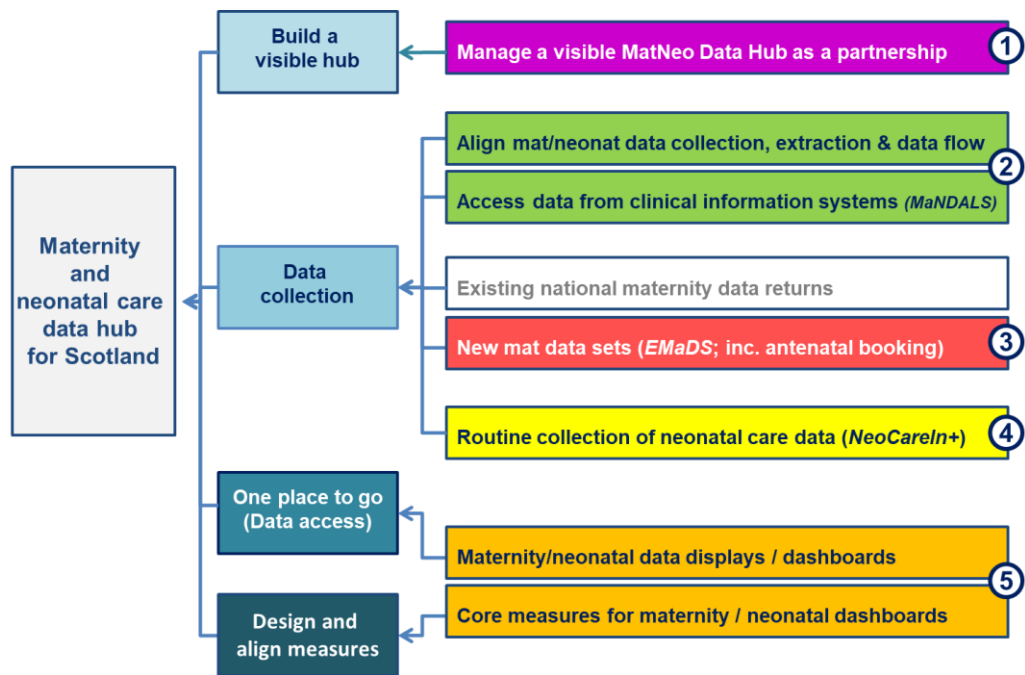
Our colleagues in Public Health Scotland publish a series of annual Official Statistics on pregnancy, childbirth and the early care of babies born in Scotland:

- **[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](#).

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 (March 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).

A MatNeo Data Hub **Programme Board**, with representatives from each delivery partner, continues to meet quarterly (most recently in March 2024) to discuss programme activities and plans.

We circulated a quarterly **e-mail update** on hub activities at the end of March 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.

The PHS-based Hub team are now part of the PHS cross-organisational Early Years and Young People Programme.

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 late April 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 have agreed that the secure automated data transfer will work by queries being sent to a System-C-hosted database, with data then pulled into a new maternity and neonatal data store hosted by NSS DaS. We have now tested this approach using dummy data. We will confirm soon when the new automated data flows 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). This dynamic cohort approach 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 plan to assess if ABC2 and MoBBa are fit-for-purpose by obtaining one-off data transfers for each dataset. This should happen by September 2024.

In parallel, we have continued to explore how we can capture data on **miscarriage** from 'early pregnancy' settings. We received positive feedback on a draft dataset from Digital Midwives in late 2023. Since most Health Boards use BadgerNet systems we have been discussing, with clinical and reporting specialists in System C, where the data items included in the draft dataset are recorded within BadgerNet Maternity and the BadgerNet Early Pregnancy and Gynaecology Unit (EPAGU) module. Similar discussions are under way with colleagues in NHS Lothian, who use Trak maternity.

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 was published for the first time on 16 January 2024 and includes information on infant feeding. Data will be refreshed quarterly. A link to data on HEYS is now available from a new **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](#).