

# 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 are funding 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 December 2023; to receive these please contact [pms.matneodatahub@pms.scot](mailto:pms.matneodatahub@pms.scot)).

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### COVID-19 & the MatNeo Data Hub

To respond effectively to the COVID-19 pandemic, work during 2020, 2021 and early 2022 differed from what we originally planned, allowing PHS to meet urgent demands for surveillance data on maternity, neonatal and paediatric care. However, the MatNeo Data Hub programme have now resumed all planned activities.

In 2020, Public Health Scotland (PHS) created a data dashboard to monitor [wider impacts of COVID-19](#) and we used that dashboard to present data on several aspects of maternity care in Scotland. 'Pregnancy' and 'Births and babies' sections of the Wider Impacts dashboard were updated each month until Sep 2023. However those sections have now been replaced by a new [Scottish Pregnancy, Births and Neonatal Data \(SPBAND\) Dashboard](#), which was published for the first time on 3 October 2023 and will be updated quarterly.

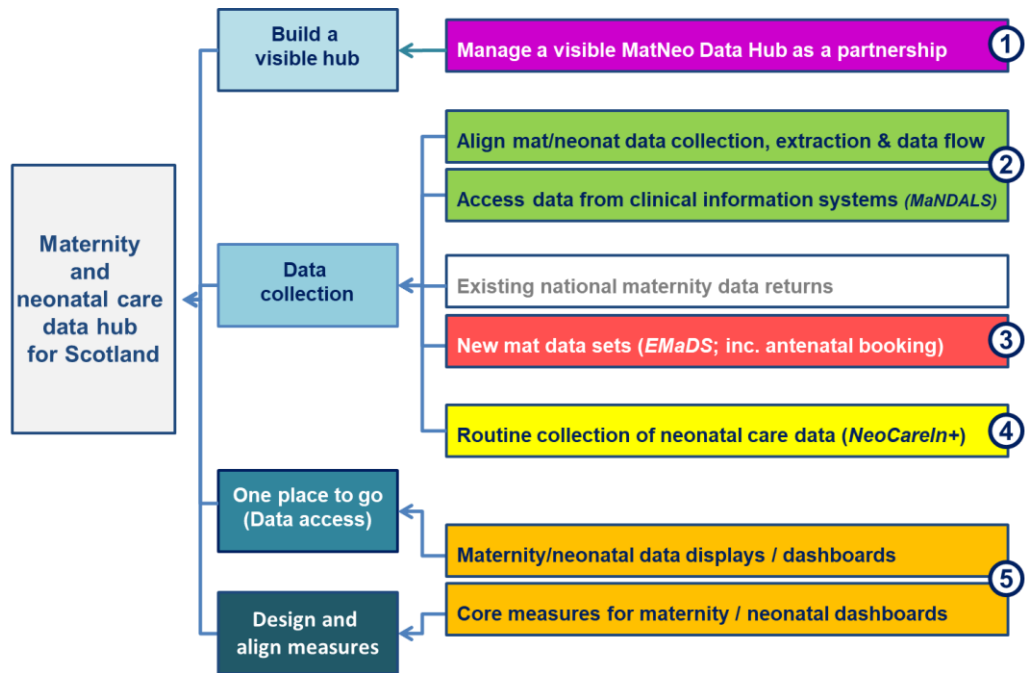
### Official statistics

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](#); [Antenatal Booking in Scotland](#); [Termination of pregnancy](#); [Teenage pregnancies](#); [Congenital Conditions in Scotland](#); [Infant feeding](#).

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 2023) 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 December 2023) to discuss programme activities and plans. The MatNeo Data Hub continues to be overseen by the **Evidence & Data sub-group** of the Best Start Programme Board.

We circulated a quarterly **e-mail update** on hub activities at the beginning of December 2023. 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 met for a tenth time in November 2023 and will meet again in spring 2024.

We are now again making progress with developing an automated way to routinely bring nationally-consistent maternity and neonatal data from clinical systems into Public Health Scotland (PHS). We are collaborating on this with colleagues in National Services Scotland Digital and Security (DaS), with colleagues in NHS Boards, and with System C (who [acquired Clevermed](#) in February 2023 and who provide the BadgerNet systems). Unfortunately, this work was delayed due to IT-development-capacity constraints within DaS, and then in System C. However, concerted work has now restarted, including on 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. We hope to confirm soon when the new automated data flows will start.

We continue to consider how data quality (completeness and consistency) can be ensured when data is sourced from clinical systems. We have had a series of meetings with System C to explore how reminders can be provided within BadgerNet to complete data fields that contribute to national data, and how data completeness reports for boards can be provided.

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

Throughout 2019 we reviewed the national maternity data return (SMR02) and the Scottish Birth Record (SBR; national baby data set), with a view to developing enhanced future maternity and baby data sets that align to current service delivery, and provide more consistent data on maternity care, births and babies.

With 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).

We have now established the Antenatal Booking Collection as a routine and enduring all-Scotland data collection. Numbers of bookings, and gestation at booking, using 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. This will allow PHS to publish statistics during 2024 on coverage and results of the fetal trisomy screening programme in Scotland.

PHS have created an expanded version 2 of the Antenatal Booking Collection (ABC2). We have also developed a Mother, Birth and Baby (MoBBa) dataset. This will 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 the viability of both ABC2 and MoBBa through one-off data transfers. However, (as already noted) this testing has been delayed by IT development capacity constraints and will not now be possible until spring 2024.

We have continued to explore how we can capture data on miscarriage from 'early pregnancy' settings. During November 2023, we shared detailed definitions for items in a draft miscarriage (early pregnancy) dataset with the Scottish Digital Midwives group, and with a key 'miscarriage' contact nominated to Scottish Government in each board. We have now started working through this feedback. We are also discussing, with clinical and reporting specialists in System C, where data on miscarriage presentations to early pregnancy services are recorded within BadgerNet Maternity and the BadgerNet Early Pregnancy and Gynaecology Unit (EPAGU) module. We gave an update on this work at a meeting organised by the Scottish Government at the end of November.

### 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 an automated route.

### 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. However those sections have now been replaced by a new [Scottish Pregnancy, Births and Neonatal Data \(SPBAND\) Dashboard](#), which was published for the first time on 3 October 2023 and will be updated quarterly.

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; mean gestation at booking; number of terminations; mean 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.

SPBAND offers three ways to view data: time series charts for individual measures and individual Health Boards; small multiple time series charts, to allow comparison (for a particular measure) across Health Board areas, and a board comparison overview that displays multiple measures simultaneously.

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](#), [Discovery](#), [NMPA](#), [NNAP](#) and [PHS websites](#).