Saving Babies' Lives 2023: Progress Report Summary

Sands & Tommy's
Policy Unit

Working together
to save babies' lives

In 2021

13

babies a day

were stillborn or died during the first 28 days of life across the UK

There are

NO

comprehensive data

on miscarriages

Approximately

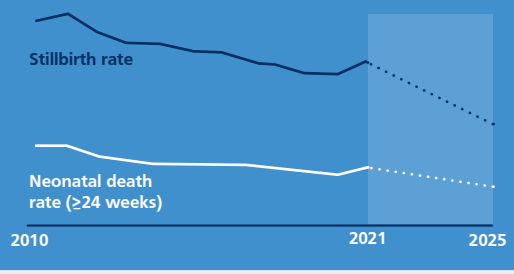
8%

of babies

are born preterm

Not enough progress has been made and there is a risk of going backwards

Stillbirth and neonatal death rates are off track to meet the 2025 target for England



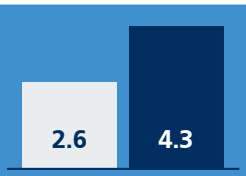
Meaningful action is needed to address stark and persistent inequalities

Black babies are almost

2x more likely to die

in the first 28 days after birth compared to white babies

Neonatal death rate 2020



Stillbirth rate 2020

Stillbirths are almost

double

among people living in the most deprived areas of the UK, compared to the least deprived

Lessons are still not being learnt when babies die

In 2021, the cause of

33% of stillbirths and **7%** of neonatal deaths

were unknown

In 2021-22, nearly

1/5

of stillbirths were found to be potentially avoidable if better care had been provided

2/3

of action plans created following the death of a baby are rated as weak

Systemic issues need to be addressed

In 2022

38%

of maternity units were rated inadequate or requiring improvement by the CQC

1/4

of respondents to the CQC maternity survey did not feel their concerns during labour & birth were taken seriously

In 2022

63%

of midwives in England had felt unwell in the last 12 months because of stress

Research and evaluation are vital

For every **£1** spent on maternity care in the NHS,

→

only **1p** is spent on pregnancy research

The Sands and Tommy's Joint Policy Unit, formed in 2022, is focused on achieving policy change so that fewer babies die. This report brings together data from different sources for the first time to show the extent of pregnancy and baby loss across the UK and provide a shared understanding of its drivers. Outlining recent trends and evidence, as well as gaps in current information, the report sets out areas where further work is required to reduce rates of miscarriage, stillbirth, preterm birth and neonatal death.

There is a long way to go to make the UK the safest place in the world to have a baby. We all want safer, more personalised, more equitable care so fewer people suffer the heartbreak of losing a baby. This is possible with political will, common purpose, and collaboration.

1. Introduction: Pregnancy loss and the death of a baby are not just 'one of those things'

Losing a baby during pregnancy or shortly after birth is not a tragic inevitability. This report shows that it is possible to save more babies' lives. We hope that by showing this, reducing baby deaths becomes the national policy priority that it deserves to be.

Over previous decades there has been a downward trend overall in rates of pregnancy and baby loss throughout the UK. However, in some parts of the UK outcomes have improved little over the last decade. There are also stark and persistent inequalities in outcomes by ethnicity and deprivation.

Despite increasing policy focus on maternity safety over recent years, the fundamental change required to ensure safe, equitable care for all is not happening. According to most recent data, progress to reduce rates of deaths is slowing or reversing and experiences of care are deteriorating.

> *You go from such a high to such a low in so short a space of time, so happy and jubilant one moment the next your world crumbles down. We were only in that room for about 5 minutes, but it's never really left me.*
>
> **Vik and Sarina**

> *Who can explain the raw emotions you feel after losing a baby? You feel so alone, even though everyone is around you. You blame yourself. You wonder what you could have done to prevent this from happening. You feel guilty for moments of happiness.*
>
> **Zoe and Dan**

2. Not enough progress has been made to reduce rates of pregnancy loss and baby death across the UK, and there is a risk of going backwards

In 2021, 13 babies a day were stillborn or died during the first 28 days of life across the UK. Comparisons with other European countries suggest that the UK could do better. While there has been progress in reducing rates of stillbirth and neonatal death over the long term, more recently this has stalled, and we risk going backwards.

In England, the government set an ambition to halve rates of stillbirths, maternal deaths, neonatal deaths and serious brain injury by 2025, relative to 2010 rates. Interim targets to reduce stillbirths and neonatal deaths by 20% were met in 2020, but rates increased again in 2021 and are off-track for the 2025 targets.

Being born preterm is an important risk factor for pregnancy loss and baby deaths: in 2020 almost three-quarters of neonatal deaths in the UK were among babies born prematurely. There has been relatively little progress on reducing the proportion of babies born preterm, which has remained between 7% and 8% of all births since 2010.

Comprehensive data on miscarriage are not reported at the UK-level or by any individual nation. Some UK nations report the number of miscarriages which result in a hospital stay. However, this is not a comprehensive view of the number of miscarriages; some women and birthing people may seek care from their GP rather than hospital, while others may not use medical services at all. Even when women and birthing people access hospital services, managing miscarriages is increasingly done without admitting patients for a hospital stay. This means that using hospital admissions to infer miscarriage rates can be very misleading.

Progress on reducing pregnancy loss and baby death goes together with other issues in maternal and neonatal services, including worsening maternal mortality rates, quality of services, and families' engagement and satisfaction.

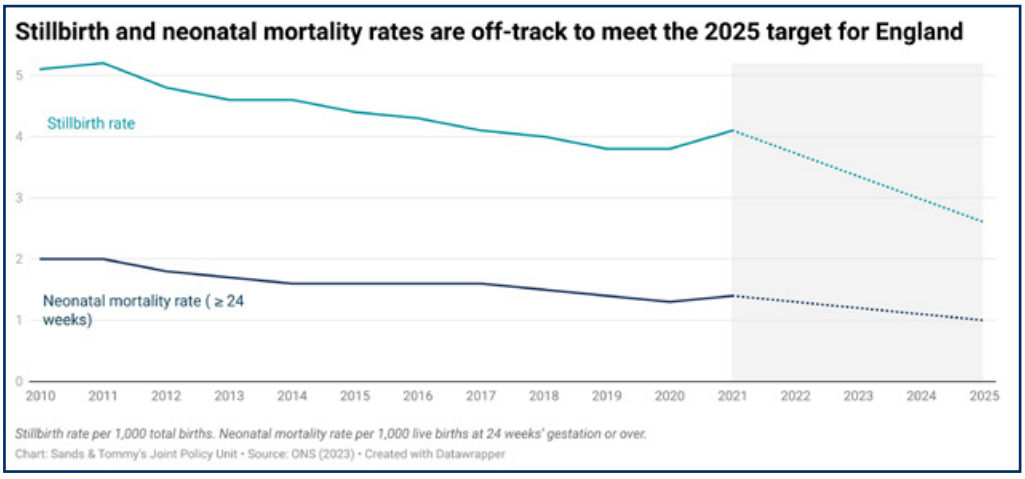


Figure 1. Stillbirth and neonatal mortality rates in England since 2010 and trajectory required to meet 2025 targets

What needs to change

The national maternity safety ambitions in England have been useful for focussing attention and challenging the idea that pregnancy loss and baby deaths are inevitable. However, a much more comprehensive approach is needed to make sure they are achieved, as well as a commitment to renew and grow ambitions beyond 2025. Future ambitions should include a commitment in each of the four nations. Any future targets must have a clear and agreed baseline to measure progress against.

Introducing a robust way to count the number of miscarriages which take place each year is vital to understand the scale of the problem, monitor trends and set meaningful targets for reduction.

3. Factors associated with higher risk for pregnancy loss and baby deaths are complex and changing

There are a range of characteristics which are associated with increased risk of pregnancy loss or the death of a baby. The risk for babies varies according to birth weight, gestational age and whether the baby is a singleton or multiple pregnancy. For women and birthing people, some characteristics including age, health behaviours and existing medical conditions also influence risk. Some risks have become more common as some women and birthing people wait until they are older before trying to conceive. Some existing medical conditions have become more common. Risk of pregnancy loss or the death of a baby is higher for women and birthing people from minoritised ethnic groups and those living in poorer areas (see next section).

As clinical knowledge of the different factors affecting pregnancy and births increases, this has implications for risk assessment, monitoring and care provided. The changing profile of women and birthing people over time and across different areas also impacts the care and resources required.

What needs to change

It is important that health services are set up to provide care and support that are tailored to an individual's needs. Maternity services need to have the capacity and resources to understand the complexity of women and birthing people's lives and provide services which meet their needs, effectively assess, and reduce the impact of risk factors.

Some of these risk factors are modifiable by health services, meaning they can theoretically be changed through additional support, such as stop smoking services. However, correctly predicting risks can be affected by bias from health care professionals. Risks should be contextualised so that women and birthing people feel supported and not stigmatised by health services.

4. Meaningful action is needed to address stark and persistent inequalities by ethnicity and deprivation

Stillbirths, neonatal deaths and preterm births are more common among babies from minoritised ethnic groups. Black, black British babies are over 2 times more likely to be stillborn and over 1.7 times more likely to die during the first 28 days after birth, compared to white babies. Black ethnicity is associated with a 43% higher risk of miscarriage compared to white ethnicity.

Living in a more deprived area is also associated with higher risk of stillbirth and neonatal death.

Stillbirth rates are almost 2 times higher among those living in the most deprived areas, compared to the least deprived. Although data are less complete, current evidence suggests that living in a more deprived area could also be associated with higher risk of preterm births and miscarriages.

Inequalities are persistent and have shown little change over time. In fact, the difference in stillbirth rates between those living in the least and most deprived areas has actually increased since 2010.

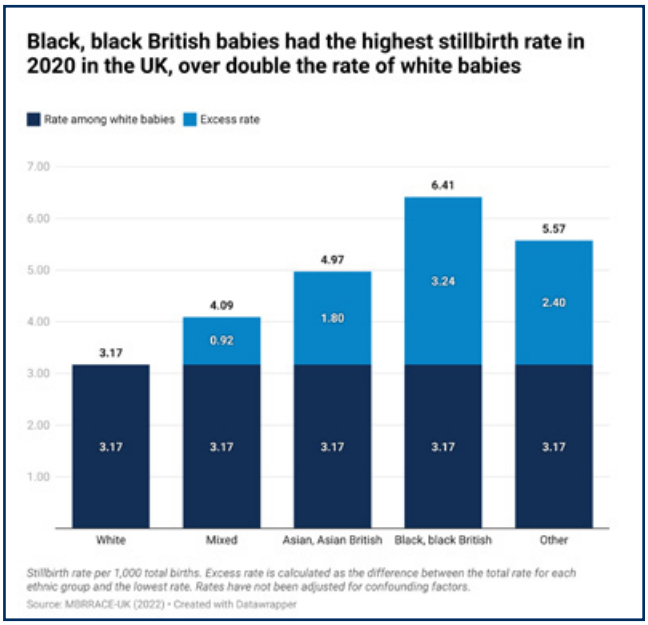


Figure 2. Comparison of stillbirth rates across ethnic groups in the UK in 2020

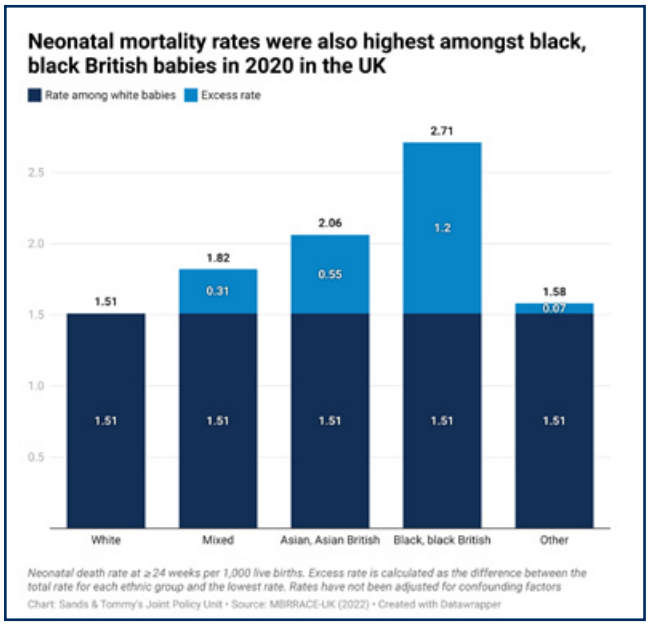


Figure 3. Comparison of neonatal mortality rates across ethnic groups in the UK in 2020

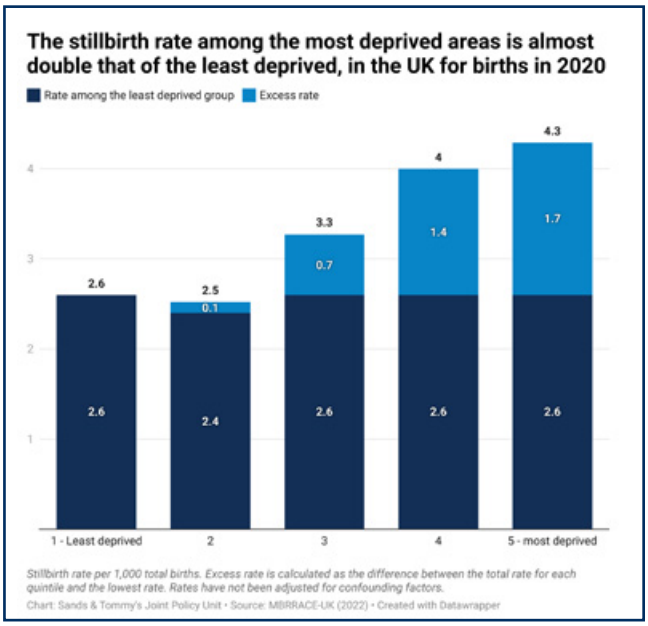


Figure 4. Comparison of stillbirth rates across areas of deprivation in the UK in 2020

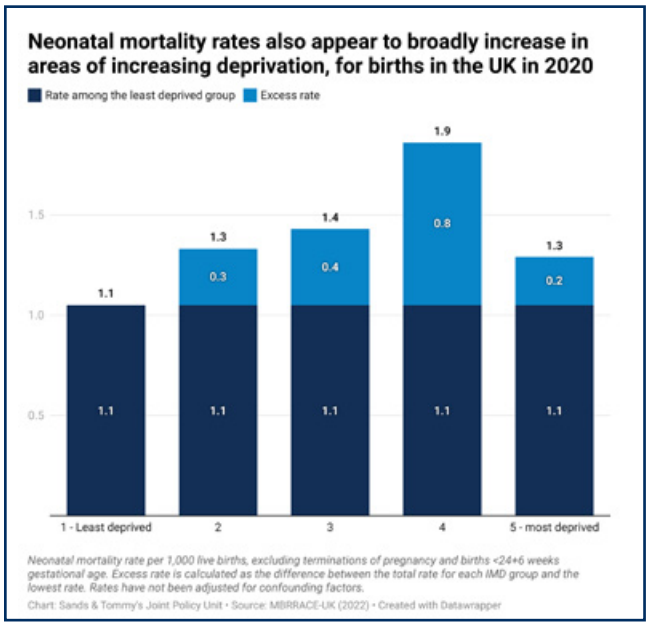


Figure 5. Comparison of neonatal mortality rates across areas of deprivation in the UK in 2020

The drivers of inequalities in pregnancy loss and baby deaths are complex and interrelated. Some ethnic groups are more likely to live in more deprived areas; however, this alone is not sufficient to explain inequalities. Even after adjusting for the level of deprivation, differences in stillbirth rates across ethnic groups remain.

Inequalities in pregnancy outcomes and baby loss have been known about for decades. Explanations include differences in access to and treatment by maternity services, health behaviours, and personal and social contexts. Multiple reports have highlighted the impact of racism and discrimination which some individuals experience when engaging with health services. Drivers of inequalities are explored in more detail in the full report.

Limitations in data and evidence prevent moving beyond diagnosing the problem to taking meaningful actions that will help address inequalities. Much of the national data are based on aggregated ethnic groups or broad categories of deprivation, which provide limited insights into individuals' lives. More detailed data on factors which could affect pregnancies or access to health services, and intersectional analysis to examine the relationship between these factors, could help inform what is driving inequality and identify potential interventions.

There are also no national targets or long-term funding to reduce inequalities between ethnic groups or areas of deprivation. Reducing all rates to the English 2025 target would require much larger reductions among some groups. For example, in England and Wales in 2021, the stillbirth rate for women and birthing people from the black African ethnic group was 7.0 per 1,000 births which would have to reduce by over 60% in four years to meet the 2025 overall population target of 2.6 per 1,000 births.

What needs to change

There needs to be a much stronger commitment, and long-term funding, from government to eliminating inequalities in pregnancy loss and baby deaths. While the problem is well known, understanding of the drivers of inequalities and solutions to overcome them is more limited. Mixed-method and qualitative research is needed to:

- Test theories about what drives inequalities and how these factors intersect.
- Identify solutions which recognise, and are adapted to, the complexity of people's lives, particularly groups who are most affected by pregnancy loss and baby deaths.
- Understand how racism, bias and discrimination operate in the health system and identify ways to change NHS cultures, processes and systems.

The quality and consistency of routine data collection should be improved, and clear metrics agreed against which progress to reduce inequalities can be measured.

5. Systemic issues in maternity and neonatal services need to be addressed

The current scale of pregnancy loss and baby death is not inevitable. Where targets have been set, the NHS is not on course to meet national ambitions to reduce their occurrence. The government and health service must look at systemic issues across maternity and neonatal units and identify areas that will make a difference to these outcomes.

The Joint Policy Unit has reviewed previous reports into maternity and neonatal services to identify key themes from the reports and the impact of current policy initiatives. More detail is provided in the main report, including the list of reports which were reviewed. This analysis will be published later in 2023. The key themes that we identified are:

Staffing levels and training	**Culture of safety within organisations**
Organisational leadership	**Personalisation of care and choice**
Data collection and usage	**Learning from reviews and investigations**
Engagement with service users	**Delivering care in line with best practice**

Ratings of maternity services suggest that safety and quality of services in England are declining, as does survey data of families' experience of care. There are persistent issues around women and birthing people not being listened to. The CQC surveys have shown a downward trend since 2017. Fewer women and birthing people felt that their concerns during labour and birth were taken seriously. Although Covid-19 may have had an impact, longer-term, systemic changes are required to reduce pregnancy losses and baby deaths. The most recent maternity survey showed that satisfaction continued to decline in 2022, after Covid-19 restrictions were eased. These trends are occurring despite several policy initiatives which have been introduced to improve the safety of maternity care in England. Policy initiatives to incentivise, support or assure maternity care are infrequently evaluated for their effectiveness. Where evaluations do take place, they tend to focus on the extent to which services have introduced changes, rather than whether those changes make care safer.

Staffing levels have increased relative to the total number of deliveries between 2009-10 and 2020-21. However, successive reports, research projects and surveys have shown the pressure that staff are under and its impact on the system's ability to deliver personalised care. Staff sickness rates, overtime and job satisfaction, among other metrics, show the impact of staffing shortages on the workforce. In 2021-22, staffing levels relative to total deliveries started to decline, suggesting that current issues may get worse.

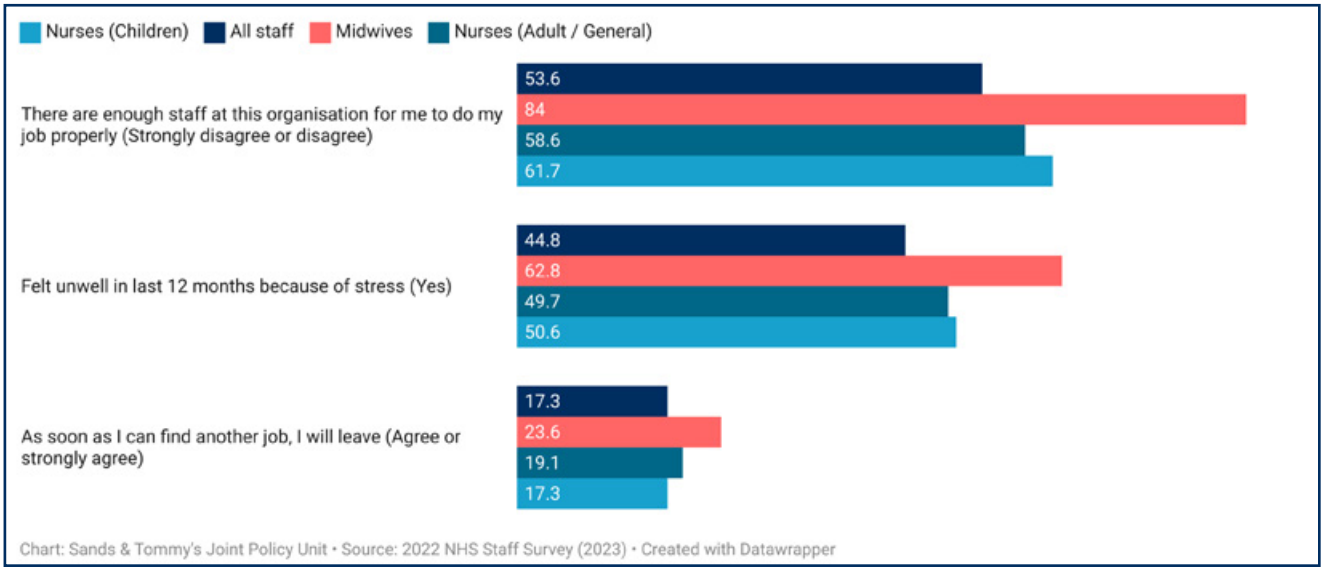


Figure 6. Selection of 2022 NHS Staff Survey responses on staffing pressures

The changing profile of the birthing population has increased the support required during the antenatal and postnatal period. This includes increasing maternal age, complexity of social needs and prevalence of co-morbidities. Interventions in pregnancy have also increased due to better knowledge of reduced fetal movements among other factors, and improved ability to save more extremely preterm babies.

National staffing ratios also conceal differences between units, Trusts and regions, as well as varying staffing levels over the year. Staffing ratios do not recognise the combination of level of experience and skills required to deliver care and manage human resources. Senior staff are needed to provide oversight, leadership and train junior staff, while more junior staff are critical for succession planning. We lack data for critical staffing groups, such as perinatal pathologists or operational staff for maternity and neonatal care, which affect how the whole service is run. Staffing levels and skills mix may also depend on specific policies, such as the introduction of new models of care. A regular review of national staffing ratios is required to ensure sufficient staffing and funding for the population the UK now serves.

Focusing on staffing levels alone can also distract from issues related to staffing dynamics which affect how well units operate. Data from CQC surveys and recent reviews into the safety of maternity and neonatal services highlight the importance of a culture of learning, teamwork and collaboration. Staff are less likely to report issues or challenge poor practice where there is a blame culture and lack of support. Services need to have a long-term commitment to improvement which is informed by families' experiences, routine data, and insights from reviews when things go wrong.

What needs to change

To make the UK the safest place in the world to have a baby, we need a much more comprehensive approach to supporting improvements in maternity and neonatal services. Quality and safety ratings are declining despite the introduction of various initiatives designed to improve safety. It is therefore important to evaluate the impact that current policy approaches are having as well as identifying any barriers to their delivery. This evaluation should be used to inform an evidence-based programme of support to improve care.

In part, this is about adequate staffing and funding. We still lack evidence of the safest and most efficient staffing levels across different types of maternity and neonatal units, or transparency on the total spend across the country against which we can monitor government commitments.

There has been a strong focus on personalisation and choice, but for people to be able to make meaningful decisions about their care there need to be the resources in place to make different options a reality – alongside evidence-based, unbiased advice.

Beyond staffing, there is a need for culture change to ensure openness, learning and transparency. We need to move from diagnosing issues with teamwork and culture to introducing effective interventions to address them. Systems must be in place to share learning locally, regionally and nationally – with clear actions to address concerns raised.

6. Lessons are still not being learnt when babies die

Understanding the cause of stillbirths and neonatal deaths through post-mortems is essential to prevent future deaths. There is a lot we still don't know: in 2021, the cause of 33% of stillbirths and 7% of neonatal deaths were unknown.

In addition to understanding the clinical causes of a death, hospital reviews and external investigations are important to identify where better care could have prevented deaths. Nearly a fifth of stillbirths which were reviewed using the National Perinatal Mortality Review Tool (PMRT) in 2021-22 were found to be potentially avoidable if better care had been provided.

The number of deaths that are classified as potentially avoidable in the PMRT reports has increased over recent years. This may reflect improving quality and thoroughness of these hospital reviews, including through parental engagement, larger and more multi-disciplinary teams with the required time and resources, and involvement of external reviewers. However, there is limited oversight as to whether the findings from the reviews are acted upon. Currently, learnings from the reviews are not integrated into the wider national system for maternity improvement.

> *The review made us feel people care and it wasn't just one of those things.*
>
> Mother of a baby who was stillborn, England, 2019 from Sands 'In their own words' research

> *I wish there had been an initial meeting to discuss what we wanted to be looked at in the review. Just having a letter saying get in touch if you have anything you want to say did not seem like a real opportunity as we weren't really sure what the process was so didn't make contact but face-to-face we would have raised our concerns.*
>
> Mother of a baby who was stillborn, Wales, 2020

What needs to change

When serious incidents occur, it is important to have an independent, standardised method of investigating. But this alone is not enough. As well as providing answers to parents and families, it is vital that the learnings from reviews and investigations are shared and acted upon, to prevent avoidable deaths in the future.

To meet the requirements of the Maternity Incentive Scheme[1], Trusts in England are required to use the Perinatal Mortality Review Tool (PMRT) to review perinatal deaths and create action plans for improvement. Despite an increasing amount of information being collected and reviews carried out, the reviews are not being used effectively enough by the health system to support improvements. In its 2022 report, the PMRT rated 60% of action plans as 'weak' and only 19% as 'strong'. Strong actions are "system level changes which remove the reliance on individuals to choose the correct action. They use standardisation and permanent physical or digital designs to eliminate human error". Sufficient resourcing and leadership commitment are required to deliver thorough reviews and develop strong action plans to improve practice. Alongside this, the PMRT has highlighted the continued need for greater parent engagement in reviews.

Recent investigations into maternity services at Shrewsbury and Telford and East Kent Trusts have highlighted that there is still a way to go in organisations holding themselves to account for the action they are taking to learn from serious incidents. As well as being used at board level, insight from reviews must be used nationally. Currently, information from the PMRT does not feed into a wider national system for improving safety.

1. The scheme supports the delivery of safer maternity care by rewarding Trusts financially if they meet ten safety actions. The safety actions are chosen based on their ability to improve the delivery of best practice in maternity and neonatal services.

7. Too often nationally-agreed standards of care are not being followed which is contributing to avoidable deaths

Too often avoidable losses continue to occur as a result of care that is not in line with recommendations in The National Institute for Health and Care Excellence (NICE) guidance and other nationally agreed standards (such as the Saving Babies' Lives Care Bundle, and British Association of Perinatal Medicine, BAPM guidance). There are a lack of comprehensive data on the implementation of national standards and guidance.

The full report explores how care may vary across different stages of pregnancy and birth. For this summary we have included some examples of systemic issues related to women and birthing people's access to services and the provision of personalised care.

Data for England show 40% of women and birthing people do not attend their first antenatal assessment before 10+0 weeks gestation, as recommended in NICE guidance. When they do attend, time pressures mean that antenatal appointments are shorter and increasingly rushed, leaving midwives unable to provide more than basic care. The 2022 CQC maternity survey found that only 49% of respondents felt that medical professionals always appeared aware of their medical history and nearly a quarter (23%) did not always feel they had enough time to ask questions or discuss their pregnancy.

NICE guidance states that women and birthing people should be able to choose any birth setting, but choice is reliant on the correct assessment and discussion of risk with parents to inform decision-making as well as the availability of staff to deliver all care options. Inappropriate mode and location of birth is frequently identified in reviews following the death of a baby. This includes inappropriate choice, timing and management. Recent investigations of maternity safety in Shrewsbury and Telford, East Kent and Morecambe Bay Trusts found that decisions on mode of delivery were not always based on parents' choice and safe outcomes but on the need to meet NHS England's targets (which have since been discontinued) which penalised Trusts with high caesarean section rates.

Standards of care outlined by the Saving Babies' Lives Care Bundle Version 2 and BAPM guidance for managing preterm births are not universally adhered to, including ensuring that women and birthing people at risk of preterm labour at less than 27 weeks of pregnancy are transferred to maternity units with a co-located neonatal intensive care unit (NICU).

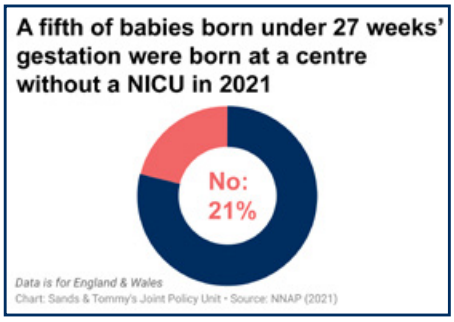


Figure 7. Percentage of babies born under 27 weeks' gestation in a hospital without a NICU.

In England and Wales, one in five preterm babies were born in a hospital without a NICU. Bliss has highlighted that the impact of staff shortages may delay the transfer of pregnant women and birthing people until after birth, which can lead to poorer outcomes and increase the likelihood of separation of babies and parents.

The Twins Trust reviewed NICE antenatal guidelines for multiple pregnancies in 2018. This research found that increased adherence to NICE guidelines was linked to a decrease in neonatal deaths for multiples in one unit within 12 months. There was also strong evidence that over a longer period, implementing the NICE standards in all maternity units could lead to a considerable fall in stillbirth rates.

What needs to change

Variation in standards of care have been highlighted in previous reviews of maternity services, which have emphasised the need to provide timely and responsive care in line with national guidelines. NHS England's three-year delivery plan for maternity and neonatal services includes a commitment to keeping best practice up to date

There must be a national policy focus on supporting services to implement guidance effectively. NHS England has committed to integrating clinical tools (for example national maternity early warning score (MEWS) and the updated newborn early warning trigger and track (NEWTT-2)) into existing digital maternity information systems. Collecting meaningful, standardised data can help services to identify where improvements to care are needed. Support for services may also include reducing the volume of guidance, identifying any areas of conflict and evaluating its impact.

Adequate resources must be put in place to ensure everyone can access best practice care. This includes sufficient staffing levels to allow health care professionals to listen to and build relationships with women and birthing people.

8. Research and evaluation are vital for improving outcomes in the future

Research is key to improving outcomes and saving more babies' lives in the future, yet relatively little is invested in pregnancy-related research. For every £1 spent on maternity care in the NHS, only 1p is spent on pregnancy research.

Most research funding has focused on discovery research, clinical trials and observational research, which are all critical for understanding causes of pregnancy and baby loss and investigating solutions to reduce their occurrence. However, other areas receive significantly less funding including social science, economic analysis and policy research, which are critical to evaluating existing interventions.

There is evidence that health services are not delivering care in line with nationally-agreed standards. A better understanding is needed of the extent to which guidelines are followed and of the barriers which prevent services from implementing them fully. Where guidelines have been fully implemented, evaluation of their effectiveness is needed to help services to prioritise the most impactful changes.

What needs to change

To achieve the ambition to halve rates of stillbirths, maternal deaths, neonatal deaths and serious brain injury by 2025, and to reduce inequalities, policymakers need to make much greater commitments to research. More research is needed to understand what is causing pregnancy losses and baby deaths, to identify interventions, and to evaluate existing programmes. This must include engagement with bereaved parents and communities at risk of the worst maternal and neonatal outcomes.

We need policies which encourage the midwifery and neonatal workforce to engage with and lead research and find approaches which meet the needs of both families and health care professionals.

A range of research is needed from identifying medical and clinical innovations to translating findings into practice. Improving the translation of research into practice will encourage more health care professionals to engage with and participate in research.