

# 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 March 2023). To subscribe contact [phs.matneodatahub@phs.scot](mailto:phs.matneodatahub@phs.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.

As part of our COVID-19 response, Public Health Scotland created a [data dashboard showing wider impacts of COVID-19](https://scotland.shinyapps.io/phs-covid-wider-impact/) at <https://scotland.shinyapps.io/phs-covid-wider-impact/>. This continues to be updated each month and includes data on many aspects of maternity care in Scotland including: breastfeeding; stillbirths, neonatal and infant deaths; antenatal bookings (numbers and average gestation; from the Antenatal Booking Collection); terminations of pregnancy (numbers and average gestation); births (gestation, type (including C-section) and whether induced); term+ singleton births that have a 5 minute Apgar score of <7, perineal tears, and extremely preterm deliveries at sites with a Neonatal Intensive Care Unit (NICU).

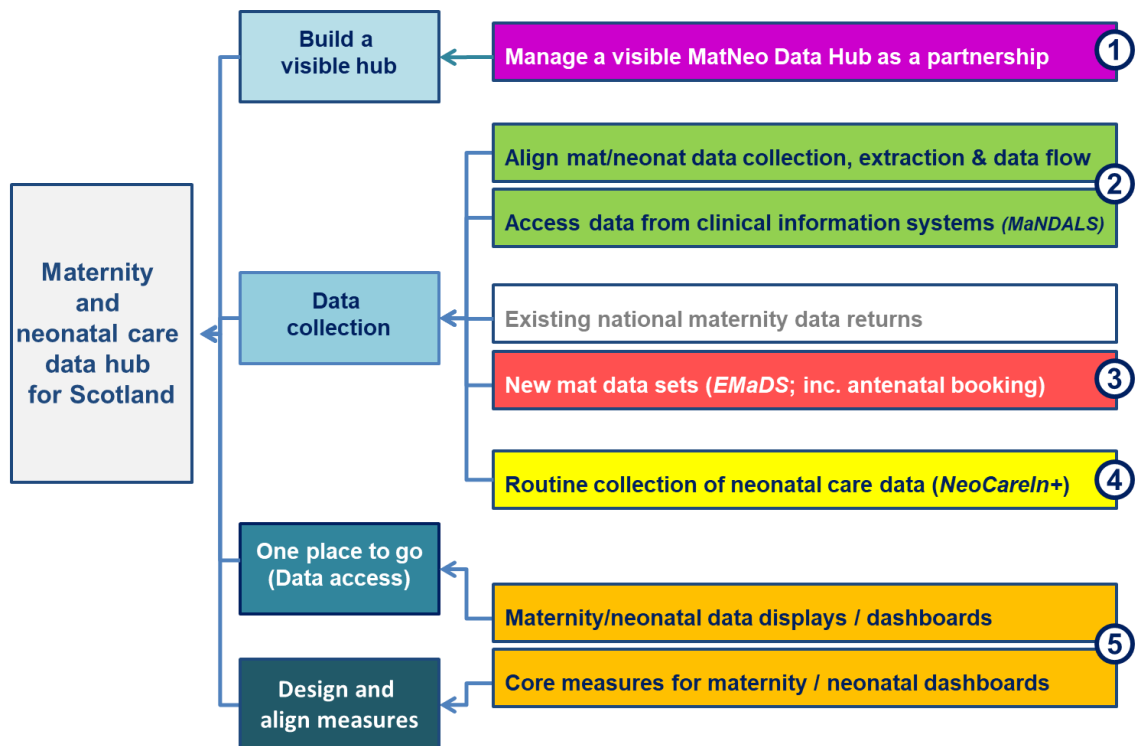
### Official statistics

Each year our colleagues in the maternity analytical team in Public Health Scotland publish a series of 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](#).

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 (March 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 have stabilised 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 a 4-nation maternal data group we established), to UK-wide audits and with IT system suppliers.

A MatNeo Data Hub **Programme Board**, with representatives from each delivery partner, continues to meet quarterly (most recently in March 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 to our mailing list at the end of March 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 will meet for an eighth time in April 2023.

We continue to work with National Services Scotland Digital and Security (DaS) colleagues, with colleagues in NHS Boards, and with Clevermed – who provide the BadgerNet systems – to bring nationally-consistent maternity and neonatal data from clinical systems in to Public Health Scotland (PHS). We are continuing to consider how data quality (completeness and consistency) can be ensured when data is sourced from clinical systems.

We are still in commercial negotiations with Clevermed to conclude a data services agreement to allow access to maternity and neonatal data that they hold on behalf of Scottish NHS boards, where boards ask them to do so. We have confirmed with Clevermed that although [Clevermed has been acquired by System C Healthcare](#), Clevermed will continue to be a legal entity with its own Information Commissioner's Office registration. We do not therefore think substantial changes will be required to the agreement we are negotiating.

### 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 were already proposing to separate the collection of antenatal booking data from collection of data on delivery (and other ends-of-pregnancy). We decided to dramatically accelerate that, and developed an [Antenatal Booking Collection \(ABC\)](#) data set (as an early implementation of a module of EMaDS). 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. This allows us to know how many women are pregnant at a point in time and therefore eligible for antenatal screening and immunisations. Numbers of women booking for antenatal care, and average gestation at booking, are published monthly in the pregnancy section of the [wider impacts dashboard](#) already mentioned.

ABC data was used by the [COVID-19 in Pregnancy in Scotland \(COPS\)](#) study to identify a dynamic cohort of pregnant women. COPS investigated how COVID-19 infection during pregnancy affects mothers and babies. They also measured COVID-19 vaccination uptake in pregnancy and assessed the effect of vaccination on outcomes for mothers and babies. The COPS team have published several key [research papers](#). Post-COVID, PHS is building on methods developed for the COPS study to maintain a dynamic pregnancy cohort (the Scottish Linked Pregnancy and Baby Dataset, SLiPBD).

PHS have finalised an expanded version 2 of the Antenatal Booking Collection (ABC). We are also developing a Mother, Birth and Baby (MoBBa) dataset. This was previously called the Delivery and Baby (DeB) dataset and will, in the initial version 1, be deployed alongside the existing SMR02 to gather additional data on mothers, births and babies that is not included in SMR02. We will be testing both ABC2 and MoBBa through one-off data transfers in spring/summer of 2023.

We are also exploring how we can capture data on early pregnancy events (including miscarriage) from early pregnancy centres. We are continuing to build a picture of how services are delivered and finalising a dataset.

### 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, and what changes we might need to make to the draft dataset we developed in 2018/19. We now have a dataset suitable for routine submission. We are still discussing with Clevermed (and NHS Boards) how we can have this dataset routinely available, how data will be stored in PHS and planning how data should be presented.

### ⑤ Data displays showing maternity and neonatal CORE measures

We have continued developing **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, will support individual services and regional collaborations to learn from each other's experience.

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

We have continued to develop additional data displays for maternity CORE measures to add to post-COVID, publically-accessible dashboards. These include time series charts to allow comparison (for a particular measure) across Health Board areas, and a multi-indicator board comparison to display multiple indicators for health board areas. We have demonstrated these to key groups and received great feedback which we have used to improve the displays. We will launch a ‘beta version’ for initial use and further comment very soon.

Members of the programme team are continuing to work with a National Neonatal Network Data Group, to develop a companion neonatal dashboard CORE and neonatal network metrics. We recently circulated a proposal for neonatal network metrics to the Data Group and received useful feedback on definitions, suggested frequency of reporting and whether data is required at unit and/or all-Scotland-network level.