University of Southampton

Gaps in Maternity Care Data

A POLICY BRIEF FOR ENGLAND

ASPIRE COVID-19 UK

University of Central Lancashire UCLan

UKRI Economic and Social Research Council

with Amsterdam University Medical Center, University of Manchester, Royal Free Teaching Hospital in London, MBRRACE-UK, Newcastle upon Tyne Hospitals NHS Foundation Trust & NPEU, University of Oxford, NHS England and NHS Improvement North West.

KEY MESSAGES

- The ASPIRE COVID-19 UK study investigated how care was made safe and personalised over the COVID-19 pandemic, to inform care provision both in future crises and under normal circumstances. The need for better quality routine data collection with more transparent data access was identified as a key finding of the study.
- Regular monitoring of quantitative Trust level maternity data over time by month or more frequently is essential both during pandemic and non-pandemic times. This includes the monitoring of health outcomes including mortality around the time of birth, background data about those giving birth and their babies (e.g. ethnicity, age etc), characteristics of the care given (e.g. antenatal care, postnatal care, caesarean sections), user and staff experience and the state of the health system to provide care (e.g. staffing, medicines). Frequent and timely monitoring facilitates speedy action in a crisis.
- To ensure patient safety, it is not only important to track key indicators frequently[1], but to also implement a transparent system of review and action. Such a system should be intensified during periods of crisis. To improve services in the long-term, it is also necessary to collect accurate, clean and accessible data sets for researchers to access under appropriate ethical protocols.
- "Safe and personalised care"; a policy imperative stated in the current agreed maternity care national strategy Better Births[1], is not clearly defined, and an associated quantitative indicator framework is not currently available.
- There has been no identification of trigger variables or ways to track early warning signs that should be monitored in order to respond to emerging crises.
- Aggregated and indicative Trust level data in England is collected and available on a range of platforms, with varying degrees of accessibility, quality, harmonisation and relevance for policy and practice. Indicators tracking various aspects of what could be considered safe and personalised care or early warning signs are not integrated and not on the same platform.
- There are key gaps in data collection and tracking. For example, there is a lack of data on postnatal care. The only routinely collected data on user experience (Friends and Family test data) is under-developed, has poor sample sizes and minimal data or question items. Staff experiences should also be more regularly monitored, as addressing some emerging problems could help stem the tide of midwives leaving the service.
- The lack of individual, rather than aggregated data, or the difficulty in accessing or compiling them means that fast turn-around quality information for policy-makers has not been available and many aspects of care, system dynamics and inequalities in maternal and newborn care have been under-investigated.

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INTRODUCTION

The monitoring of maternal-newborn health and health services in the UK is important for identifying trends over time that could cause concern or require action to protect patients at national, regional or individual Trust level. Accountability at international level can also raise flags for patient safety tracking national progress towards international goals[2], as recently seen in the highlighting of continued rise and inequalities in maternal mortality in the USA[3].

Monitoring has been particularly important during the COVID-19 pandemic, as ongoing policy-making has needed to become very responsive to changing circumstances as successive waves and different strains of COVID-19 have unrolled. Monitoring our core maternity system, whether during a pandemic or not, should be comprehensive, fully include all Trusts, and be based on current agreed policy tenets. Comparing maternity provision and outcomes between different Trusts can be fraught with difficulty, as each Trust has its own characteristics and different caseloads, but its only by monitoring and comparing Trusts with care that we can identify good performers, share best practice, and draw lessons for policy and practice.

In England, individual Trusts are responsible for collecting, cleaning and using data for their own management given their own particular characteristics. But quality of data, data collection and expertise in analysis varies from Trust to Trust, causing problems for nationwide data systems that inform overall or regional strategies and policy development. During COVID-19, data collection and monitoring has become even more challenged, while at the same time more urgent, with a growing public understanding of health statistics and policy responses in real time.

The ASPIRE study investigated the use of quantitative data for monitoring maternity services throughout the pandemic. Available data were examined across the COVID-19 pandemic starting from one year before its onset in English Trusts. The study focussed on seven Trusts, but data from all English Trusts have been assessed in order to see each case study Trust in the context of nationwide variations. This policy brief presents findings on the data available to monitor maternity services, the quality of that data and identifies the strengths and shortcomings of the data for responsive policy-making in a pandemic. Recommendations from the study are pandemic-specific, as well as more wide reaching and universal, using COVID-19 as an example of a crisis.

“It’s only by monitoring and comparing Trusts with care that we can identify good performers, share best practice, and draw lessons for policy and practice.”

BACKGROUND

Data on maternal-newborn health and care are available from a number of national sources as below.
National maternity data platforms and datasets aimed at improving services

Sources	Type and purpose of platform and frequency of data collection	Scope and range of variables	Data availability, completeness and reporting
1. Maternity Services Data Set (MSDS)[4]	Aggregated **monthly** totals of women by Trust in England posted monthly. Developed in response to Better Births report in 2015 to improve monitoring, outcomes, inform commissioning, address inequalities.	Information at each stage of the maternity care pathway, including demographic data, information on antenatal care, labour, intrapartum and newborn care and outcomes.	All Trusts in England submit data by legal requirement. Downloadable as csv files monthly per Trust. Most recent available month is four months previous to accessed time. Significant missing data, definitional problems and comparability issues exist across time and between Trusts.
2. Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBBRACE)[5]	Confidential **yearly** clinical reviews of all UK maternal, perinatal and neonatal deaths and selected serious morbidities, and stillbirths by MBRRACE-UK at Oxford University NPEU.	Maternal mortality, late fetal losses, stillbirths and infant deaths.	Perinatal data by year and Trust available to download. Also regular reports published and aggregate statistics available from report tables for maternal and perinatal mortality and some morbidities.
3. Safe staffing data[6]	The UK National Quality Board report of 2013 recommended publishing **monthly** staffing levels across all hospital settings in response to the Francis report[7]. Monthly maternity staffing data can be extracted for nurses and midwives.	Numbers of registered, non-registered staff working on each ward, percent shifts meeting safe staffing guidelines by ward/unit and broken down by day/night, planned/actual hours, fill rate.	Varies by Trust on how easy this is to access and how complete their submitted data. No central source and reaching across Trusts is problematic. Queries have been raised on the effectiveness of the methodology for assessing safe staffing levels.
4. Hospital episodes data[8]	Individual person level data for all hospital episodes for research /planning. Collected on ongoing, **continuous** basis prospectively at NHS hospitals in England as part of the CDS .	Information on all admissions, durations of stay, conditions, procedures and outcomes including A and E attendances and outpatient appointments.	Available given a successful research-related application to NHS Digital (can be a lengthy process and data completeness not guaranteed). Aggregated reports published monthly for some health themes and annually for maternity since 2004-05.

Sources	Type and purpose of platform and frequency of data collection	Scope and range of variables	Data availability, completeness and reporting
5. Friends and Family test data[9]	NHS-wide data for all English Trusts designed to give all NHS service users the opportunity to feedback on experiences. Started 2013. Data are available **monthly.**	Tracks the likelihood of users recommending services for antenatal, birth and postnatal services. Can be followed up with further questions by Trusts.	In 2020 revisions were made to the data collected, but there are delays in rolling this out. The survey was suspended throughout 2020 due to the COVID-19 pandemic and once re-introduced coverage has been very low.
6. Care Quality Commission (CQC) Maternity Services Survey[10]	Conducted **every two years**. Data used to inform the CQC's ratings published for Trusts and to inform CQC inspectors.	Women's experience of choice and continuity of care in maternity services in hospital.	Data collection started from 2019. Data available only as report pages or tabulations.
7. NHS Staff Survey and Doctors in Training Survey[11]	Both conducted **annually**. Carried out by NHS Survey Co-ordination Centre and General Medical Council to assess training levels of staff and staff satisfaction	Staff and trainer views about working in their NHS, and training needs.	Data available only as report pages or tabulations.
8. National Maternity and Perinatal Audit (NMPA)[12]	**Annual** RCOG audit of the NHS maternity services across England, Scotland and Wales. Aims to identify good practice and areas for improvement in the care of women and babies in NHS maternity services.	Evaluation of a range of care processes and outcomes.	Data available only as report pages or tabulation of aggregate data.
9. United Nations (UN) Sustainable Development Goals (SDG) reporting[13]	Global accountability system co-ordinated by UN. Country-level reporting **(annually, or five yearly)** of key national health outcomes to track progress towards goals.	Maternal mortality ratio, neonatal and U5 mortality rate, adolescent fertility and percent births attended by a skilled provider under SDG3.	Mandatory country reporting. Mainly complete for the UK, though percent women who give birth with a skilled provider is missing. Data downloadable from year 2000 in spreadsheet format.

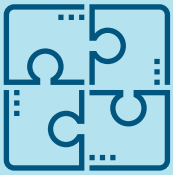
Each listed dataset is the result of a separate data collection task apart from 8 and 9 which are exercises in bringing together existing data.

Maternity data and the new government data quality framework

According to new government guidelines[14] on data quality there are six core data quality dimensions that are fundamental to effective, evidence-based decision-making. These have been identified from the 2019 Public Accounts Committee Report[15] which showed that data has too often not been treated as an asset, and it has become normal to 'work around' poor-quality, disorganised data.

The key to effective data:

Completeness



Uniqueness

Consistency

Timeliness

Validity

Accuracy

The core maternity data set in English Trusts; the MSDS, has considerable challenges in each of those domains. Improvements in the culture of data quality, also recommended as part of the data quality framework, are desperately needed in maternity. Not only will this ensure transparent use and accountability, and better management through better quality data, but recent Department of Health and Social Care Policy[16] has acknowledged that good quality data also saves lives. Under the recent policy directive for England a pledge has been made to provide up-to-date sophisticated data to policymakers to make effective decisions, plan national programmes, respond to crises and pandemics and target areas that need support, especially where there are serious failings. A very crucial health sector to make a start on this would be maternity.

FINDINGS

Data accessibility

Issues of accessibility of quantitative, timely information on maternity services have been problematic before and during the pandemic. The list of different and sometimes incompatible data sets have varying accessibility, and are dispersed on different platforms. Many reporting cycles are annual rather than monthly and do not provide accessible downloadable data across Trusts. For both MSDS and staffing data - where critical aggregate data are publicly available, it is possible to extract data for one or two Trusts over time - though there is a need to merge every month's file, to create a view of changes over a period of months. However it is very difficult to compare trusts or manipulate data from the whole country. Even NHS Digital National Maternity Services Dashboard[17], currently under development, can only query data from one Trust at a time, and the current "compare" function only places different MSDS indicators from a single Trust side by side.

Aggregate data are very important to track crude trends, but individual data are also needed to understand and tackle inequalities in care and outcomes. But currently there are no transparent processes for obtaining anonymised individual data. Even aggregate data from individual Trusts to supplement MSDS information, is a struggle for some Trusts to provide. Monetary charges for maternity-related data are quoted by private platforms which in many instances are out of reach of research budgets, not regularised and clearly not available to policymakers. On the positive side, NHS Digital is developing accessibility platforms for maternity data so that service users can access their own data confidentially on an individual basis. When complete, this will be a great step forward but these data are not intended for use by researchers or policymakers. Two initiatives under development which might improve the situation for researchers are the Federated Data Platform (FDP)[18] and Secure Data Environments[19] at national and regional level which may allow restricted access to data at a significant scale.

> "currently there are no transparent processes for obtaining anonymised individual data..."

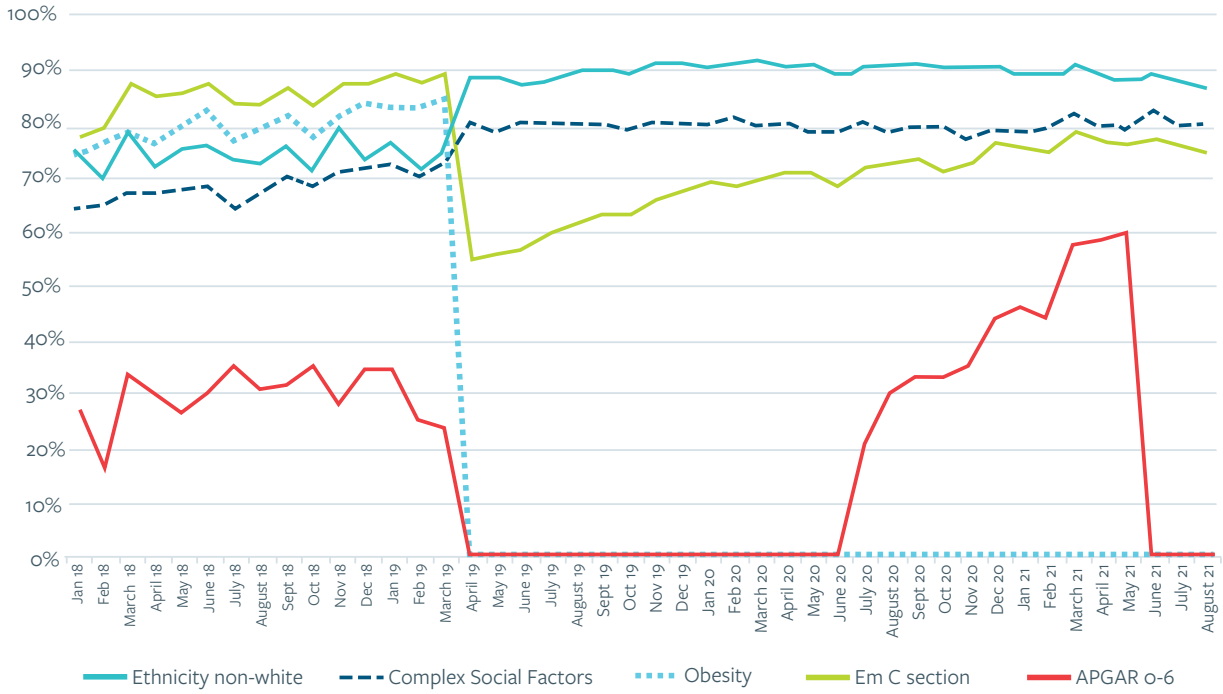
Data quality

Poor data quality is evident when there are inconsistencies from different sources of maternity data. For example, basic total numbers of births occurring in hospitals across English Trusts is reported as one number from the MSDS, another (higher total) using the HES. Assuming the episodes are more complete - this implies that births are under-reported on MSDS. Numbers of registered births in the UK from vital registration is yet another conflicting source. The MSDS is described as "experimental" and that the data cannot necessarily be relied on, but this has been the case for six years now, and given some improvements and upgrades, and the experience of the pandemic, there should now be a plan to remove the experimental label and encourage Trusts to return more reliable data.

Tackling missing data should become a priority for the MSDS. Key data tracking women's existing health conditions, continuity and personalised care during antenatal care, birth and postnatal care, and baby health checks at birth were all substantially below 50% complete over the COVID-19 pre-pandemic and pandemic months[20].

Looking at completeness of key data over time in recent years (see graph) some changes and improvements were seen after March 2019, when the platform was overhauled to some extent, but these changes have meant that some essential variables for the pandemic, such as women's obesity and newborn APGAR scores, have not been available. Others however, such as ethnicity and complex social factors, improved in time for the pandemic. Data returns have not been seriously affected by the COVID-19 waves, although a drop off in more recent months is discernible. Few indicators, however, reach 85% completeness even in the best of times.

Completeness in all English -Trust data reporting to MSDS before and during COVID-19 for key selected maternity indicators



Source: MSDS

There are key gaps in data collection and tracking across all platforms. For example, there is a lack of data on postnatal care. The only routinely collected data on user experience (Friends and Family test data) is under-developed, has poor sample sizes and minimal data or question items. It was also discontinued during the COVID-19 pandemic. Staff experiences should also be more regularly monitored, as addressing some emerging problems could help stem the tide of midwives leaving the service.

Harmonisation of data

Trusts maintain their own data through various systems, often using Badgernet[21], while some others use a variety of different platforms. Trusts do not always produce data that is comparable to other Trusts, and ongoing important data can be difficult to access even within Trusts and across time. To improve harmonisation across Trust boundaries, some Trusts have joined with groups or their regional neighbours to harmonise systems (see, for example dashboard standardisation attempts in the South West of England Strategic Health Authority region[22]). However, this does not allow for an effective survey of all UK or English maternity provision around a core set of indicators with common definitions.

Building a core set of maternity indicators would also encourage the integration of the many disparate and un-linked data sources which are currently not on the same platform. The NHS Digital Maternity Dashboard platform goes some way to improving this, but key data sets, such as safe staffing, and frequently collected user experience data are missing.

Data for policy and action

During the COVID-19 pandemic there has been a need for identification of trigger variables (e.g. staffing, early warning signs) that should be monitored in order to respond to the emerging crisis. The uncertainty around appropriate thresholds for alert even during non-pandemic times within the current Trust-based dashboards and the associated lack of harmonisation between them has not been addressed and remains a key weakness of the system. Future pandemics and other crises will have their own particular characteristics and specific trigger variables may need to be developed quickly for each situation. However, building an integrated core set of frequently collected and standardised variables firmly based in policy directives drawing on broad platforms that do not miss out key variables can go a long way towards creating a resilient, crisis-ready system.

The first step towards making the system policy relevant would be to address and quantify the concepts associated with "Safe and personalised care"; a policy imperative stated in the current agreed maternity care national strategy Better Births[23]. This is currently not clearly defined, and an associated quantitative indicator framework is not currently available. Also, the lack of analysis of individual data (with the notable exception of the Hospital Episodes Data, which is currently under-analysed for maternity) means that inequalities in maternal and newborn health have not been investigated and policy directions have not been identified.

> “The only routinely collected data on user experience (Friends and Family test data) is under-developed, has poor sample sizes and minimal data or question items.”

RECOMMENDATIONS*

- **Build a framework** to describe the essential characteristics of safe and personalised care to include important trigger variables with agreed action thresholds that can inform and provide early warnings both in a pandemic and in non-pandemic times. Use this framework to build an accountability system with core policy-linked indicators to monitor maternity care.
- Make sure the **core policy-linked indicators consider all the key domains** important for maternity: demographics (age, ethnicity, deprivation), outcomes (births, mortality etc), health system (staff levels, bed occupancy), care processes (c-sections, ANC, etc)
- **Plug the gaps in the data** by ensuring that meaningful user and staff experience data are regularly collected and data on postnatal care are included in platform and dashboards.
- **Allow researchers and policy makers to access data** both for research and tracking/ surveillance. Individual, as well as aggregate level data should be regularly available for analysis, allowing researchers and policy-makers to access data - including staffing data
- **Harmonisation efforts** are urgently needed e.g. the same platform is needed for all data, agreed definitions of variables and common denominators. This is widely agreed as a recent survey of more than 100 key workers across UK maternity facilities call for the development of a single website[24] that signposts to all national maternity reports and datasets, and contains up-to-date guidance on all mandatory reporting requirements.
- **Quality of data** should improve the missingness, definitions, lack of consistency between different data sources. Aggregated data e.g. the MSDS platform's monthly view could be more effective if more frequently delivered - e.g. weekly or fortnightly.
- **Restore motivation and trust in quantitative data** collection for policy action in maternity services. Develop systems to reduce data collection workloads on midwives and also that maximise on the data they work so hard to input and process, building coherent systems. Currently it is very difficult to interpret non standard, poor quality and patchy data and there is a lack of trust that data input can be effectively used to feedback and improve services in a timely way. Indeed there is a culture of mistrust related to quantitative analysis in maternity which is understandable, but needs to be addressed and challenged. Deteriorations in quality care before and during the COVID period are going undocumented and policymakers need to know the scale and characteristics of the ongoing problems in order to tackle them.

**These recommendations should not be considered in isolation but integrated within the efforts to adopt the ASPIRE Policy brief on maternity care staffing, the ASPIRE Policy Brief on data and the ASPIRE policy brief on personalisation.*

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The ASPIRE COVID-19 UK study was funded by the Economic and Social Research Council (ESRC) to determine what worked to make care safe and personalised over the COVID-19 pandemic, to inform care provision both in future crises and under normal circumstances. The study included the collection and analysis of clinical outcomes data and interviews with staff and service users, from seven Trusts across England, purposively selected for geographic and demographic diversity.

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and the ASPIRE COVID-19 steering and stakeholder groups, which includes representatives from over 30 trusts, non-governmental organisations, networks, professional bodies and academic institutions.

Magnification of the change needed for **safe, personalised and sustainable care**.
Achieving balance across the key messages to achieve **optimal results.**

Remove red tape

Target the targets

Make data available

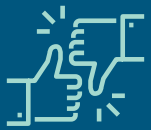
Foster a team ethos

Enable autonomy

Embed equity

Ensure companionship

Integrate user and staff voices



Consider unintended consequences

Support staff well-being

Find out more

www.aspire-covid19.com

www.uclan.ac.uk/research/strengths/maternal-and-child-health/aspire-covid-19

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