

National Maternity and Perinatal Audit

Bloodstream Infections in NHS Maternity and Perinatal Care for Women and their Babies

A Feasibility Report of Linking Maternity, Neonatal and Infection Datasets in England



Key Information

Infections during pregnancy can have serious or life-threatening effects on both mothers and babies.

Bacteria and viruses that cause infections may be transferred from a pregnant woman or person to their baby during pregnancy or during labour and birth. Infections in the newborn baby can also be caused by direct contact with the mother or with other environmental sources in the postnatal period.



A bloodstream infection may lead to sepsis, a life-threatening condition that can lead to organ damage or death.

In the UK, maternal sepsis is the second leading cause of maternal death during pregnancy, or in the six weeks following birth. This equates to the death of 8 in 100 000 women or birthing people.



Early onset neonatal infection is defined as infection affecting a baby within the first 72 hours of life. Group B Streptococci (GBS) are the most common bacteria to cause these infections in babies born at term, meaning at or after 37 completed weeks of pregnancy. In England in 2020, early onset GBS infection was reported in 0.5 per 1000 live births of all gestations.



If there are concerns that a mother or baby may have a bacterial infection, they may be given antibiotics while clinicians wait for blood test results to show whether they have an infection or not. Mothers may also be given antibiotics during labour to offer protection against infection to them and their baby.

Some women and birthing people or their babies may become unwell enough with an infection that they need admission to adult intensive care or a neonatal unit.

Information is collected in hospitals about admissions to maternity units, intensive care and neonatal units, as well as tests and treatment for infections.

Research is underway into infections in women and birthing people and their babies, but none are linking infection data with maternity and neonatal datasets.



An increase in infections that do not respond to treatment (antimicrobial resistance) is a concern for global public health. Reducing the rates of antimicrobial resistant infections is on the agenda of the UK Government.

Ongoing routine linkage of maternity, neonatal and infection data is required to monitor: (1) the rates of infection and of antimicrobials given during pregnancy, in labour or soon after birth; (2) antimicrobial resistance.



Questions have been asked about the rates and patterns of infection, and antimicrobial use in maternity and neonatal care, and the effect of bloodstream infections on women and birthing people, their babies, and their families. These questions continue to be asked periodically by clinicians, service users, stakeholders, and the media, at a local, regional and national level, as well as at a parliamentary level.



Yet these questions about bloodstream infections and the effect on women and birthing people, their babies, and their families remain unanswered without linked data.

“This data would assist the [UK] Government in meeting its national ambition for safer maternity care.”

(NMPA advisory group member)

Key Findings

The NMPA, along with those who work with the neonatal dataset (NNAP) and infection dataset (UKHSA) have tried to link maternity, neonatal and infection data together. This linkage has not been achieved, despite the existence of datasets and demand from clinicians, service users and other stakeholder groups, such as researchers and charities.



All parties involved agree this linkage is important, and are willing to help facilitate this, yet for a number of reasons, it has still not been possible.



The key barriers to obtaining linked data are largely due to timescales, resources and processes, as well as the capacity to collaborate in driving this forward.

- Datasets are held within different organisations, and it is necessary for some steps of the data linkage process to be carried out by a third party.
- The process for information governance approvals and the capacity of NHS Digital* (now NHS England) to perform the dataset linkage has not been feasible within the NMPA contract period that ended on 31 December 2022.



There were also factors beyond the control of the NMPA, NNAP and stakeholder groups, which affected the capacity for, and prioritisation of, data and data linkage requests. These include the COVID-19 pandemic and the recent restructuring of Public Health England (now United Kingdom Health Security Agency (UKHSA)).



Ongoing routine linkage of maternity, neonatal and infection data is required for infection and antimicrobial monitoring.

Our advisory group conversations highlighted a need for more information to be made available to families about the effects of infection during or after pregnancy on mothers and babies, as well as the wider impact on the whole family.



CALLS TO ACTION:-



NHS Digital (and equivalent bodies in the devolved nations) should prioritise reviewing and optimising data items for linking routinely collected data, with the aim of describing the rates, and variation in care and outcomes relating to infection in maternity and perinatal care.



As part of a quality improvement strategy, we would like to see individual units and organisations verify their own data entry to ensure data completeness for the relevant data items necessary for ongoing perinatal infection monitoring.

* Since this feasibility study was carried out, NHS Digital has merged with NHS England. NHS England is now the single executive non-departmental government body with responsibility for digital technology, data and health service delivery in the NHS. Throughout this report we refer to NHS Digital, from 1 February 2023, NHS England has assumed responsibility for all activities previously undertaken by NHS Digital.

NOTE

Throughout this document we use the terms 'mother', 'women and birthing people' and 'pregnant women and people'. It is important to acknowledge that it is not only people who identify as women that access maternity and gynaecology services.

What is the National Maternity and Perinatal Audit?

The National Maternity and Perinatal Audit is a large-scale project established to provide data and information to those working in and using maternity services.

We do this to evaluate and improve NHS maternity services, as well as to support women, birthing people and their families to use the data within their decision-making.

For more information about the NMPA, please see www.maternityaudit.org.uk

What is the bloodstream infections report?

The NMPA helps us understand the maternity journey by bringing together information about maternity care, information about hospital admissions and information recorded about babies in the mother's record. We call these different collections of information "datasets". The aim of this report was to link datasets that contain information about mothers, their babies, and infection data.

The NMPA has been unable to obtain linked datasets within the timeframe of the audit programme contract, which ended on 31 December 2022. Therefore, this report focusses on how important it is to join together the datasets that hold different information about infections during and after pregnancy in women and birthing people and their babies. For example, data collected about pregnancy, labour and birth, information about infections and data about admissions to hospital. Had the joined dataset been available, this could have been used to look at aspects of maternity care and outcomes specifically for women and birthing people who had a bloodstream infection during pregnancy or in the six weeks after birth; and for babies who had a bloodstream or CSF infection in the first 3 days of life. Ongoing linkage of these datasets could be used for longer term surveillance of infection and antimicrobial use in women and birthing people, and babies.

Why is linking data important?

Linking maternity and baby/neonatal data together with infection data is essential to explore how bloodstream infections affect both mothers and babies. For example, families may be separated if either the mother or baby are unwell, require admission to intensive care or a neonatal unit, if either are transferred to a different hospital; there may even be a period of separation if a baby needs to be taken to a treatment room to be given antibiotics.

NOTE

This report uses the term 'bloodstream infection.' If there are concerns about possible infection in a baby, they will sometimes have a test called a 'lumbar puncture' which takes a sample of the cerebrospinal fluid (CSF) that flows around their brain and spinal cord.

"I didn't even get to see [my daughter], they whisked her off to give her antibiotics. Then they gave her to my husband, I got to see her face but then they said 'they've got to leave the room...' [By the time] I managed to get the strength to hold her, it was about 72 hours later."
(NMPA advisory group member)

Physical separation may not always be due to mothers and babies being cared for in different clinical areas but simply the fact that the equipment involved interferes with the normal activities of a mother and her new baby, such as feeding, changing nappies or skin-to-skin.

“...because I was so hooked up to lines and things like that, I couldn't breastfeed my daughter for the first 24 hours ...”
(NMPA advisory group member)

Monitoring bloodstream infection rates and antimicrobial use during or soon after pregnancy for both women and birthing people and their babies is essential to understanding these infections at a national level and in developing strategies to reduce and prevent infection. Datasets containing information to facilitate this exist but are not currently linked together. Without this linkage, we cannot fully evaluate the scale of bloodstream infections affecting pregnant women and people and their babies.

NOTE

It is important to clarify that bloodstream infections and sepsis are not one and the same, although the terms are often used interchangeably in the literature and in clinical practice

What is a bloodstream infection?

The most common bacteria found in pregnant women and people dying from sepsis are Group B streptococcus (GBS) and *Escherichia coli* (E. coli). It is estimated that between 20% and 40% of women carry GBS in their digestive system or vagina. Early onset neonatal infection is defined by the National Institute of Health and Care Excellence (NICE) as infection affecting a newborn baby within the first 72 hours of life. GBS is the commonest bacteria causing early onset neonatal infection in babies born at term, that is at or after 37 completed weeks of pregnancy. In England in 2020, early onset GBS infection was reported in 0.53 per 1000 live births across all gestations.

If there is a concern or suspicion of an infection in a pregnant woman or person, in those who have given birth, or a baby, blood tests to check for infection should be taken before antimicrobials are given but it is not necessary to wait for the result before starting treatment. Some women will be given antibiotics during labour to offer protection to them and their babies. Babies, who are either showing signs of infection or for those of whom maternal risk factors are identified, may be observed or given antibiotics while clinicians wait for the results of the bloods tests. These will be stopped when the medical team are reassured there is no infection present. Antibiotics have been shown to disrupt the development of so-called 'friendly bacteria' in a newborn baby's gut, although the longer-term effects are uncertain.

Why is this important?

Adverse outcomes from infection during pregnancy may include pregnancy loss or stillbirth, babies being born early or small for dates, maternal death, death of a baby, and long-term disabilities for either mother or baby. There might also be a longer stay in hospital for mothers and/or their babies.

“It wasn't until during my [emergency] c-section that I was put on the Sepsis Six pathway, which we only know from looking at my notes. [There was] no communication whatsoever. I wasn't told I had sepsis, just 'you've got an infection. You're on antibiotics, you can't go home because your blood levels aren't right”
(NMPA advisory group member)

If infections are diagnosed and treated quickly, many women and birthing people and babies recover without long lasting physical effects, however, for some there may be an ongoing physical or psychological impact.

“[after discharge home] I didn't know the world that I was walking into. It [the experience] had a lot of psychological effects. I was diagnosed with PTSD.”
(NMPA advisory group member)

NOTE

Antimicrobial resistance occurs when micro-organisms, such as bacteria, viruses, fungi or parasites, no longer respond to medications used to treat them, making infections harder to treat and increasing the risk of disease spread, severe illness and death.

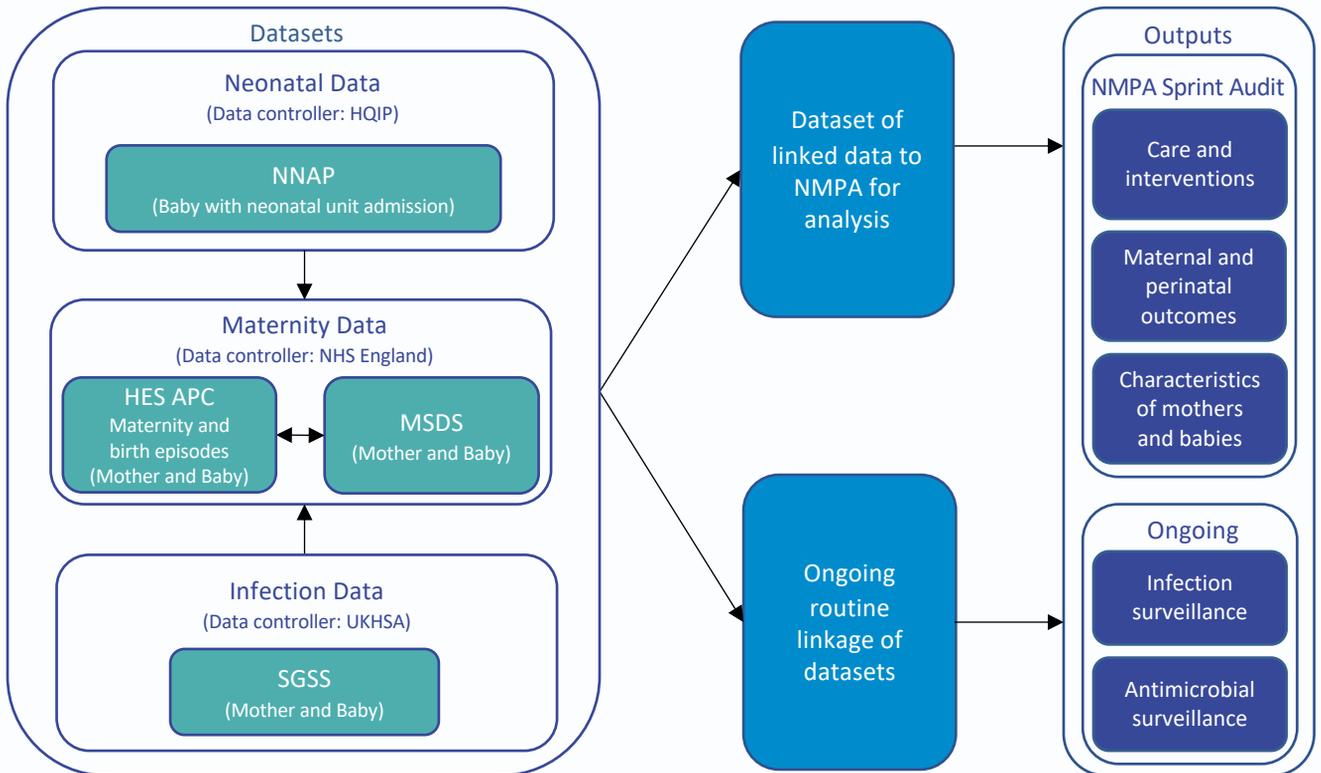
Antimicrobial resistance is a concern for global public health. The World Health Organisation (WHO) and UK Government have called for the monitoring of antimicrobial use, with the WHO emphasising that data is key to monitoring and understanding antimicrobial use and the impact of increasing resistance. In 2019, it is estimated that just under 1.3 million deaths worldwide were due to bacteria resistant to treatment. In England, this figure is an estimated 2 596 deaths in 2019.

By monitoring the organisms that cause infections in women and birthing people and their babies during pregnancy or after birth, healthcare providers are better able to choose who to treat and when, and which is the most appropriate antimicrobial to use.



Data sources

It is possible to link the relevant sources of data (datasets) containing information about maternity care for mothers and babies, neonatal unit admission for babies who require it, and infection data. The diagram below explains which datasets are required to be linked together, which organisation controls the data held within them and the potential outputs that could be produced from the linked data. Further details about specific data items that are relevant to this topic can be found in appendix 2 of the supplementary information.



HQIP = Healthcare Quality Improvement Partnership, NNAP = National Neonatal Audit Programme, HES = Hospital Episode Statistics, APC = Admitted Patient Care, MSDS = Maternity Services Data Set, UKHSA = United Kingdom Health Security Agency, SGSS = Second Generation Surveillance System, NMPA = National Maternity and Perinatal Audit.

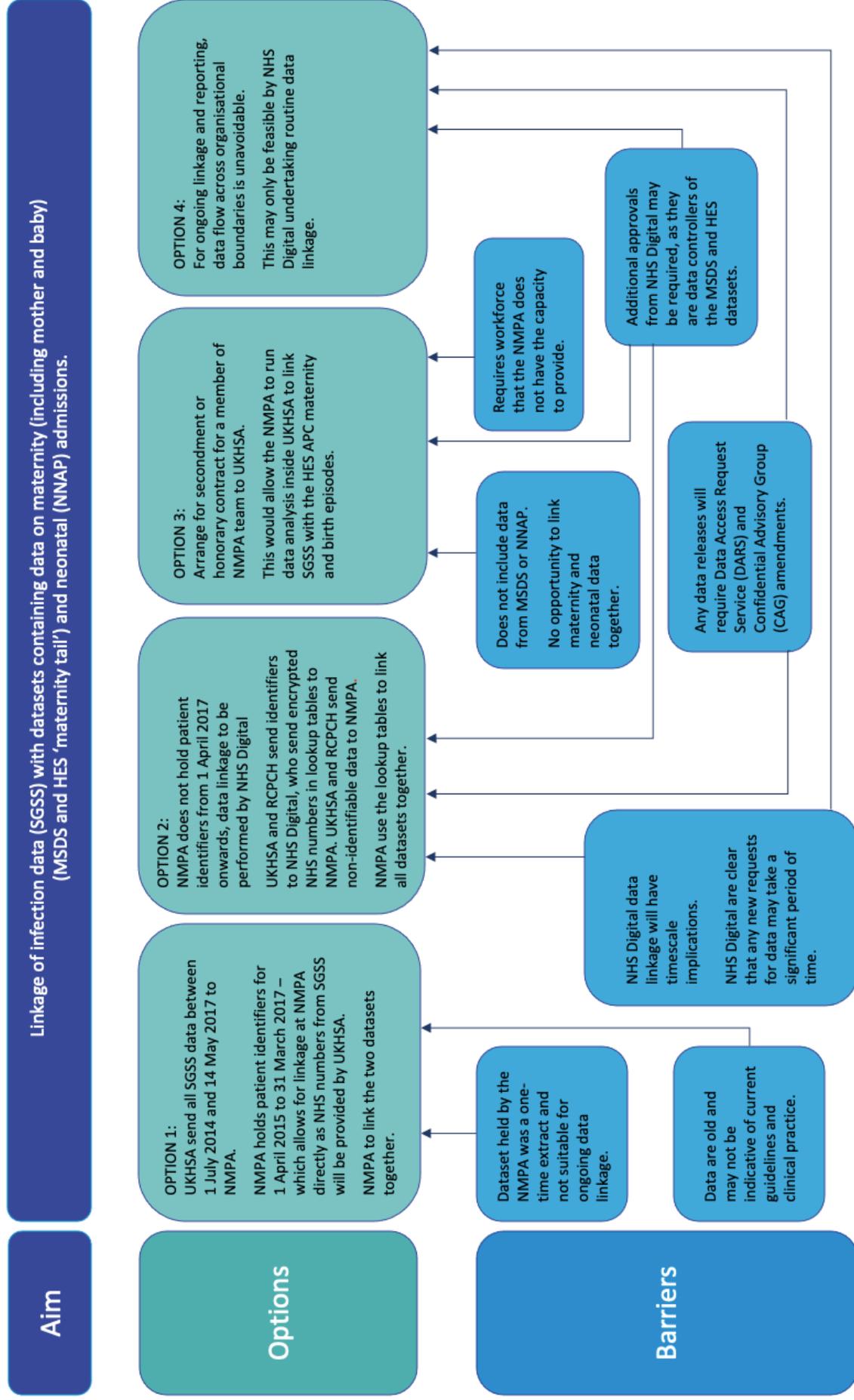
Working together

A collaboration of professional organisations representing adult, paediatric and neonatal intensive care, and paediatric and neonatal audits, as well as infection data, titled the “Infection in Critical Care Quality Improvement Programme (ICCQIP)”, aims to obtain a national picture of bloodstream infection rates in English intensive care units (ICUs). The programme relies on data being uploaded by participating ICUs, the number of units providing data has risen from 19 in 2016 to over 75 across the UK in adult, paediatric and neonatal units. Maternity data sources are not currently included.

“The ICCQIP and NNAP data linkage only captures babies who have been admitted to a neonatal unit. There is some information about the mother in the baby’s record and likewise, in MSDS, there are some details for the baby. It’s about making sure you’ve got the mother and baby dyad, together with infection data; that’s really important because we’re just missing out a big chunk of what’s happening by not linking them together. There are going to be mothers and babies who are missed because they don’t fall into those two datasets.”

(NMPA advisory group member)

The NMPA, along with those who work with the neonatal dataset (NNAP) and the infection dataset (UKHSA), explored the feasibility of obtaining these linked datasets to report on the characteristics, care and outcomes for women and birthing people and their babies. Several options were explored, these and the barriers encountered are illustrated in the diagram below.



How can this report be useful?

The findings of this report can help inform maternity services and those who provide care in this area about the benefits of joining different sets of information together to examine bloodstream infections and antimicrobial use in women and birthing people, and their babies. It also emphasises the importance of linking these data at a national level, in order to identify where any gaps in information and data quality may be present. This would enable steps to be taken to improve availability and completeness of information such that further work on this topic in all UK nations is possible.

This report highlights the necessity that information on bloodstream infections be made available to women and pregnant people and their families, to enable them to have conversations with their care providers about infection during pregnancy or soon after birth.

What can be done in the future?

This report highlights the difficulties the NMPA has experienced in accessing datasets that are needed for ongoing routine linkage of mother and baby data with infection data. This is essential not only for ongoing monitoring of those who have confirmed bloodstream infections, but also pregnant women and people who are treated with antibiotics during labour, and babies who receive antibiotics. Linking these data is essential to explore how characteristics, differences in care and outcomes impact each other, and how these differ between mothers and their babies.

Increasing rates of antimicrobial resistance and changes to clinical guidelines and practice demonstrate urgency in evaluating infection data for mothers and their babies, during pregnancy and in the period following birth. There are ongoing programmes exploring data linkage of ICU admissions and infection datasets, and investigating infection in babies admitted to a neonatal unit. However, the missing link is combining maternity, neonatal and infection datasets.

The organisations that control the datasets, NHS Digital (now NHS England), HQIP and UKHSA, need to work together to find a way to establish ongoing data linkage for future monitoring of infection and antimicrobial use during pregnancy and in the period following birth.

Who was involved in the production of this report?

The work was supported by an advisory group that comprised professionals from obstetric, midwifery and neonatal specialties, executive members from UK charities UK Sepsis Trust and Group B Strep Support, and women and families with lived experience of perinatal sepsis. The group shared their experiences and knowledge to help shape the report and recommendations.



UK Sepsis Trust aims to save lives and improve outcomes through raising awareness of sepsis by educating both the public and healthcare professionals campaigning for political change and providing support for those affected by sepsis. The charity devised the Sepsis Six tool in 2005, it is now used in 30 countries worldwide.

The Group B Strep Support charity is the world's leading charity working to eradicate GBS infection in babies. The charity works to raise awareness among parents and to educate healthcare professionals, as well as campaigning and making recommendations for routine GBS testing in pregnant women and people.



Group B Strep Support

Recommendations

Aimed at this audience

Recommendation 1

Identify and explore the key reasons behind the significant delays in data provision and data linkage and propose an action plan to reduce these in the future.



Organisations who collect, provide, or link data



Individual groups who undertake research

Recommendation 2

Provide reasonable estimates of the anticipated date for receiving data and data linkage requests.



Organisations who collect, provide, or link data

Recommendation 3

Establish ongoing routine data linkage of maternity, neonatal and infection datasets for infection and antimicrobial surveillance in the population in order to describe rates of and variation in care and outcomes for:

- Blood or CSF culture confirmed infection in mothers and babies
- Intrapartum antibiotic administration
- Empirical antibiotic administration
- Number of mother-baby separation days attributable to infection
- Number of baby days of antibiotic administration



Organisations who collect, provide, or link data

Recommendation 4

Review and optimise data items required for linking routinely collected data and ensure system compatibilities with futureproofing to guarantee ongoing linkage.



Organisations who collect, provide, or link data



Healthcare software developers

Recommendation 5

Prioritise identifying areas for further research into preventing maternal and neonatal infection, and reducing antimicrobial resistance, utilising quantitative and qualitative methodologies.



Organisations and Individual groups who undertake research

“This is one of those situations where the data are available, but we can’t currently link it together. Also, the ideas around screening, treating, and preventing infections, such as GBS early onset neonatal infections is changing over time... and we want to know what is happening, does it make a difference?”
(NMPA advisory group member)

Glossary and References

A glossary of terms, and references can be found [online](#).

Acknowledgements

Complete acknowledgements are available in the [supplementary information](#).

Funding statement

The NMPA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies www.hqip.org.uk/national-programmes.

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www.maternityaudit.org.uk

Alternatively you can contact us at:



nmpa@rcog.org.uk



020 7045 6798

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