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 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 October 2023; to receive these please contact 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.

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.

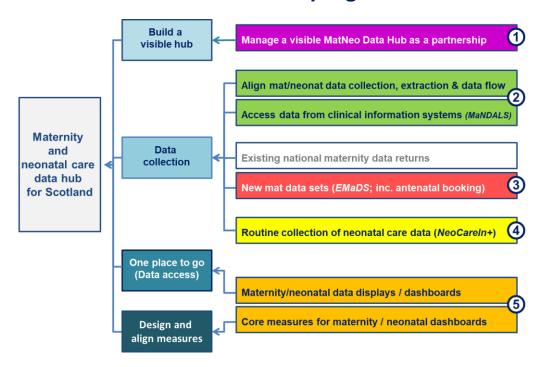
Official statistics

Our colleagues in the maternity analytical team 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;

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 (October 2023) on each work stream

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 <u>Scottish Perinatal Network, Healthcare Improvement Scotland, Scottish Government, National Records of Scotland, and Public Health Scotland</u>). 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), 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 September 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 October 2023. With the assistance of the <u>Scottish Perinatal Network</u> (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 a ninth time in November 2023.

We have worked (intermittently) over the last couple of years with colleagues in National Services Scotland Digital and Security (DaS), with colleagues in NHS Boards, and with Clevermed – who provide the BadgerNet systems – to develop an automated way to bring nationally-consistent maternity and neonatal data from clinical systems into Public Health Scotland (PHS). Unfortunately, this was delayed due to IT-development-capacity constraints within DaS. However, we are now restarting concerted work and should be able to confirm new timescales soon.

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 Clevermed 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.

The slow progress with IT has delayed completion of commercial negotiations with Clevermed (now part of <u>System C Healthcare</u>) on a data services agreement. This agreement will facilitate access to maternity and neonatal data that Clevermed hold on behalf of Scottish NHS boards, where boards ask Clevermed to allow access.



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 refocussed 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. Furthermore, ABC data is being 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. Such cohorts also allow us to do studies on medicines use in pregnant women, which are now starting. Finally, ABC data allows us to know how many women are 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. This will be deployed alongside the existing SMR02 to gather additional data on mothers, births and babies that is not included in SMR02. We still plan to test 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 probably not now happen until early 2024.

We have continued to explore how we can capture data on miscarriage from 'early pregnancy' settings. We have continued to develop detailed definitions for a draft miscarriage (early pregnancy) dataset, and have shared these with the Scottish Digital Midwives group and a key 'miscarriage' contact nominated to Scottish Government in each board. We have also continued to establish how we can collect the data items included in the dataset from the electronic data already collected by 'early pregnancy' settings. We have been working with board contacts (and Scottish Government colleagues) to check some points from a survey run last year by Scottish Government about which services are using which clinical information systems.



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 still discussing with Clevermed (and NHS Boards) how we can have this dataset routinely available via an automated route and how data will be stored in PHS.



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, will 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.