

# Saving Babies' Lives 2023: A report on progress



Working together to save babies' lives

May 2023

### Foreword

#### Behind every statistic in this report is a real and tragic story of loss.

At Sands and Tommy's we share a common belief that pregnancy loss and the death of a baby are not inevitable. It is possible to save more babies' lives and make sure fewer people suffer the heartbreak of losing a baby. Sadly, this report reveals that there is still much work to be done.

We are proud to have come together to form a Joint Policy Unit. Through our collective voice we want to make sure that pregnancy loss and baby death stay high on the political agenda. That they are treated as the urgent priorities we know they deserve to be.

This first report from the Unit brings together a range of evidence to identify the key changes needed to save more babies' lives and reduce inequalities in pregnancy and baby loss. None of the individual data it contains is new, but it gives decision makers a clear view of where we are now, and where action is required to make progress.

We recognise that raising awareness alone is not enough. That we need to go beyond highlighting the problem. This is not a one-off report - we will continue to provide independent oversight of progress, and are committed to working constructively with government and policymakers to secure change that will save more babies' lives in the future.



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# Glossary of key terms and terminology

- Birth: a baby born live at any gestational age or a stillbirth. Live birth refers only to babies born alive and excludes stillbirths.
- Ethnicity is a form of collective social identity which encompasses elements of physical features (such as skin colour and hair texture), language, culture, shared history and common ancestry. It is socially constructed and dynamic; identities and meanings are shaped by ethnic groups' own members and wider society. Data on ethnicity is based on self-declaration by adults and for children under the age of 12 guidance from the child's parent, guardian or carer. This report refers to ethnicity not race, in line with the language used during data collection and reporting. We do not use collective terms such as black, Asian and minority ethnic (BAME) which emphasise certain groups and exclude others, while also masking differences between groups. Where it is necessary to refer to broad categories to describe inequalities, we refer to 'minoritised ethnic groups' to recognise that individuals have been minoritised through social processes of power rather than existing in distinct statistical minorities.
- Deliveries the total number of distinct women, or birthing people, and pregnancies, with one or more babies born in the period. Total deliveries is different from total births, which specifies the number of babies which were born in a given time period.
- Deprivation the term commonly used by the government and the NHS to describe a lack of income and other resources, which can also be referred to as socio-economic status. People may be considered to be living in poverty if they lack financial resources to meet their needs. Deprivation is a wider measure which goes beyond income to consider employment, health, education and skills, crime, housing and living environment. Deprivation is measured on a relative rather than absolute scale. We refer to people living in areas of high or low deprivation or within certain deprivation quintiles or deciles as deprivation is based on geographical area and not individual circumstances.
- Maternal mortality death while pregnant or within 42 days of the end of pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes. In this report, we present the maternal mortality rate per 100,000 maternities. Direct maternal mortality are deaths related to obstetric complications during pregnancy, labour or postnatally (up to 42 days). Indirect deaths are deaths resulting from existing disease of health conditions, or disease/health conditions which developed during pregnancy, the effect of which were aggravated by pregnancy. Late maternal mortality includes deaths after 42 days and less than 1 year after the end of the pregnancy.
- Maternities Maternities are pregnancies resulting in the birth of 1 or more children, including stillbirths. Some Trusts record maternities as the number of women and birthing people with booking appointments for antenatal care. The precise definition is specified throughout this document to reflect the underlying data.

- Miscarriage Pregnancy loss before 24 completed weeks of pregnancy is legally known as a miscarriage. A miscarriage which occurs between 13 and 24 weeks of pregnancy is termed a late miscarriage, second trimester baby loss or a late fetal loss. It is important to note that some parents find this term upsetting as it does not acknowledge that their baby existed<sup>1</sup>. Other parents will use the term miscarriage freely. Within this report we have used the legal definition and terminology because there is no legal registration of a birth or death for a baby born showing no signs of life before 24 completed weeks of pregnancy. We make the case for better data to understand the extent of miscarriage.
- Neonatal mortality / neonatal death the death of a live born baby in the first 28 days of life. Usually expressed as the neonatal mortality rate per 1,000 live births. Early neonatal mortality refers to death before 7 days and late neonatal mortality refers to deaths between 7 and 28 days old.
- Perinatal describes the period surrounding birth, usually from about 24 weeks of pregnancy up to either 7 or 28 days of life.
- Perinatal mortality / perinatal death perinatal mortality includes both stillbirths and early neonatal deaths. The perinatal mortality rate is calculated per 1,000 total births. Extended perinatal mortality includes late neonatal mortality up to 28 days.
- Preterm birth any birth before 37 weeks of pregnancy.
   Preterm births can be further broken down according to gestational age:
  - Extremely preterm (less than 28 weeks)
  - Very preterm (28 to 32 weeks)
  - Moderate to late preterm (32 to 37 weeks).
- Pregnancy loss and baby death this report uses pregnancy loss and baby death to refer to a range of types of losses. Where relevant, we have focused on particular types of loss where data are available particularly, stillbirth and neonatal death. We recognise that this does not encompass all types of loss which include ectopic pregnancies and terminations for medical reasons (TMFR). However, we also use the broader term of pregnancy loss and baby death when discussing systemic issues, such as health inequalities and the health system, which are relevant to all types of pregnancy loss.
- Rate an amount of something measured per unit of something else. Where its occurrence is relatively rare the rate may be expressed per 1,000 or even 100,000 of the denominator. For example, the stillbirth rate is the number of stillbirths divided by the total number of births (live births + stillbirths) during a given period (usually per year). In 2020, the stillbirth rate in the UK was 3.3 per 1,000 total births meaning that out of 1,000 births, 3.3<sup>a</sup> sadly resulted in a stillbirth.
- Stillbirth the death of a baby after 24 weeks of pregnancy before or during birth. Usually expressed as the stillbirth rate per 1,000 total births (live births + stillbirths). Antepartum stillbirths are those which occur prior to labour, while intrapartum stillbirth is when a baby was thought to be alive at the start of labour but was born with no signs of life.

a. This is a mathematical calculation but a practical improbability.

# Common acronyms

•	APPG	All-Party Parliamentary Group
•	BAPM	British Association of Perinatal Medicine
•	BMI	Body Mass Index
•	CODAC	Cause of Death and Associated Conditions
•	CQC	Care Quality Commission
•	CTG	cardiotocograph
•	DHCW	Digital Health and Care Wales
•	FTE	Full-time equivalent
•	GIRFT	Getting It Right First Time
•	HEE	Health Education England
•	HES	Hospital Episode Statistics
•	IMD	Indices of Multiple Deprivation
•	LGBT+	Lesbian, gay, bisexual, transgender / transexual plus other identities
•	LNU	Local Neonatal Units
•	LSOA	Lower-layer Super Output Areas
•	MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
•	NICE	National Institute for Health and Care Excellence
•	NICU	Neonatal Intensive Care Unit
•	NCMD	National Child Mortality Database
•	NHS	National Health Service
•	NIHR	National Institute for Health and Care Research
•	NISRA	The Northern Ireland Statistics and Research Agency
•	NMC	The Nursing and Midwifery Council
•	NMPA	National Maternity and Perinatal Audit
•	NNAP	National Neonatal Audit Programme
•	NPEU	National Perinatal Epidemiology Unit
•	NRS	National Records of Scotland
•	ONS	Office for National Statistics
•	PMRT	Perinatal Mortality Review Tool
•		Qualification Compile
	QIS	Qualified in Service
•	QIS RCM	Royal College of Midwives

TMFR Termination for Medical Reasons



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

#### Sands and Tommy's Joint Policy Unit

In 2022 the charities Sands and Tommy's came together to form a Joint Policy Unit. Together we are focussed on achieving policy change that will save more babies' lives during pregnancy and the neonatal period and on tackling inequalities in loss, so that everyone can benefit from the best possible outcomes.

This report brings together data on pregnancy and baby loss across the UK. It highlights key trends to allow us to assess progress to save more babies' lives throughout pregnancy and the neonatal period. As well as these headline figures it takes a more detailed look at some of the wider factors relevant to achieving our vision of a future where fewer babies die, and inequalities in baby loss are eliminated so that everyone can benefit from the best possible outcomes. By bringing together existing evidence on the state of maternity and neonatal services, we will draw attention to gaps in the evidence and set out areas where further work is required to reduce rates of miscarriage, stillbirth, preterm birth and neonatal death.

In recent decades there has been a downward trend in rates of pregnancy and baby loss throughout the UK. However, this overall picture masks important nuances. In some parts of the UK outcomes have improved little over the last decade. There are stark and persistent inequalities in outcomes by ethnicity and deprivation. Most recent data also paints a concerning picture – with progress to reduce rates of death slowing or reversing and experiences of care deteriorating.

Through this report, we hope to ensure that saving babies' lives and reducing inequalities in loss are the national policy priorities they deserve to be. Losing a baby throughout pregnancy or shortly after birth is not just 'one of those things' – not a sad inevitability that must be accepted. This report highlights that in many instances improvements in care could have prevented the death of a baby. There remains a significant gap between the UK and those countries with the best pregnancy outcomes, suggesting a further reduction in mortality rates is possible. Through a greater focus on research and innovation, more deaths can be avoided in the future.

This is the first in a series of progress reports from the Sands and Tommy's Joint Policy Unit. We will use it as a tool to drive change. The report is aimed at policy makers from government and the NHS, charities, and professional bodies. Through the series, we will monitor progress and report on the work that we are doing, to support policy change that will save more babies' lives and help tackle inequalities.

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<sup>2</sup>

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<sup>3</sup>



 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

#### **Chapter Summary**

- In 2021, 13 babies a day were stillborn or died during the first 28 days of life across the UK<sup>4</sup>. Comparisons with other European countries suggest that the UK could do better.
- Improvements are possible, as shown by the long-term progress in reducing rates of stillbirth and neonatal death. However, more recently this progress has stalled, we are not on track to meet national ambitions, and we risk going backwards.
- There has been relatively little progress on reducing the preterm birth rate across the UK. Reducing the number of preterm babies is important to reduce stillbirth and neonatal deaths; in 2020 almost three-quarters of stillbirths and neonatal deaths were among babies born prematurely in the UK.
- The overall perinatal mortality rate does not include miscarriages and miscarriage rates are not reported at the UK-level or by any individual nation. The lack of systematic counting and reporting of miscarriages conceals the full picture of pregnancy loss across the UK. Although we do not have precise figures, we know that miscarriage affects many people.
- Progress on reducing pregnancy loss and baby death goes hand-in-hand with other issues in maternal and neonatal services, including worsening maternal mortality rates, quality and safety of services, and families' engagement and satisfaction.

#### 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.

# Rates of stillbirth, neonatal and perinatal mortality across the UK

The UK perinatal surveillance programme conducted by MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK) publishes data on perinatal mortality for Trusts and Health Boards. Between 2013 and 2020 there was an overall downward trajectory in perinatal mortality in the UK.

MBRRACE-UK reports hospital data from 2013 onwards and combines mortality data with information on the baby and mother's characteristics and cause of death to enable richer analysis. However, the additional information requires more time to prepare so data is reported later. The latest MBRRACE-UK data available at the time of publication was from 2020<sup>5</sup>.

To analyse more recent trends as well as differences across the four nations of the UK, this report also uses data from the Office for National Statistics (ONS) for England and Wales, the Northern Ireland Statistics and Research Agency (NISRA), and National Records of Scotland (NRS) between 2010 and 2021. Using data from the four nations allows us to examine data from a longer time period and differences between the nations in the rate of deaths and efforts to reduce them.

#### Stillbirth, neonatal and extended perinatal mortality rates declined in the UK between 2013 and 2020

- Stillbirths - Neonatal deaths - Extended perinatal mortality rate





#### **Rates of stillbirth**

While at the UK-level the rate of stillbirths has declined overall over the last decade, there has been variable progress across the four nations of the UK (see Figure 2). Stillbirths have declined steadily in England since 2010, although there was an increase in the most recent data for 2021. Annual stillbirth rates in Northern Ireland, Wales and Scotland are more variable year-on-year, which is likely to reflect their smaller population sizes which means that a slight change in stillbirth numbers will have a greater effect on the overall rate. Despite this volatility, we can see that early progress in Scotland between 2011 and 2015 has slowed. The stillbirth rate has been highest in Wales since 2014, where it has remained over 4.4 per 1,000 births between 2010 and 2016.

The stillbirth rate in Northern Ireland has remained at a similar level overall, although it has the highest volatility year-on-year (linked to its small population size).





In England the government has set an ambition to halve rates of stillbirth by 2025 relative to 2010 rates (see Fig. 3). This equates to 2.6 per 1,000 births. An interim target of a 20% reduction by 2020 (4.1 per 1,000 births) was exceeded with a 25% reduction (3.8 stillbirths per 1,000 births) in 2020. However, stillbirth rates in 2021 increased back up to 4.1 per 1,000 births. This increase could be linked to the impact of the Covid-19 pandemic; however, the data are not clear. Future data will provide an indication as to whether 2021 was an anomaly in the downward trend, or whether progress has stalled. The impact of the pandemic on pregnancy and baby loss is discussed further on p.12.

Much more rapid progress is required if the government is going to meet this ambition. In its 2021 Safer Maternity Care progress report NHS England stated that it anticipated that the pace of reducing the rate of stillbirth will increase as interventions continue to embed<sup>6</sup>. An alternative view, however, is that reduction could stagnate after interventions achieve initial progress, further reductions may require more intractable issues to be addressed.

None of the other UK nations are currently working towards targets, against which we can track progress.





#### Neonatal mortality rates

Like the stillbirth rate, there is high year-on-year volatility in the data for Northern Ireland, Wales and Scotland due to the smaller population size (see Fig. 4). The neonatal mortality rates in Northern Ireland and Wales have remained broadly similar between 2010 and 2021, albeit with annual variations. In Scotland, rates of neonatal death in 2021 were nearly 8% higher than they were in 2010. This is largely driven by a substantial increase between 2020 and 2021, which is subject to an ongoing review by Healthcare Improvement Scotland. The neonatal mortality rate at 24 weeks gestation and over has shown a steady decline in England between 2010 and 2020 (a 35% reduction overall), although the rate increased again in 2021. Higher neonatal mortality rates in Northern Ireland could be influenced by laws governing termination of pregnancies.





The neonatal mortality rates in Figure 4 are limited to births at 24 weeks' gestation and over, and do not include babies born before 24 weeks. There has been less progress to reduce the neonatal mortality rate across all gestational ages in England. The neonatal mortality rate for all gestational ages was 2.7 per 1,000 live births in 2021 – 10% lower than in 2010, but higher than in 2014 (2.5 per 1,000). We are not currently on track to meet the government's original target of a 50% reduction in neonatal deaths across all gestational ages, which would equate to 1.5 per 1,000 live births by 2025. In 2021 the ambition was revised to 1.0 neonatal deaths per 1,000 live births among babies born at 24 weeks or over. Rates of neonatal death using this revised measure increased in 2021 to 1.4 per 1,000 live births, compared to 1.3 in 2020.



#### Figure 5. Neonatal mortality rate forecast scenarios for births over 24 weeks and all gestational ages.

Assuming current birth rates, if the neonatal mortality rate among babes born at 24 weeks and above declined each year towards the 2025 target, there would be approximately 600 fewer deaths between 2022 – 2025, compared to if rates remained at current levels. If the original target for reducing all neonatal deaths by 50% by 2025 was achieved there would be over 1,700 fewer deaths between 2022-2025.

The target was changed to reflect the fact that more extremely preterm babies are being classified as live births, whereas previously they may have been classified as late fetal losses. Recognising a live birth relies on health care professionals identifying signs of life (including heartbeat, breathing and movements). Due to the low number of births which occur before 24 weeks, health care professionals may be involved in few such births and may struggle to distinguish between true signs of life and brief reflex activity that can occur after deaths<sup>7</sup>. There may also be variations in policies across organisations which creates variation in identification of live births. MBRRACE-UK developed guidance and resources in 2020 to address issues related to the assessment and documentation of signs of life and reduce variability across organisations, although this will not correct historic variability.

#### **Rates of preterm birth**

There has been relatively little progress on reducing preterm birth rates across the UK. The total proportion of births that were preterm (born before 37 weeks of pregnancy) was 7.8% in 2020, down from 8.3% in 2017. Preterm birth rates in the UK are higher than the average of 6.9% in Europe<sup>8</sup>.



Figure 6. Proportion of preterm babies according to gestational age at birth, between 2016 and 2020 in the UK

In England, the government is not on track to meet its ambition to reduce the preterm birth rate to below 6% by 2025 – the rate has remained between 7 and 8% since 2010 (see Fig.7). Although the proportion of preterm births decreased between 2018 and 2020, it started to increase again in the latest data (7.6% in 2021).

#### The proportion of babies born preterm started to increase again in 2021 in England



Figure 7. Proportion of preterm babies according to gestational age at birth, between 2010 and 2021 in England

Reducing the number of preterm births is important to reduce stillbirth and neonatal deaths. In 2020, almost three-quarters of stillbirths and neonatal deaths were among babies born prematurely in the UK (73% and 71% respectively).

#### Neonatal mortality rate decreases with increasing gestational age at birth

Total live births and neonatal deaths according to gestational age in England between 2010 and 2021

Gestational age at birth	Live births	Neonatal deaths	% of live births	Neonatal mortality rate	% survival rate			
Under 24+0 weeks	9,160	7,588	0.12%	828.38	17.16%			
24+0 - 27+6 weeks	25,497	3,942	0.33%	154.61	84.54%			
28+0 - 31+6 weeks	61,038	1,821	0.79%	29.83	97.02%			
32+0 - 36+6 weeks	489,304	2,425	6.30%	4.96	99.50%			
37+0 weeks and over	7,152,545	4,486	92.02%	0.63	99.94%			
Total	7,772,495	21,424	100.00%	2.76	99.72%			
Table: Sands & Tommy's Joint Policy Unit • Source: ONS (2023) • Created with Datawrapper								

 Table 1.
 Number of live births, neonatal deaths, and survival rates across gestational age at birth in England

The neonatal mortality rate for babies born before 24 gestational weeks was 844.87 per 1,000 live births based on data for England between 2010 and 2021. The neonatal mortality rate is substantially lower for babies born between 24 and 27 weeks (219.71 per 1,000 live births) and continues to decline with increasing gestational age.

Since 2010 survival rates have improved for preterm babies (see Fig.8). Advances in perinatal care have led to steadily improving outcomes for babies admitted to neonatal intensive care units (NICU) in the UK<sup>9</sup>.

Survival rate has increased amongst babies born after 24 weeks gestation in England, but has fluctuated for those born before 24 weeks





#### Figure 8. Survival rates for preterm babies in England between 2010 and 2021, according to gestational age.

As well as changes to clinical management over time, there has been variation in clinical practice regarding the classification of live births or late fetal losses. As previously mentioned, ONS stated that the increase in the proportion of live births before 24 weeks completed gestation has contributed to an increase in the neonatal mortality rate from 2.5 deaths per 1,000 live births in 2014 to 2.8 in 2019<sup>10</sup>. However, Figure 9 shows that while there is a correlation between total live births before 24 weeks and neonatal deaths in babies born before 24 weeks, the correlation with the overall neonatal death rate (shown by the dotted line) is less clear. This suggests there may be further reasons for the lack of progress on reducing the neonatal mortality rate for all gestational ages.



Figure 9. Number of live births and neonatal deaths for babies born before 24 weeks' gestation compared to the total neonatal mortality rate

#### Impact of Covid-19 pandemic on pregnancy and baby loss



There was an increase in rates of stillbirth in England and Wales in 2021, and an increase in neonatal mortality in Scotland over the same time period. It is not clear the extent to which the direct and indirect impacts of Covid-19 may have contributed to these increases. We know that the pandemic had a significant impact on maternity and neonatal services, and also that Covid-19 can lead to adverse pregnancy outcomes. Covid-19 infection is associated with higher likelihood of preterm birth<sup>11</sup>, and may be associated with increased incidence of Small for Gestational Age babies<sup>12</sup>. Covid-19 infection has also been associated with higher risk of stillbirth and neonatal death<sup>13</sup> The Covid-19 in Pregnancy in Scotland (COPS) observational study used health records of all women in Scotland who were pregnant on or after 1 January 2015 to investigate links between Covid-19 infection, Covid-19 vaccines and early pregnancy complications. The study, which included pregnancies between September 2021 and January 2022 and pre-pandemic data, found no evidence of higher miscarriage risk following vaccination of Covid-19 infection.

The risk of severe pregnancy complications may also differ between variants of Covid-19. The Covid-19 in Pregnancy in Scotland study<sup>14</sup> compared preterm births, stillbirths, neonatal deaths and neonatal infection rates during the Delta and Omicron waves of the pandemic. The study found that the Omicron wave (which became the most common variant in Scotland from 15 December 2021) was not as strongly associated with Covid-19 pregnancy complications and adverse outcomes as the Delta variant (which was the most common variant in Scotland from 17 May to 14 December 2021).

There were also significant changes to the way maternity and neonatal services were delivered and accessed during the pandemic, including an increase in telephone or virtual engagement with women and birthing people, and restrictions on birth partners attending appointments. Attending services alone, particularly for those with previous experience of pregnancy loss, was an isolating experience for many<sup>15</sup>.

"My pregnancy was a high risk pregnancy and I did not know when I was going to go into labour or even if my baby was going to survive. I had weekly appointments which my partner couldn't attend due to COVID, and each week was nerve wracking as we were having scans to check for a heart beat, so this was very distressing having to go alone" Respondent to NPEU survey<sup>16</sup>

There are advantages and disadvantages to remote care and while some more transactional elements of antenatal care may be suited to remote delivery, it can create barriers to developing trusting relationships<sup>17</sup>. The NPEU survey found that using technology enabled care was viewed less favourably by parents compared to face-to-face and made it harder to establish rapport with staff. Disadvantaged women and birthing people may also have been at greater risk of exclusion due to Covid-19 restrictions, particularly digital exclusion due to the increased reliance on technology for the delivery of care. Evidence from neonatal units suggests that restrictions on parents' access had a detrimental effect on their involvement in their baby's care, their bonding as a family, and parents' mental health<sup>18</sup>.

While the impact of the pandemic on pregnancy outcomes may only become clearer with time and analysis of long-term trends, it is important to note that prior to 2020 we were not making fast enough progress to reach the target in England of reducing stillbirths by 50% by 2025.

#### **Rates of extended perinatal mortality**

Looking at rates of extended perinatal mortality (which includes stillbirths and neonatal deaths) provides a picture of overall progress. Because stillbirth and neonatal deaths are still relatively rare occurrences it also provides a larger sample to review progress over time.

#### While extended perinatal mortality rates have decreased since 2010, rates increased across all nations between 2020 and 2021



#### Figure 10. Extended perinatal mortality rates across England, Northern Ireland, Scotland and Wales between 2010 and 2021.

Between 2010 and 2021 there was a 17.2% decrease in perinatal mortality rate in Scotland. While rates in Scotland decreased sharply between 2010 and 2013, they plateaued between 2013-17 and since 2019 have increased. Since 2013 Northern Ireland has consistently had the highest rate of perinatal mortality in the UK and rates for 2021 were the highest since 2013. In England there was a consistent decline in extended perinatal mortality between 2010 and 2020, a reduction of over 28.7%. However, the extended perinatal mortality rate increased again in 2021. As a result the rate has declined 23.5% since 2010. In Wales, the perinatal mortality rate declined 17.3% during this period, although it has fluctuated year-on-year. Stillbirths were the largest contributor to extended perinatal mortality in the UK over the past 5 years – with some differences across the four nations. Early neonatal mortality contributes a larger proportion of the overall extended perinatal mortality in Northern Ireland, which may be linked to the restrictions on abortion in Northern Ireland.

#### Stillbirth is the largest contributor to extended perinatal mortality across the UK over the last 5 years



#### Figure 11. Stillbirths, early neonatal deaths and late neonatal deaths as a proportion of extended perinatal mortality across UK nations.

# Rates of stillbirth and neonatal death – comparison with other European countries

Although international comparisons can be useful to benchmark the UK's progress and to see what is possible elsewhere, comparing progress on reducing stillbirths and neonatal deaths internationally is challenging as we need to recognise the differences in the populations between countries, the health care systems and policies related to pregnancy and maternity care. Countries also vary in the timing of screening for congenital conditions and legislation regarding the gestational age limit for terminations of pregnancy, both of which may affect stillbirth and neonatal mortality rates. Even the indicators themselves vary between countries – which use different thresholds for birth weight and/or gestational age for reporting stillbirths and neonatal deaths. Such national differences in data collection and analysis are a key barrier to meaningful international comparison. Despite these limitations, international comparisons show that it is possible for the UK to continue to reduce perinatal mortality rates.

Euro-Peristat compiles national data on stillbirth and neonatal rates across Europe using common definitions<sup>19</sup>. Map 1 shows comparable data for stillbirths at or after 24 weeks of gestation in 2019. The UK, Sweden, Germany, Iceland and Spain were all within 10% of the median stillbirth rate (3.2 per 1,000 total births) in 2019, although performance was worse than in Norway, Denmark, Finland, Estonia, Italy and Slovenia. Four countries reported stillbirth rates which were below England's 2025 target of 2.6 per 1,000 total births: Denmark (2.2), Finland (2.4), Norway (2.5), and Slovenia (2.0), showing that it is possible for this target to be achieved. In 2019 UK (3.3) performed slightly better than France (3.6) and Germany (3.4) which have comparably large populations.

While 25 countries provided data on neonatal deaths, many - including France and Germany - do not routinely link mortality data with birth data while Ireland only reports early neonatal deaths. Data for these countries are excluded from Euro-Peristat analysis and are shown as grey in Map 2. Due to national differences in criteria for birth registration, what is recorded as neonatal or fetal deaths, and policies and practices of active management for births at 22 or 23 weeks means that comparisons for extremely preterm births are complicated. Euro-Peristat present neonatal mortality rates for births at or after 24 weeks' gestation.

Rates of neonatal death are highest in several eastern European countries, including Lithuania, Hungary and Croatia, as well as Belgium and the Netherlands. In some countries, restrictions on terminations of pregnancy may influence higher neonatal mortality rates such as in Malta (3.8) and Poland (2.2), due to deaths from fatal congenital conditions. Malta, where termination of pregnancy is illegal, has the highest proportion of neonatal deaths attributed to congenital anomalies<sup>20</sup>. The UK neonatal mortality rate (1.7) is average for those European countries where data are available, but underperforms compared to Scandinavian countries and Estonia, Slovenia, Austria, Czech Republic and Switzerland.



Map 1. 2019 stillbirth rate across European countries, compared to the European average rate.



Map 2. 2019 neonatal death rates across European countries, compared to the European average rate

#### Gaps in the recording of miscarriages across the UK

Unlike stillbirths and neonatal deaths, the total number of miscarriages and miscarriage rates are not reported at the UKlevel or by any individual nation. Partial figures are published by some UK nations on miscarriages which result in a hospital stay (see Appendix 1). However, this is not a comprehensive view of the incidence of miscarriages, particularly as health services have become better at managing miscarriages in the outpatient setting, reducing inpatient treatment. This means that using hospital admissions to infer miscarriage rates can be very misleading.

#### Estimating miscarriage risk

Instead, we are reliant on different methods to estimate the total number of miscarriages. A systematic review<sup>21</sup> of nine large cohort studies in Europe and North America found a pooled miscarriage risk of 15.3% (with a 95% confidence interval between 12.5% - 18.7%) of all recognised pregnancies. Using NHS England data on total deliveries<sup>b</sup> and the pooled miscarriage risk of 15.3%, we estimate that there may have been over 100,000 miscarriages in England during 2021-22, although this may have been as high as 133,00 miscarriages based on the upper confidence interval.

This estimate is over three times higher than the number of miscarriages which resulted in a hospital stay reported by NHS England during 2021-22 (See Fig.12). This shows the inadequacy of the current data to understand the incidence of miscarriage.

#### The number of miscarriages resulting in a hospital stay in England 2021-22 was less than a third of estimated miscarriages



Total miscarriages are estimated using pooled miscarriage risk of 15.3% (95% confidence interval of 12.5% - 18.7%)

Chart: Sands & Tommy's Joint Policy Unit • Source: Hospital Episode Statistics (2022) • Created with Datawrapper

#### Figure 12. Estimated number of miscarriages in the UK in 2021

However, it is also reasonable to assume that the pooled miscarriage risk under-estimates the true extent of miscarriages in the UK. The pooled miscarriage risk of 15.3% is based on clinically recognised pregnancies but does not include pregnancies which were unknown at the time of miscarriage. The underlying studies also used a range of methodologies to measure miscarriages. Some studies used self-reporting while others relied on miscarriages which resulted in hospital treatment, which may underestimate true risk.

The data also covered a wide time period, between the 1970s and early 2010s, with a lack of recent data available. This may fail to capture changes in miscarriage rates due to improvements in pregnancy information – which may have led to a reduction in the miscarriage rate over time – or demographic changes, including increasing maternal  $age^{22}$  – which could have increased the miscarriage rate over time.

#### **Recording miscarriages**

Different methods can be used to estimate the number of miscarriages in the UK and while the exact numbers may vary, they point to the scale of the problem and the need for better data. Having a robust mechanism to count the number of miscarriages which take place is extremely important. Without this, we cannot fully understand the scale of the problem nationally or know whether levels of loss are increasing or decreasing. It also means that we are not able to set meaningful targets for reduction or know whether preventative interventions are having the desired effect. The lack of recording is also a source of considerable distress for parents, for whom the loss of a baby is a significant event<sup>23</sup>. Finally, recording miscarriages may be important for women and birthing people's own medical records, as a history of miscarriage or recurrent miscarriage is associated with higher risk of coronary heart disease<sup>24</sup>.

Following the publication of Tommy's research on miscarriage in the Lancet in 2021, there has been a call for all miscarriages to be recorded so that the rate of miscarriage can be accurately measured nationally. Data on the number of miscarriages should be made available so they can be viewed alongside data releases on stillbirth and pre-term birth rates.

When a miscarriage takes place, GP surgeries, Early Pregnancy Units and Accident and Emergency Units will routinely record this in some form on individual patient records. However, there is no standardised approach to doing this, and neither is there a process to bring together the data collected centrally.

As a first step, there is a role for the NHS to standardise and bring together existing records of miscarriage from across the key healthcare settings where pregnant women present. This could be achieved by coding individual healthcare records and then bringing the data together in the annual maternity statistics release. This would be a technological solution which would provide accurate, anonymised and consistent data on pregnancy loss which could be tracked year-on-year to establish trends. In this way, there would be no requirement on bereaved parents to formally register a loss, as is the process in the case of stillbirths. Once this process has been put in place, further consideration should then be given to practical ways in which losses which take place in the community can also be recorded and counted.

The Scottish government committed to take forward specific recommendations from the Miscarriage Matters Lancet series by the end of 2023. The UK government is considering the recommendations and more detail may be provided when the government responds to the Independent Pregnancy Loss Review<sup>c</sup> once it is published.

b. Total deliveries is assumed to represent 84.7% of all known pregnancies.

c. The Pregnancy Loss Review is currently considering the impact of the current threshold of 24 weeks of gestation to formally register the loss of a baby and whether it would be beneficial to amend legislation to allow parents to register a miscarriage if they wish. The aim of the review is to improve the support and experience of care for women and birthing people, and families who have a pre-24 week gestation baby loss.

#### Maternal mortality

While this report is focused on monitoring progress to reduce miscarriages, preterm births, stillbirths and neonatal deaths and reducing inequalities, these outcomes go hand-in-hand with worsening maternal mortality rates, quality and safety of services and decreasing parental engagement and satisfaction (see Chapter 5).

The overall maternal mortality rate, which includes deaths during or within 42 days of the end of pregnancy, has decreased 21.9% between 2003-05 and 2018-20 in the UK (see Fig.13). Maternal mortality is divided between direct and indirect mortality. Direct deaths are related to obstetric complications during pregnancy, labour or postnatally (up to 6 weeks) and have declined by 23.2% in the UK between 2003-05 and 2018-20, although the most recent three-year period showed a rise. Thrombosis and thromboembolism (VTE) is the leading cause of direct deaths followed by deaths due to suicide, sepsis and obstetric haemorrhage. Indirect deaths comprise over half (52%) of all maternal deaths in the UK and have showed a slightly smaller decline of 20.6% between 2003-05 and 2018-20. Cardiac disease is the largest single cause of indirect maternal deaths, followed by neurological causes. Between March and December 2020, 9 deaths of women who were pregnant or within six weeks of end of pregnancy were directly attributed to Covid-19 and the additional pressures on health services due to the pandemic may have contributed to other maternal deaths during this period.





There was a statistically significant increase in maternal deaths from direct causes in the three years leading up to 2018-20 and although the rates also increased for maternal mortality overall and indirect causes, these changes were not statistically significant.

The rate of late maternal mortality, which captures direct and indirect deaths between six weeks (42 days) and one year after the end of pregnancy, was 13.7 per 100,000 maternities in 2018-20. The late maternal mortality rate has remained between 12 and 14 deaths per 100,000 maternities since 2009.

The risk of maternal mortality is higher among certain groups including women and birthing people from deprived areas, minoritised ethnic groups and those facing severe and multiple disadvantage<sup>25</sup>. Health inequalities which affect maternal mortality also affect pregnancy and baby loss and will be explored in Chapter 4.

The government aims to reduce maternal mortality in England by 50% between 2010 and 2025. However, maternal mortality rate data are not routinely published for England. ONS holds data on deaths in England and Wales where a pregnancy-related cause is listed on the death certificate. Combining this data with ONS data on total births, we calculated maternal mortality estimates in Figure 14.



#### Figure 14. Maternal mortality rates in England between 2013 to 2020

Due to the thankfully rare occurrence of maternal deaths, there is high year-on-year variation in maternal mortality. Maternal mortality rates appear to be broadly declining since 2013. While the 2010 rate is not publicly available for England, progress appears slower than required.

A 50% reduction of the maternal mortality rates for the UK, presented by MBRRACE-UK, would represent a rate of 1.86 per 100,000 maternities for direct maternal deaths, 3.21 for indirect deaths and 5.06 for overall maternal deaths. Most recent data shows that the UK is far from reducing 2010 rates by 50%. In 2018-20, there were 229 maternal deaths, an overall rate of 10.9 per 100,000. This is echoed by the MBRRACE-UK data for the UK, which show an 7.7% increase in overall maternal mortality between 2010-2012 and 2018-20, and a 40.0% increase in direct deaths.

As well as falling behind national targets, the UK has worse maternal mortality metrics compared with other European countries. While the same caveats for international comparisons apply (see p. 13), a recent study<sup>26</sup> collected maternal mortality data across eight European countries. The study found that the UK and Slovakia had the worst rates of maternal mortality, which were approximately four times higher than the lowest rates in Norway and Denmark.

From the countries included in the study, only the UK and France, monitored and reported mortality up to one year after the end of the pregnancy.

Certain conditions contributed more to maternal mortality in some countries compared to others – for example, there were relatively high rates of maternal death associated with venous thromboembolism in the UK and Netherlands. While some variations may be influenced by the sociodemographic characteristics of pregnant women in different countries, it is important to understand how the quality of maternity services and performance of health systems may have influenced these outcomes. Although maternal mortality rates and some specific causes differed, there were some commonalities in the leading causes of maternal death: cardiovascular diseases and suicide. There is a need to learn and share health strategies to prevent mortality and morbidity related to cardiovascular disease and suicide, which are particularly challenging as they reach beyond maternity services direct remit.

Wider data on maternal outcomes, such as on maternal morbidity, are important for any future approaches aimed at detecting early warning signs of falling maternity service quality or safety.

# Maternal mortality is highest in Slovakia and the UK, compared with six other countries with enhanced surveillance systems Image: Inhanced surveillance system\* Image: Inhance system\* Image: Inhance system\* Image: Inhance system\* Image: Inhance system\* Imance system\* Image: Inhance syst

Figure 15. Maternal mortality ratios across European countries based on enhanced surveillance system and vital statistics.

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

#### **Chapter Summary**

- There are a range of characteristics which are associated with increased risk of pregnancy loss and baby deaths. Deaths are highest among preterm babies – almost three-quarters of stillbirths and neonatal deaths were among preterm babies in the UK in 2020. Risks are also interlinked as preterm babies are more likely to be low birth weight. Multiple birth pregnancies are at higher risk of being born preterm and/or low birth weight.
- Maternal characteristics, including age, diet and obesity, and smoking, drug and alcohol use are associated with higher rates of stillbirth and neonatal death. The profile of the population giving birth has changed over time and, today, is varied across different parts of the UK.
- Belonging to a minoritised ethnic group and/or living in areas of higher deprivation are also associated with pregnancy loss and baby death. This is explored in more detail in Chapter 4.
- There are various characteristics which are associated with increased risk of stillbirth and/or neonatal death which require health services to provide tailored services and support.



#### 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<sup>27</sup>. Risks should be contextualised so that women and birthing people feel supported and not stigmatised by health services.

#### Risk factors associated with a baby's characteristics

Birthweight has the most significant effect on stillbirth and neonatal deaths; deaths are highest among very low-birth weight babies (under 1,500 grams) and become less common with increasing birth weight, up to 4,499 grams<sup>d</sup>. Stillbirth and neonatal mortality rates are higher for multiple-birth pregnancies. While the UK rates have declined in singleton pregnancies between 2018 to 2020, the rates have risen or remained broadly constant for multiple pregnancies – with the highest rates among pregnancies are also at a higher risk of being born low birth weight, compared to singletons, and are

therefore more likely to develop adverse health outcomes as a result of being underweight<sup>28</sup>.

Babies' ethnicity is another characteristic which is associated with different outcomes, with deaths higher amongst Asian and black babies compared to white, mixed or other. Health inequalities based on ethnicity are explored in Chapter 4.

A table outlining risk factors related to a baby's characteristics is included in Appendix 1.

#### Risk factors associated with a mother's characteristics

The changing profile of women and birthing people in the UK today has implications for the type of care required. As we increase our understanding of different factors affecting pregnancy and births, this has implications for risk assessment, monitoring and support provided. In this section, we explore some of the known factors associated with stillbirths and neonatal deaths; however, this is an area of ongoing research and exploration.

#### Maternal age

In 2021, the average age of mothers was 30.9 years and 33.7 years for fathers, the highest since data collection began in 1938 and 1964 for mothers and fathers respectively. Data for the UK show that stillbirth and neonatal death rates are highest for mothers below 20 years old and older than 35°. Studies<sup>29</sup> have shown that this may be due to uterine functions declining in older women as the muscle produces less energy and contractions are less effective, which affects labour. Adolescent women and birthing people may be at higher risk of giving birth to very or extremely preterm babies and/or babies with extremely low birth weight<sup>30</sup>, although further research is required to understand the drivers of worse outcomes among younger women.



Figure 16. Rates of multiple pregnancies across maternal age groups in England and Wales between 1990 and 2021

The rate of multiple pregnancies also increases with maternal age, shown in Figure 16, which also has implications for the care that women and birthing people require.

The increase in multiple births for older ages may also be associated with fertility treatment. The fall in multiple pregnancy rates since 2014, which was particularly steep among mothers aged 45 and over, may be due in part to changes in vitro fertilisation (IVF). The average UK multiple birth rate from IVF treatment has decreased from around 28% in the 1990s to 6% in 2019.

#### **Diet and obesity**

Current evidence suggests that maternal diets before and during pregnancy could influence rates of preterm birth, low birth weight and small for gestational age births, although findings have been inconsistent. A systematic review<sup>31</sup> found that diets at lower risk of preterm births were commonly characterised by high consumption of vegetables, legumes, seafood and milk products. A systematic review and metaanalysis<sup>32</sup> of the association between diet and risk of miscarriage found evidence that diets with a high intake of fruits, vegetables, seafood, dairy products, eggs and cereal (grains) lead to a reduction in miscarriage odds. High amounts of processed food were found to be associated with increased miscarriage risk while evidence of associations with other food groups, such as meat, fat and oil, and sugar substitutes, were inconclusive.

The risk of pregnancy loss and baby death, is highest among mothers who are underweight<sup>f</sup> and those who are overweight or obese<sup>33</sup>. Higher body mass index (BMI) is associated with increased likelihood of maternal or baby health complications<sup>34</sup> and risk of stillbirth<sup>35</sup>. Obesity is also associated with other health conditions which are linked with poorer pregnancy outcomes, such as gestational diabetes, Type 2 diabetes and hypertension<sup>36</sup>.



d. Rates of stillbirth and neonatal death are similar among babies with a birthweight of 4,500g and babies with a birthweight between 2,500 and 3,499g. Babies born at between 3,500 and 4,499g have the lowest rates of stillbirth and neonatal death. For more detail, see Table 13 in Appendix 1.
 e. See Table 14 in Appendix 1

Although few studies have found a statistically significant relationship between being underweight and the risk of stillbirth or neonatal death, this may be due to studies lacking significant statistical power to prove an association, rather than proof of no effect.

#### **Pre-existing conditions**

Pre-existing conditions including poor mental health<sup>37</sup>, special educational needs and disabilities, and medical conditions (such as cardiovascular disease<sup>38</sup>, epilepsy<sup>39</sup> or diabetes) can affect how women and birthing people access health services and the type of care that they require. The impact of individual conditions is compounded if women and birthing people experience multiple conditions - affecting an estimated one in five pregnant women in the UK<sup>40</sup>. This may increase as maternal age increases and if BMI increases also, making it increasingly important for health care professionals to provide tailored information on preconception and pregnancy care<sup>41</sup>.

#### Smoking, drug and alcohol use

Smoking is associated with an increased rate of stillbirth, miscarriage and birth defects<sup>42</sup>.



#### Figure 17. Percentage of women who smoke at the time of delivery in England between 2013-14 and 2021-22

The number of women who smoke while pregnant, based on reported smoking at the time of booking appointment and delivery, has declined in England.

However, we also know that rates of smoking during pregnancy varies across different regions of the UK. This reflects overall population trends and links to socio-economic status, including employment status and level of education (See Map 3).



Map 3. Regional variation in the percentage of women who smoke at delivery in England in 2022

In England, the maternity services data set (MSDS) does not currently publish data on alcohol consumption due to the low volume of data which are submitted. However, it is anticipated that completeness will increase over time and MSDS will start reporting, when possible, which will give a better picture of the impact of alcohol consumption on maternal and fetal health in the future.

There is relatively little research on the impact of illegal drug use on pregnancies. Most of the available research comes from America and is based on relatively old data. One study<sup>43</sup> found that methamphetamine use was associated with higher risk of gestational hypertension, intrauterine fetal death, preterm birth and neonatal death.

NHS England does not collect data on illegal drug use in pregnancy. In Scotland in 2021/22, drug use was recorded in 786 maternities, or a rate of 16.8 per 1,000 maternities<sup>44</sup>. Drug use during pregnancy was highest in the under 20 age group (60.2 per 1,000 maternities) and was nearly four times higher in the most deprived areas compared to the least deprived.

Analysing trends in drug use during pregnancy in Scotland over time should be treated with caution due to the high proportion of missing data (29.7% of data were missing in 2018/19). Despite recent improvements in the quality and completeness of data, comparing geographic areas is still challenging due to data variability between NHS Boards.

#### **Complex social factors**

Examples of complex social factors in pregnancy include but are not limited to homelessness, recent arrival as a migrant and immigration status, difficulty speaking or understanding English, or experience of domestic abuse. Women and birthing people who experience some complex social factors are more likely to experience others, for example women with experience of abuse and violence are more likely to live with poor mental and physical health, disability, homelessness or poverty, amongst others<sup>45</sup>.

Some aspects of complex social factors are explored in Chapter 4. Further research is needed to better understand the relationship between different aspects of social disadvantage and pregnancy and baby loss and inform the care provided.

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

#### **Chapter Summary**

- Stillbirths and neonatal deaths are more common among women and birthing people from minoritised ethnic groups and those living in the most deprived areas across the UK. The risk of preterm birth and miscarriage is also higher among minoritised ethnic groups<sup>9</sup>.
- 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.
- The drivers of inequalities in pregnancy loss and baby deaths are complex and interrelated. Some explanatory theories include differences in access to and treatment by maternity services, differences in health behaviours (including diet and smoking), and differences in personal and social contexts. Inequalities can be driven by racism and discrimination which some individuals experience when engaging with health services<sup>46</sup>.
- Ethnicity and deprivation are interrelated; a greater proportion of births to minoritised ethnic groups are among those living in the most deprived areas, which may be connected to systemic racism in wider society. However, having a higher chance of living in more deprived areas alone does not explain differences in risk of pregnancy loss and baby death between ethnic groups.
- Limitations in data and evidence make it challenging to understand what is driving inequalities and identify potential interventions to reduce them.



#### 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 operates 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.



# Inequalities in pregnancy loss and baby deaths between ethnic groups

Accuracy of ethnic group coding is higher for aggregate groups – such as Asian, Asian British - compared to individual ethnic codes – such as Bangladeshi, Indian, Pakistani, other Asian. For the purposes of this report, we will present data at the aggregate and individualised level. While data at individual ethnic code level need to be interpreted with caution due to smaller data sizes, it does highlight important differences in outcomes within aggregate ethnic groups which merits further exploration. See Evidence Gaps for further information.

#### Ethnicity and stillbirth rates

In 2020, stillbirth rates in the UK were lowest among white babies (3.17 per 1,000 total births). Black and black British babies were over twice as likely<sup>47</sup> to be stillborn (6.41 per 1,000 total births) and Asian, Asian British babies over 50% more likely to be stillborn (4.97 per 1,000 total births) (see Fig.18).





Source: MBRRACE-UK (2022) • Created with Datawrapper

0.92

3.17

#### Figure 18. Comparison of stillbirth rates across ethnic groups in the UK in 2020

If the stillbirth rate amongst black, black British babies were equal to white babies, there would have been 94 fewer stillbirths in 2020 (see Table 2). If the stillbirth rate amongst Asian, Asian British babies were equal to white babies the number of stillbirths would be reduced by 128. While the stillbirth rate was lowest among white babies, the total number of stillbirths was highest among this group due to the higher number of births (1,486 in 2020).

	Total stillbirths (2020)	Number of stillbirths prevented if rate were equal to stillbirth rate amongst white babies
White	1,486	-
Mixed	160	36
Asian, Asian British	353	128
Black, black British	186	94
Other	96	42
Total	2,281	300
Pagad on MRRRACE LIK data for LIK and Crown	Dependencies	

Table: Sands & Tommy's Joint Policy Unit • Source: MBRRACE-UK (2022) • Get the data • Created with Datawrapper

Table 2.Total UK stillbirths in 2020 across ethnic groups and potential<br/>number of stillbirths prevented if the rate across all groups were<br/>equal to the stillbirth rate amongst white babies

These rates have not been adjusted for confounding factors – we know that other characteristics vary between ethnic groups, including level of deprivation, BMI, smoking status. However, a cohort study<sup>48</sup> using data from English hospitals found that adjusting for socioeconomic deprivation, smoking and BMI reduced but did not remove the difference in stillbirth rates between ethnic groups. The relationship between socioeconomic deprivation and ethnicity will be explore further in the 'Drivers of ethnic inequality' section below.

Looking at individual ethnic groups in the UK data reported by MBRRACE-UK can provide more nuance compared to the five broad groups (see Table 3). Stillbirth rates were highest among black African babies (7.8 per 1,000 total births between 2016 – 2020) and lowest among white babies (3.43 per 1,000 total births 2016 – 2020). Within the Asian, Asian British group rates varied – the rate was lowest for other Asian ethnicities (4.53) and Indian (4.88) compared to Bangladeshi (5.60) and Pakistani (6.21). Pakistani stillbirth rates were closer to black Caribbean and other black groups than Indian and other Asian groups.

#### Stillbirth rates were lowest amongst white babies and highest amongst black African babies in the UK between 2016 and 2020

Ethnicity group	Stillbirth rate (2016 - 2020)
White	3.43
Other	3.88
Mixed	4.09
Other Asian	4.53
Indian	4.88
Bangladeshi	5.60
Pakistani	6.21
Other black	6.22
Black Caribbean	6.42
Black African	7.80
Table: Sands & Tommv's Joint Policy Unit • S	ource: MBRRACE-UK (2022) • Created with Datawrapper

 Table 3.
 Stillbirth rates between 2016 – 2020 across individual ethnic aroups in the UK

#### Changing inequalities over time

Between 2016 and 2020 rates of stillbirth in the UK declined among white, Asian and Asian British, and black and black British babies (see Fig.19). The steepest decline was among black and black British (22.7%), although the rates remained the highest among this ethnic group. Stillbirth rates were more variable for mixed and other ethnic groups, although stillbirth rates increased overall for both between 2016 and 2020. Stillbirths among ethnicities recorded as 'other' declined between 2016 – 2019 but increased sharply from 2.95 per 1,000 births in 2019 to 5.57 per 1,000 births in 2020. Rates of stillbirth among babies of mixed ethnicity were 2% higher in 2020 than they were in 2016. Stillbirth rates declined for three ethnic groups between 2016 and 2020, although rates continue to be highest amongst black, black British babies





#### ONS data show variation in the reduction of stillbirth rates between ethnic subgroups in England & Wales



Figure 20. Changes in stillbirth rates between ethnic sub-groups in England and Wales, 2016 to 2020.

The latest data from ONS for 2021 show that mixed/multiple and any other ethnic group categories have higher rates of stillbirth (4.4 and 4.5 respectively) compared to the overall rate of 4.1 for England and Wales. ONS data also showed an increase in stillbirth rates among babies with no stated ethnicity, which was the highest of any group based on 2021 data (7.1 per 1,000 total births). In contrast, 2021 neonatal mortality rates in England and Wales for mixed and other groups were below the neonatal mortality rate overall, although the rate for not stated remained higher. Changes could be due to poorer data quality<sup>49</sup>. Increases could have been due to changes to the definition of 'other' ethnic group categories.

While individual ethnic codes provide more nuance, research<sup>50</sup> suggests that robust conclusions are only possible for aggregated ethnic groups. Data quality limitations are explored in more detail later in the chapter.

#### Ethnicity and neonatal deaths

In 2020 the neonatal death rate among babies born at 24 weeks gestation and over was the lowest among white babies (1.51 per 1,000 live births) and highest amongst black, black British babies in 2020 (2.71 per 1,000 live births) (see Fig. 21). Neonatal death rates were also significantly higher among Asian, Asian British babies (2.06 per 1,000 live births).

#### Neonatal mortality rates were also highest amongst black, black British babies in 2020 in the UK



#### Figure 21. Comparison of neonatal mortality rates across ethnic groups in the UK in 2020

If the neonatal mortality rate amongst black, black British babies were equal to white babies, the number of deaths would be reduced by almost half (44.4%). This would mean a reduction of 35 deaths in 2020 (see Table 4). Similarly, deaths among Asian, Asian British babies would be reduced by a quarter (26.7%). While the rate of neonatal death was lowest among white babies, the total number of deaths was highest among this group due to the higher number of births (706 deaths).

	Number of neonatal deaths (2020)	Number of neonatal deaths prevented if rate were equal to neonatal mortality rate amongst white babies				
White	706	-				
Mixed	71	12				
Asian, Asian British	146	39				
Black, black British	78	35				
Other	27	1				
Total	322	87				
Based on MBRRACE -UK data for UK and Crown Dependencies Table: Sands & Tommy's Joint Policy Unit • Source: MBRRACE-UK (2022) • Get the data • Created with Datawrapper						

 
 Table 4.
 Total UK neonatal deaths in 2020 across ethnic groups and potential number of deaths prevented if the rate across all groups were equal to the neonatal mortality rate amongst white babies

As for stillbirths, these rates have not been adjusted for confounding factors.

Analysis of individual ethnicity groups shows that between 2016 and 2020 rates of neonatal death among babies of Pakistani and Bangladeshi ethnicity are much higher than Asian, Asian British babies overall (see Table 5). The Pakistani group had the highest rate of neonatal death (3.45 per 1,000 live births), followed by black African (2.67). Over this longer time period, rates among babies of mixed ethnicity were the lowest (1.54), followed closely by those recorded as "other ethnicity" (1.56) and white (1.63).

#### UK neonatal mortality rates were lowest amongst Mixed ethnicity babies and highest among Pakistani babies between 2016 and 2020

Ethnicity group	Neonatal mortality rate (2016 - 2020)
Mixed	1.54
Other	1.56
White	1.63
Indian	1.74
Other Asian	2.15
Black Caribbean	2.20
Other Black	2.31
Bangladeshi	2.62
Black African	2.67
Pakistani	3.45

Table: Sands & Tommy's Joint Policy Unit  ${}^{\star}$  Source: MBRRAC0-UK (2022)  ${}^{\star}$  Created with Datawrapper

#### Table 5. Neonatal mortality rates between 2016 – 2020 across individual ethnic groups in the UK

#### Changing inequalities over time

In 2016 rates of neonatal death were highest among babies of Asian, Asian British ethnicity, but between 2016 and 2020 have decreased by nearly 30% (see Fig.22). Rates of neonatal death were highest among black, black British babies, in 2020 than in 2016. Neonatal mortality rates declined among Asian and white groups in the UK but were variable amongst black, mixed and other groups



Figure 22. Neonatal mortality rates across ethnic groups in the UK between 2016 and 2020

Data from the ONS over the same time period provides more detail into ethnicity sub-groups (see Fig 24). This highlights increased rates of neonatal death among babies of Bangladeshi and black Caribbean ethnicity, as well as among babies recorded as 'other ethnicity'.



Figure 23. Changes in neonatal mortality rates between ethnic sub-groups in England and Wales, 2016 to 2020.

#### Ethnicity and preterm births

The proportion of preterm births out of total live births is highest among black babies (8.7%) in England and Wales. This rate has remained consistently above all other ethnic groups since 2010, despite declining slightly since 2020 (see Fig. 24). The percentage of preterm births is also higher among babies of Asian ethnicity compared with white babies. Although over time it has remained closer to the overall population, in 2021 there was a sharp increase to 8.1% from 7.5%. Black Caribbean babies and babies from any other black background had particularly high preterm birth rates relative to other ethnic groups.



Figure 24. Preterm birth rates across ethnic groups in England and Wales between 2010 and 2021

Some ethnic groups, particularly black, had a higher proportion of extremely and very preterm births compared with white babies (see Fig. 25). Very and extremely preterm babies have lower survival rates, relative to moderate to late preterm.





Having a higher proportion of preterm births may influence overall neonatal mortality rates for different ethnic groups, due to the higher mortality rates at lower gestational ages. However, Figure 26 shows that in 2021, there was no clear correlation between the proportion of preterm births and neonatal mortality rates among different ethnic groups.



Figure 26. Proportion of preterm births and neonatal mortality rates across ethnic groups in England and Wales in 2021

Reducing preterm births remains an important strategy for reducing neonatal mortality overall. Targeted efforts to reduce preterm births or improve care for preterm babies for particular ethnic groups could help to reduce disparities in neonatal mortality overall.

#### Ethnicity and miscarriage

A Tommy's study<sup>51</sup> found that maternal ethnicity was associated with miscarriage risk, in particular black ethnicity which has a 43% higher risk of miscarriage compared with white ethnicity. The study found that risk of miscarriage increased to 63% after adjusting for key confounding variables, particularly maternal age. However, there was no association between Asian ethnicity in mothers and miscarriage, either before or after adjusting for confounding factors.

# Drivers of inequalities between ethnic groups

It is clear from looking at the outcomes data<sup>52</sup> and evidence from qualitative research that ethnic inequality exists in pregnancy and baby loss, and that current progress to reduce these inequalities is insufficient. However, it is less clear what exactly is driving these inequalities, a better understanding is needed to inform effective interventions.

Many of the explanatory theories outlined below relate to how women or birthing people's ethnicity affects their access to and experience of care, while many of the outcomes we measure are based on the baby's ethnicity. A baby's ethnicity may not be the same as the mother or birthing person. For example, a baby of mixed ethnicity may be born to a mother of a minoritised ethnic group, who may be more likely to experience discrimination or issues with care, suggested by higher rates of miscarriage and maternal mortality, or to a white mother.

#### Accessing healthcare services and systems:

A systematic literature review<sup>53</sup> of ethnic inequalities in maternity services highlighted five themes which may influence inequalities: access to health services, communication, midwifewoman relationship, cultural and religious preferences, and social needs.

There is some evidence that timing of antenatal care initiation varied according to maternal ethnicity. While one-fifth of mothers in one study<sup>54</sup> started antenatal care late (after 12 weeks' gestation), rising to over a third of mothers identifying as black African. Black African mothers were 4 times more likely to start antenatal care after 20 weeks' gestation compared with white mothers, after adjusting for confounding factors. Some healthcare professionals interpreted non-attendance or late booking for antenatal care as avoiding care or a lack of respect. Whereas the study found multiple, compounding factors which affected the accessibility of services, including transport or domestic issues (such as lack of childcare), uncertain immigration status or a lack of permanent address, concerns around interpretation, as well as knowledge of the importance of booking before 13 weeks' gestation. These factors may affect access to services throughout pregnancy and the neonatal period.

When women and birthing people do access care, there are reports of racism or discrimination based on their ethnicity, class, migration status or other factors. Participants<sup>h</sup> in a Birthrights focus group<sup>55</sup> spoke of health professionals seeing white bodies as the 'norm' and failing to recognise symptoms on black or brown skin, such as jaundice and sepsis. Some fear judgement of health care professionals or view maternity services as systems of surveillance rather than support (ie. surveillance of immigration status, drug and alcohol use)<sup>56</sup>.

Issues with relationship building and a lack of trust is a recurring theme in research. Some women reported condescending or dismissive attitudes from midwives which led to a perceived lack of care. There is a large variation in women and birthing people's expectations, which health care professionals need to recognise and respond to. Some studies found that midwives preferred holistic approaches while women preferred professional and task-oriented relationships<sup>57</sup>. Another reported that care was fragmented and task-focused which meant midwives were unable to engage with complexity of women and birthing people's lives<sup>58</sup>.

Building relationships and trust can also be more challenging due to staff shortages and short appointment times which strains communication between staff and families. Families and health workers may use different terminology which creates barriers to understanding each other. Further, women who were not confident in English said that this created communication issues and that health-trained interpreters were rarely used, which led to reliance on friends and family<sup>59</sup>. There may also be some cultural practices which influence access to health services and relationships with healthcare providers. Some cultural or religious preferences may require health services to tailor their care, which some women felt were seen as time-consuming and burdensome. Some cultural practices, such as first cousin unions, may lead to an elevated risk of congenital abnormalities among babies of Pakistani origin60 This can be compounded by parents' choices not to screen for congenital abnormalities or terminate pregnancies for medical reasons, which could lead to higher rates of stillbirth and neonatal death.



Birthrights study<sup>61</sup>

h. The study did not explicitly include or exclude bereaved parents, but focused on individuals with lived and professional experience of racial injustice in maternity care.

Ethnic groups bring together a mixture of national, cultural and religious identities, which makes it difficult to disentangle some of the influences. Here we explore the experience of Muslim women in UK maternity services, in particular:

#### Systematic review of Muslim women's experience of maternity services in the UK<sup>62</sup>

The review considered the distinct experience of religion rather than ethnicity, and identified five themes:

- Islamic practices: religious practices such as fasting were not disclosed for fear of misunderstanding from health professionals. The majority also declined screening tests and wanted care that reflected values of privacy and modesty, including the absence of men. Many appreciated being able to build trusted relationships through continuity of care and preferred Muslim health professionals who would understand their preferences.
- 'If Allah wills': the influence of spirituality on the experience of pregnancy and birth was a common theme, with many calling on God for support. For some, this influenced their decision not to carry out prenatal screening or take medication, as they believed Allah's will would decide their child's health.

- Communication: language barriers were a common issue for educational resources and obtaining informed consent for care.
- Inequality and intolerance: women shared their experience of stereotyping, prejudice and discrimination. They felt that their clothing clearly identified them as Muslim and made them more prone to discrimination.
- Positive experiences: some reported positive experiences where midwives understood Islam and took an individualised approach to care. This improved their experience of maternity care overall. However, sadly, negative experiences were still common.

Studies<sup>63</sup> highlight the intersection of additional aspects of social disadvantage with minoritised ethnic identities that can further compromise access to care. Groups requiring additional support include Roma, Gypsy and Traveller women, those seeking asylum or with recent refugee status, those with mental health conditions and teenage women and young mothers. Dealing with complex social needs requires more time resources and workforce capacity.

#### Wider health and societal disparities:

Beyond interactions with health services, there are a range of other factors which may contribute to health disparities, including:

- Socioeconomic status and the over-representation of some ethnicities within areas of lower deprivation. For example, in the UK in 2020 69% of babies of black African ethnicity were born to mothers living in the two most deprived quintiles, over double the 36% of white babies (see Fig. 27). While controlling for social deprivation appears to reduce some inequality in outcome by ethnicity, it does not remove all.
- Physiological: maternal age, BMI, and medical co-morbidities which may be pre-existing or occur during pregnancy. For example, NMPA analysis of routine health records between 2015 – 2018 in England, Scotland and Wales found rates of pre-existing diabetes were highest for women from South Asian and black ethnic groups (1.4% and 1.3% respectively) compared with women from white ethnic groups (0.6%)<sup>64</sup>
- Health behaviour: differences in individual behaviour such as diet, exercise and smoking which may contribute to pregnancy risk. However, there is insufficient evidence that this alone can explain ethnicity differences.



#### Figure 27.

Proportion of births occurring in each deprivation guintile across ethnic groups in the UK between 2016 and 2020

While important to understand health behaviours and physiological differences, there is insufficient evidence that these factors alone lead to inequalities. Focusing on individual choices and behaviour puts the onus on individual women and birthing people to control risk factors, and ignores the systems, societal attitudes and social context which influence health outcomes. For example, the over-representation of certain ethnic groups in lower socioeconomic quintiles may be partly explained by institutional racism which limits minoritised ethnic groups' access to education, jobs etc with knock-on effects on health outcomes<sup>65</sup>.

#### Migrant women and birthing people

MBRRACE-UK records data on maternal mortality according to mother's country of birth. Just over a quarter of women who died between 2018 and 2020 (26%) - or 55 deaths - were born outside of the UK, when birthplace was known. 6% of the women who died were not UK citizens (13 women in total), although this may be an underestimate as citizenship was not recorded for 11% of deaths. Of these 13 women, two (15%) were refugees/asylum seekers, three (23%) were EU citizens and eight (62%) had another or unknown status.

#### Approximately two-thirds of stillbirths and neonatal deaths occur in mothers born in the UK



#### Figure 28. Proportion of stillbirths and neonatal deaths based on mother's place of birth in the UK in 2020

2020 data show that approximately two-thirds of stillbirths and neonatal deaths occur in mothers born in the UK. This is in line with the MBRRACE-UK estimate<sup>i</sup> that 27.5% of total maternities 2018-20 were to women born outside of UK. Broadly, suggesting that women born outside the UK are not more likely to experience stillbirth or neonatal death, although maternal place of birth is unknown for 7.9% and 11.6% of stillbirths and neonatal deaths respectively. However, place of birth is a broad category which does not provide information on migration status specifically. Recent migration has been linked to some challenges outlined above – including knowledge of health system and when to book antenatal care, language and communication barriers, and experiencing discrimination. People who are 'ordinarily resident' in the UK are entitled to free NHS care, including maternity services; however, women from overseas, including migrant women, face charges, sometimes by up to 150% of the cost<sup>66</sup>. Maternity Action research found that charging has a deterrent effect on access to maternity care which creates risks to mothers and pregnancy outcomes.

A third of participants in qualitative research by Birthrights and Birth Companions<sup>67</sup> were current or recent asylum seekers. The research highlighted multiple disadvantage which they faced, and which affected their maternity care, including living in insecure housing, social isolation, late or no antenatal care and worse experience of choice and consent. While none of them were asked to pay NHS charges, midwives who were interviewed by Birthrights expressed unhappiness with charging policies and shared concerns that they were leading to women avoiding care and presenting with greater emergency needs in labour.

However, it is not clear whether migration status itself adds to risk of adverse perinatal outcomes. Comparisons have found both negative and null associations between being born outside of the UK and perinatal outcomes<sup>68</sup>. Further research is required to understand the issues that underserved migrant women and birthing people face, and the impact of perinatal outcomes. Upcoming research funded by National Institute for Health and Care Research (NIHR)<sup>69</sup> will explore this topic further.

i. Estimates are based on proportions of births to UK and non-UK born mothers applied to number of maternities.

#### Gaps in the evidence - inequalities in pregnancy loss and baby deaths between ethnic groups

#### **Ethnic categories**

Ethnicity codes are a crude measure of individual experience and only offer proximate guides to experiences, lifestyles, practices and beliefs<sup>70</sup>. Understanding of ethnicity varies from person to person and there are differences of opinion as to whether skin colour, nationality or religion should be included<sup>71</sup>. The breadth of the aggregated ethnic categories causes some to question the appropriateness of categories as well as their usefulness in understanding drivers of health inequalities. Some individual ethnic groups also create contradictions based on geographical and racial identities, such as black African and Arab groups. The use of arbitrary, non-specific categories, such as 'not known' or 'other', creates a portion of data which is virtually unusable. There is no incentive for health care professionals to confirm the ethnicity of patients at a later stage if 'not known' has been recorded.

#### Data quality and completeness

A review of Hospital Episode Statistics between 2010/11 and 2019/20 by the NHS Race and Health Observatory<sup>72</sup> found that while overall recording of ethnicity was high - 87% of over 17 million inpatient records included a valid ethnic group in 2019/20 - there was incomplete coding and inconsistent use of ethnicity codes. Missing ethnicity codes were not evenly distributed, and some minoritised ethnic groups were under-represented in health data in comparison with national population records while "other" ethnicity codes were over-represented.

While the NHS Race and Health Observatory focused on the completeness of data, another study<sup>73</sup> looked at agreement between hospital episode statistic data and maternity information records to infer the level of accuracy. This study also found a high level of completeness of ethnicity information (91.3% of records). Agreement between the two datasets was highest for aggregate ethnic categories, particularly for white (98.5% agreement), South Asian (94.5%) and black (92.1% records. Agreement was lower for individual ethnic codes (90.5%), as well as non-specific aggregate codes such as "other" (74.7%) and "mixed" (35%). The study suggests that hospital data can be used to draw robust conclusions between aggregated ethnicity groups and outcomes, but researchers and analysts should be aware of poorer quality of mixed coding and use caution when analysing outcomes or individual ethnic codes.

Beyond mortality outcomes, recording of ethnicity data for maternity and neonatal care (e.g. antenatal care, breastfeeding support, caesarean section rates) is inconsistent.

#### Lack of generalisable evidence to explain ethnic inequalities

There have been several important pieces of qualitative research which have sought to understand some of the reasons for inequalities in perinatal outcomes between different ethnic groups, including by Five X More<sup>74</sup>, Muslim Women's Network<sup>75</sup>, Maternity Action<sup>76</sup>, and Birthrights and Birth Companions<sup>77</sup>. These have provided important insights into women and birthing people's experience and can inform service improvements.

The Care Quality Commission (CQC) publishes subgroup analysis from their maternity survey<sup>i</sup> which provides information on a national scale. The sub-group analysis considers the average probability that people in a certain sub-group, controlling for other characteristics in the model, selected the most positive answer(s). The CQC categorised the survey questions into 16 care themes, such as respect for patient-centred values, preferences and expressed needs (respect), information and communication in hospital, availability of staff.

The CQC presents sub-group analysis separately for ethnicity and religion (see Table 6). However, responses from minoritised ethnic groups were typically more positive compared to average, while white responses were slightly worse. This does not reflect mortality outcomes data, or qualitative studies, and could reflect lower expectations rather than a more positive experience. Further research is needed.

The CQC survey collects data on experience from a relatively large sample of people using maternity services. However, there are a number of limitations with it. Most marginalised people may be less likely to respond to the survey which may create some response bias. Bereaved parents, who have experienced the worst outcomes, are also not included. The CQC maternity survey measures people's experience of care which may be influenced by differential expectations between individuals and groups. The ethnicity categories used by the CQC are not aligned with ONS data and only a high-level summary is provided, which limits the ability of others to carry out further analysis on the survey results. Qualitative research could be used to explore some of the themes raised by the the CQC data.

Of the 16 themes, black or black British responses were significantly better than average experience for 8 categories (50%), including respect, feeding support, availability of staff, and involvement across antenatal, labour and postnatal care. Responses for the remaining 8 categories were not significantly different from average experience. In contrast, white respondents reported significantly worse experience for two categories in 2022 (12.5%) - feeding support and information about Covid-19. This varies significantly year to year. In 2021 black or black British experience was only above average for one category – information about Covid-19.

Data on religion are limited, with most religious groups not reporting experiences that were significantly different from average. Christian respondents had more positive experience for one category (respect) and Sikh respondents had a more positive experience for two categories (confidence in staff during antenatal and postnatal care) in 2022. The worst experience reported was for 'prefer not to say' which was below average for 12 out of 16 categories (75%) in 2022, an increase from 8 categories of below average experience in 2021.

j. The CQC maternity survey excludes anyone who has experienced a pregnancy loss or baby death

Ethnicity	Respect	Feeding support	Experience of induction	Mental health - antenatal	Mental health - postnatal	Information in hospital	Availability of staff	Being taken seriously	Involvement - antenatal	Involvement - labour	Involvement - postnatal	Confidence - antenatal	Confidence - labour	Confidence - postnatal	Information about COVID	Left alone
White		w													w	
Multiple ethnic groups	w						w				w				w	
Asian / Asian British										В					В	
Black / Black British	В	В	В				В		В	В	В				В	
Arab / other ethnic group										w						
Not known										w						
Religion																
No religion															w	В
Buddhist																
Christian	В															
Hindu																
Jewish																
Muslim											w					
Sikh												В		В		
Other																
Prefer not to say	w	W		W	W		w		W	W	W	W	W	W	w	

**N** Significantly worse than average experience

**B** Significantly better than average experience

No significant difference with average experience

 Table 6.
 The CQC maternity survey findings significantly above (B) or significantly below (W) average according to subgroup category under each theme.

#### What works to reduce inequalities

Many qualitative studies on ethnic inequalities in maternity and neonatal care focus on previous experience and rarely ask about solutions, which women report finding disempowering<sup>78</sup>.

Some examples of interventions to reduce ethnic inequalities, include continuity of carer for minoritised ethnic groups, increased availability of translators, community engagement and outreach, use of health advocates, and targeted interventions such as vitamin D supplements, cognitive behavioural therapy or prenatal screening. There are very few studies into the effectiveness of some of these interventions. Of the studies which exist, most are in London, have small sample sizes and lack comparator groups, which limits the external validity of the findings<sup>79</sup>. Even fewer studies consider policy interventions to reduce inequalities and there are no evaluations of interventions on institutional or interpersonal racism.

#### **Government targets on inequalities**

While there is a target for NHS England to reduce overall stillbirth, neonatal deaths and preterm births by 50% in 2025, there is no target to reduce inequalities for different ethnic groups. Due to the disparity in current stillbirth and neonatal mortality rates, reducing all rates to 50% of the overall population's 2010 stillbirth and neonatal rates would require much larger reductions amongst some ethnic groups. For example, stillbirth rates among black ethnic groups (black African, black Caribbean, and any other black background) would have to decrease by more half to meet the 2025 target for England. In 2021, in England and Wales the stillbirth rates for black African, black Caribbean, and any other black background were 7.0, 6.6 and 6.8 respectively<sup>80</sup>.

Maternity care is one of five clinical areas of focus in NHS England's Core20PLUS5 approach<sup>81</sup>. As part of this approach, NHS England aims to ensure continuity of carer for women from minoritised ethnic groups and from the most deprived groups. However, this model requires sufficient staffing levels to be implemented safely - which we explore in more detail in Chapter 5.

# Inequalities in pregnancy loss and baby deaths between areas of deprivation

There is no single measure of socioeconomic deprivation or poverty in the UK, and there are benefits and drawbacks to all available measures<sup>k</sup>. Despite these limitations, these measures are important to understand inequalities in pregnancy and birth outcomes based on a range of socio-economic factors.

#### Deprivation and rates of stillbirth

Rates of stillbirth are closely linked to deprivation. In 2020 the stillbirth rate was lowest amongst people living in the least deprived areas of in the UK (2.6 per 1,000 total births) and highest for those living in the most deprived (4.3 per 1,000 total births)(see Fig.29) – this follows a similar pattern to previous years. Except for the second quintile, which had a lower rate of stillbirths compared to the first quintile, stillbirth rates increased with increasing deprivation.



#### Figure 29. Comparison of stillbirth rates across areas of deprivation in the UK in 2020

If the stillbirth rate amongst those living in the most deprived areas were equal to those living in the least deprived, there would have been approximately 500 (or 22%) fewer stillbirths in 2020 (see Table 7). However, these calculations have not been adjusted for other characteristics which vary between levels of deprivation, including ethnicity, BMI, smoking status.

	Total stillbirths (2020)	Number of stillbirths reduced if all rates were equal to IMD 1				
1 - Least deprived	359	0				
2	340	-17				
3	446	92				
4	553	194				
5 - most deprived	590	233				
Total	2,288	502				
Total number of stillbirths in the UK and Crown Dependencies in 2020						

#### Table 7. Total UK stillbirths in 2020 across deprivation quintiles and potential number of deaths prevented if the rate across all groups were equal to the stillbirth rate amongst the least deprived quintile.

The ONS publishes deprivation data across 10 indices of multiple deprivation (IMD) for England and Wales – 1 being the most deprived, 10 being the least deprived - although separate indices are used for each nation.

In 2021 in England, there were more live births to mothers who lived in the 10% most deprived areas of the country (12.8% of live births) compared to mothers who lived in the 10% least deprived areas (7.7% of live births). The difference between the two rates has remained broadly consistent since 2015.

The most recent data for England, in 2021, show stillbirth rates decline with decreasing levels of deprivation (see Fig. 30), although there is some variability amongst the least deprived areas. The four most deprived areas had a higher rate of stillbirths than the population overall.



#### Figure 30. Stillbirth rate across 10 deciles of deprivation in England in 2021

I. Deprivation quintiles reported by MBRRACE-UK are based on mothers' postcodes at time of birth, using the Children in Low-Income Families Local Measure

k. For a short summary of measures, please see further notes in Appendix 1. Data limitations are explored further in the Evidence gaps section.

#### Changing inequalities over time

When looking at rates of stillbirth by deprivation, there is a consistent pattern of higher stillbirth rates among mothers in the most deprived areas and a slower rate of decline over time in these areas (see Fig.31). In the least deprived areas, stillbirth rates were 32.5% lower in 2021 than they were in 2010. Over the same time period rates of stillbirth rates in the most deprived areas declined by only 11%. The gap between the most and least deprived was higher in 2021 than it was in 2020.

#### Stillbirth rates declined across all levels of deprivation in England between 2010 and 2021; however, the difference between the most deprived and least deprived increased



Figure 31. Stillbirth rates across levels of deprivation in England between 2010 and 2021

#### **Deprivation and neonatal death**

Between 2016 and 2020 the neonatal mortality rate was also lowest among babies born to mothers living in the least deprived 20% of areas (1.2 per 1,000 live births). This rate grew with increasing levels of deprivation until the fourth quintile (1.9 per 1,000 live births) before decreasing for the most deprived quintile (1.3 per 1,000 live births) (see Fig.32). As with stillbirths, the total number of neonatal deaths also grew with increasing deprivation, as the number of births were broadly similar for each IMD.

Neonatal mortality rates also appear to broadly increase with increasing deprivation, for births in the UK in 2020



Neonatal mortality rate per 1,000 live births, excluding terminations of pregnancy and births <24+6 weeks gestational age. Excess rate is calculated as the difference between the total rate for each IMD group and the lowest rate. Rates have not been adjusted for confounding factors. Chart: Sands & Tommy's Joint Policy Unit ' Source: MISRACE-UK (2022) • Created with Datawrapper

Figure 32. Comparison of neonatal mortality rates across areas of deprivation in the UK in 2020

Overall, if all groups had the same neonatal mortality rate as the least deprived, there would have been approximately 250 fewer deaths - a decrease of 24%.

	Total neonatal deaths (2020)	Number of neonatal deaths prevented if all rates were equal to IMD1
1 - Least deprived	145	0
2	181	39
3	195	52
4	256	112
5 - most deprived	271	51
Total	1,048	252

Total number of neonatal deaths in the UK and Crown Dependencies in 2020 Table: Sands & Tommy's Joint Policy Unit • Source: MBRRACE-UK (2022) • Created with Datawrapp

Table 8.Total UK neonatal mortality rates in 2020 across deprivation<br/>quintiles and potential number of deaths prevented if the rate<br/>across all groups were equal to the neonatal mortality rate amongst<br/>the least deprived quintile.

In 2021, the data for England show neonatal mortality rates broadly decreasing with decreasing levels of deprivation – with rates in the five most deprived deciles being equal to or higher than the neonatal mortality rate for the population overall.

The neonatal mortality rate is almost double among those living in the most deprived areas compared with the least deprived areas in England in 2021



Figure 33. Neonatal mortality rates across deprivation deciles in England in 2021

#### Changing inequalities over time

Unlike stillbirths, rates of decline in neonatal mortality are more mixed across different indices of deprivation. Between 2010 and 2021 there remained a persistent gap in rates of neonatal death among babies born in the most deprived compared to least deprived areas.

#### Changes to neonatal mortality rates have been variable across different levels of deprivation in England, with some plateauing or increasing between 2010 and 2021 1 - most deprived — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 - least deprived Rate difference between highest and lowest vest deprivation levels were highest in 2010 and 201 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021 y's Joint Policy Unit · Source: ONS (2023) · Created with Data



#### Deprivation and preterm births

Gestational age at birth and deprivation status are not included in annual reports by MBRRACE-UK or ONS, but some studies suggest an association between deprivation and preterm birth. A cohort study by the NMPA<sup>82</sup> using NHS administrative hospital data found that the risk of preterm birth was 4.9% in the least deprived group and 7.2% in the most deprived group. The study found that 18.5% of preterm births could be attributed to socioeconomic inequality, although this estimate was reduced to 11.9% after adjusting for ethnic group, smoking and BMI. A retrospective cohort study<sup>83</sup> of preterm birth in Scotland 1980 – 2003 found that preterm births were more likely in lower deprivation quintiles, which was partly, but not entirely, explained by smoking status at first antenatal contact and increased obstetric intervention. A retrospective cohort study of routinely collected obstetric and neonatal data at the Liverpool Women's NHS Foundation Trust between 2002 to 2008, found deprivation of area of residence was associated with higher risk of preterm birth in a cohort of women with no identifiable risk factors, even after adjusting for smoking and being underweight (both important independent risk factors).

#### **Deprivation and miscarriages**

NHS England reports the number of miscarriages which result in a hospital stay and the number of deliveries according to IMD. To control for differences in the number of births, although we do not have data to control for total pregnancies, we can express the number of miscarriages resulting in a hospital stay as a ratio of the number of deliveries in that group. Miscarriages resulting in a hospital stay declines with increasing level of deprivation. The data only capture those miscarriages which result in a hospital stay and cannot be used to infer differences in miscarriage rates by deprivation more broadly. It could, for example, be that living in more deprived areas affects the likelihood of women experiencing a miscarriage to access healthcare, be referred for in-patient treatment, or other outcomes.





# Drivers of inequality between areas of deprivation

Data from the National Child Mortality Database (NCMD) highlights a clear association between risk of death and level of deprivation for children who died in England between 2019 and March 2020<sup>84</sup>. There was a 10% increase in relative risk of perinatal/neonatal event resulting in death at any age between each decile of increasing deprivation. 1 in 12 child deaths reviewed in 2019/20 found one or more modifiable factors related to deprivation – including social environment, physical environment, child health (maternal health during pregnancy and extreme prematurity), and service provision.

An individual's social and economic circumstances impact on their exposure to factors which are associated with worse pregnancy and neonatal outcomes. Economic hardship influences women and birthing people's home environment and poverty can lead people to have unhealthy behaviours, such as smoking or alcohol consumption, as coping mechanisms<sup>85</sup>. In 2021, an estimated 6.2 million workers (19.8% of the UK labour market) experienced severely insecure work – based on contractual insecurity, financial insecurity and access to workers' rights<sup>86</sup>, while 33% experienced low or moderate insecurity. Women are more likely to be in insecure work compared with men (25% vs 15%) and individuals from ethnic minorities are more likely to be severely insecure than white workers (24% vs 19%).

#### Cost of living crisis

Over half of the population feel that their health has been negatively affected by the rising cost of living, according to a YouGov poll commissioned by the Royal College of Physicians<sup>87</sup>. 16% of those impacted by the rising cost of living had been told by a doctor or health professional in the last year that stress caused by rising costs had worsened their health.

Research from the Resolution Foundation<sup>88</sup> found that 45% of 10,000 respondents are quite worried about their energy bills over the winter months, rising to 63% of workers in the bottom quintile. This may affect how well heated people's homes are with knock-on effects on housing conditions, such as damp and cold. In November 2022, 28% of adults said they could not afford to eat balanced meals (up from 9% pre-pandemic) and 11% reported being hungry in the past month because they lacked enough money to buy food (up from 5% pre-pandemic).

Current estimates suggest that the cost-of-living crisis will ease in 2024, although real wages are not expected to return to early 2022 levels until the end of 2026. Absolute poverty is set to rise in the short term from 17.2% in 2021-22 to 18.3% in 2023-24. The equivalent of an additional 800,000 people in poverty. While stillbirths, preterm births and neonatal deaths appear to increase with increasing levels of deprivation, there is some evidence from observational studies<sup>89,90</sup> that after controlling for ethnicity and risk factors including increased BMI, smoking and chronic hypertension that IMD alone did not predict stillbirth. However, the studies cannot claim causal relationships between individual and household measures of social disadvantage and pregnancy outcomes and some individual socio-economic metrics, such as housing, income or exposure to domestic violence, remain underexplored.

Obesity and smoking during pregnancy are two health behaviours which are associated with adverse pregnancy and neonatal outcomes, as outlined in Chapter 3.

Insufficient income can lead to food insecurity, which in turn leads to vitamin deficiency and higher risk of diet-related ill health including obesity and type-2 diabetes. Obesity rates rose in England in 2020/21<sup>91</sup> across every deprivation decile – with the highest percentage of adults classified as obese living in the most deprived areas (36.8%). The gap between the most deprived and the least deprived (19.2%) increased to nearly 18 points.

Smoking is more common among people with lower incomes<sup>92</sup>. In 2020, 14.8% of adults (aged 18 or over) living in the most deprived areas were current smokers compared with 9.0% of people living in the least deprived areas<sup>93</sup>. Data based on areas of deprivation show that both the proportion of smokers in England overall and the gap between smoking rates in the least and most deprived areas has reduced since 2018. However, the disparity in smoking rates is higher for individual-level data. In 2021, smoking prevalence was higher amongst those who were defined as unemployed (25.7%) compared to those in paid employment (13.3%), although people who were economically inactive had the lowest percentage of reported current smokers (12.2%)<sup>94</sup>. In 2021, 28.2% of people with no qualifications were current smokers, higher than 6.6% of people with a degree as their highest level of qualification.

The Marmot Review<sup>95</sup> identified physical environment factors such as air quality, access to green space and housing which impact on people's health. Air pollution concentrations have been found to be highest in the most deprived areas. In London, 46% of lower super output areas (or small neighbourhoods) in the most deprived areas, have concentrations of nitrogen dioxide above the EU limit value, compared with 2% in the least deprived<sup>96</sup>. Highest air pollution levels are also associated with more ethnically diverse areas (where more than 20% of the population are non-white).

Exposure to poor housing conditions – including damp, cold, mould and noise – is strongly associated with poor health, both physical and mental, specifically respiratory conditions, cardiovascular disease and communicable diseases. Poor living conditions are also associated with increased stress and reduced sense of control over one's life<sup>97</sup>.

#### Carbon monoxide and poor housing

The National Institute for Health and Care Excellence (NICE) uses exhaled carbon monoxide as an indicator of smoking, not environmental exposures in the home or local area, such as others' tobacco smoke or air pollution. Among women who do not smoke but who produce high carbon monoxide levels when tested during pregnancy, environmental carbon monoxide has been suspected.

The main sources of carbon monoxide in domestic settings are combustion heating and cooking appliances, although outdoor pollutants and cigarette smoke can also contribute to indoor concentrations. If combustion appliances (cookers, boilers, water heaters etc.) are in good condition and properly ventilated, levels should not be dangerous to participants. On the other hand, badly fitted or faulty appliances and poor ventilation can lead to carbon monoxide exposure<sup>98</sup>. A study<sup>99</sup> measuring carbon monoxide concentration in low-income households found above recommended levels in 18% of homes – generally due to old and poorly maintained gas appliances. Servicing rates of appliances are low, perhaps due to a lack of awareness of servicing requirements as well as the cost implications. Households in more deprived areas are more likely to be reliant on gas or solid fuel fire<sup>100</sup> and are less likely to own a carbon monoxide alarm<sup>101</sup>.

Research suggests that factors which cause fuel poverty, including living on low income and living in an energy inefficient property may also increase carbon monoxide risk – potentially due to reducing ventilation and using unsafe appliances in an attempt to heat properties. Homes which reported stress and anxiety about energy affordability and with lower minimum and mean temperatures had significantly higher maximum carbon monoxide levels<sup>102</sup>, suggesting a possible relationship between under-heating and elevated carbon monoxide.

There is evidence that fetal blood takes up carbon monoxide more readily and releases it more slowly – so the concentration and duration of carbon monoxide has a greater impact on the fetus than the mother. Toxicological studies suggest there is an association between low level chronic carbon monoxide exposure and reduced foetal growth and low birth weight of babies.

However, detecting mothers and birthing people at risk of exposure at home is challenging because carbon monoxide starts to leave the body when uncontaminated air is breathed in. Data from three NHS Trusts have shown that approximately 7% of non-smoking pregnancy women have CO2 readings above the threshold which triggers healthcare action<sup>103</sup>. Healthcare workers need to work with families to understand the source of exposure and the implications for readings in order to provide suitable interventions. The impact of financial hardship on accessing maternity and neonatal services is not as well understood, although socioeconomic status is associated with late or inadequate antenatal care access<sup>104</sup>. Affordability of transport or lack of childcare<sup>105</sup> may affect women and birthing people's ability to engage with antenatal care. One study found that while odds of late initiation of antenatal care did not increase with increasing deprivation quintiles, those with the highest risk of moderately late initiation lived in the two most deprived areas<sup>106</sup>. Women and birthing people with precarious employment contracts may also not be able to take time to visit health services for regular or emergency appointments.

As well as physical and practical barriers, access to health services may be affected by complex life factors and judgemental or stigmatising attitudes by health care professionals<sup>107</sup>. Some studies report a lack of individualised care and emotional support. as well as a lack of coordinated response across different services to complex vulnerabilities. One study suggests that women from lower socio-economic status were more likely to report that they were not treated respectfully or spoken to in a way they could understand by doctors and midwives<sup>108</sup>. However, the CQC analysis of the 2022 maternity survey does not report statistically significant differences in patient experience across IMD, with the exception of information about Covid-19 which women from deprived areas were more likely to respond positively about compared to women from the least deprived areas. Women from the second least deprived areas also reported a worse than average experience regarding the availability of staff, however, this could also reflect higher expectations than other groups.

m. https://www.nea.org.uk/wp-content/uploads/2021/03/NEA-Report-CO-and-Fuel-Poverty2.pdf
# Gaps in the evidence – inequalities in pregnancy loss and baby deaths between areas of deprivation

### Accuracy of area-based methods

Indices of multiple deprivation (IMDs) combine metrics on a range of dimensions of deprivation for geographic classifications. This can be better than single indicators, especially given the interaction between different aspects of deprivation. However, constructing an index requires decisions about which indicators to include and what weighting to apply which can leave indices open to criticism<sup>109</sup>. English IMD is comprised of 39 indicators across seven domains of deprivation: income, employment, education, health, crime, barriers to housing & services, and living environment<sup>110</sup>.

Deprivation is measured on a relative scale, so a neighbourhood ranked 50th is more deprived than the 25th but not twice as deprived. However, the relative nature of IMD means that it cannot be used to state definitively if an area is deprived or not and cannot robustly measure whether absolute deprivation in an area has improved or declined. If an area was in the second from lowest IMD decile in 2015 but within the lowest in IMD2019, it does not mean that deprivation increased. Deprivation may have reduced but at a slower rate than in other geographic areas.

Reporting at a local authority level can also mask large differences within that area. For example, Kensington and Chelsea ranked 122 out of 317 local authorities in England (the top 50%, with 1 being the least deprived) but it contains 23 Lower-layer Super Output Areas (LSOA) within the 20% most deprived in England, 9 of which are within the 10% most deprived<sup>111</sup>. This can dilute the true effect of socioeconomic deprivation on pregnancy outcomes and overall health.

Combined indices also make it harder to understand if any specific dimensions of deprivation have a larger impact on pregnancy outcomes. A systematic review of social disadvantage on infant outcomes in 2012 recommended that further research is required to explore proximate and individual-level factors which have a more direct impact on infant outcomes<sup>112</sup>. There are, however, a lack of individual-level data on deprivation, such as highest level of education or employment status. NCMD has recommended that specific and structured questions related to social deprivation should be included in the child death review reporting form to enable a more systematic collection and analysis of contributory and modifiable factors<sup>113</sup>. However, we also need to have this data for the population overall to understand if certain groups are under/overrepresented.

### Lack of experiential data

Compared to ethnicity, there is less evidence on individuals' access to and experience of care. People from time-poor and marginalised groups, who may be more likely to be in lower IMD deciles may also be less likely to participate in research. Further evidence is required to understand why deprivation may be associated with worse outcomes, and to inform interventions.

### Lack of intervention research

While there is some evidence on interventions which are aimed at targeting specific risk factors which are more common among deprived groups, such as stopping smoking, there is a lack of evidence on interventions aimed to reducing inequalities for people from deprived areas.

### **Government targets on inequalities**

There are no disaggregated targets for reducing inequalities across different areas of deprivation in England. To achieve the overall ambition of halving stillbirths by 2025, rates would have to decline by more than half (53.6%) in the most deprived area, from 5.6 to 2.6 per 1,000 total births. In contrast, the stillbirth rate among those living in the least deprived areas (IMD10) was 2.7 per 1,000 total births in 2021 – just short of the 2.6 target.

# Future work on health inequalities

# Understanding the problem

While it is clear that health inequalities exist in the UK, many demographic measures are broad which can make it challenging to understand what is driving pregnancy losses and baby deaths. More granular data which documents risks, such as maternal age, smoking status, level of English, exposure to air pollution, could help inform what is driving inequality.

While there is research which explores user experience of maternity care and health system, we still lack evidence on how the different axes of inequality intersect. The lack of data on other variables beyond ethnicity or IMD makes it difficult to adjust crude mortality rates for other, potentially confounding, factors. While MBRRACE-UK reports total stillbirths and neonatal deaths according to maternal characteristics, without data on the whole birthing population, we cannot draw associations.

We need to look across the data to identify groups with intersecting identities at higher risk, including other protected characteristics such as disability, gender identity, religion and sexual orientation. A cohort study by NMPA<sup>114</sup> using NHS administrative hospital data found that the risk of stillbirths and fetal growth restrictions were highest among the most socioeconomically deprived South Asian women and black women.

Looking at the influence of intersecting identities can help to tailor maternity and neonatal service provision, rather than putting the onus on individuals to control their own risk factors. To do this we need an intersectional understanding of the reality and complexity of people's lives. Further work is needed to develop a more holistic framework and data approach, which balances the level of detail needed for intersectional analysis with the realities of data collection in hospitals.

## LGBT+ health inequalities

This progress report has initially focused on health inequalities related to ethnicity and deprivation. The lesbian, gay, bisexual, transgender / transexual plus other identities (LGBT+) community is less well understood. The most recent censuses in the four nations of the UK were the first to collect data on sexual orientation and gender identity. While data on LGBT+ identities is still nascent on a national level, data on maternity and neonatal outcomes is limited. The small population size makes it hard to study rare outcomes, like stillbirths and neonatal deaths.

Some data sources are ambiguous as to whether trans men have been included. As well as improving data collection, greater consistency in language used in research can help to pinpoint issues which LGBT+ communities face in maternal and neonatal health.

However, some data suggest that LGBT+ women and birthing people may be at higher risk of adverse pregnancy outcomes. Women who identify as lesbian, bisexual or transgender experience disproportionately high rates of discrimination, harassment and domestic violence, which have been shown to affect access to maternity and support services as well as potentially impact pregnancy outcomes<sup>115</sup>. A comparison<sup>116</sup> of the Improving Trans and Non-binary People's Experiences of Maternity Services survey with the CQC maternity survey found that trans and non-binary respondents reported poorer experiences in every question.

This is an area for future research to understand the drivers of inequalities related to gender and sexual orientation, the impact of inequalities on pregnancies, and potential interventions.



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

### **Chapter Summary**

- The scale of current pregnancy loss and baby death is not inevitable, and we are not on course to meet national ambitions to reduce their occurrence. We must look at systemic issues across maternity and neonatal services and identify areas that will make a difference to these outcomes.
- Inspections of maternity services suggest that safety and quality of services in England<sup>n</sup> are declining; as do survey data of families' experience of care. There are persistent issues around women and birthing people not being listened to. CQC surveys show that fewer women and birthing people felt their concerns during labour and birth were taken seriously in 2022 compared to 2017.
- While Covid-19 may have had an impact, longer-term, systemic changes are required to reduce pregnancy losses and neonatal deaths.
- Improving services requires a culture of learning from mistakes, teamwork and collaboration, and ongoing learning and development.
- Evidence suggests that staffing levels are a critical issue facing many maternity and neonatal units.



## 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

n. Whilst much of the data presented in this chapter is for England – the lessons are relevant across the four UK nations.

# Safety and quality of services

The Care Quality Commission (CQC) regulates and inspects health and social care providers in England. The CQC publishes data annually on the number of maternity services rated outstanding, good, requires improvement and inadequate. In the CQC's 2017 report<sup>117</sup>, half of all maternity services were rated 'requires improvement' or 'inadequate' for maternity safety. By March 2020<sup>118</sup>, this had improved slightly to 39%.

The most recent data from the CQC show a decline in overall maternity service ratings between 2021 and  $2022^{\circ}$  (see Fig.36). In 2022, 6% of services were rated inadequate and 32% required improvement.



# Figure 36. Change in maternity service ratings by the CQC between 2021 and 2022.

Concerns regarding patient safety were also echoed in NHS staff surveys (see Fig.37). While nearly 75% of midwives agreed that their organisation would act on concerns raised by patients, 40% would not be happy with the standard of care provided by their organisation for a friend of relative.

## Midwives in England were less happy with the standard of care compared with all staff and nurses



Figure 37. Comparison of NHS staff survey results related to safety and quality of services

o. The CQC does not keep a public record of annual data, so it was only possible to compare results between 2021 and 2022. It would be valuable to explore records from a longer time period.

The CQC describes recurring concerns around the quality of staff training, strained working relationships between midwifery and obstetric teams, and a lack of robust risk assessment which affect the safety of maternity services. There is less evidence on the quality and safety of maternity services across other UK nations, where reviews take place on a more sporadic basis<sup>®</sup>.

In 2021, the CQC ran a programme of focused inspections to look at the safety of maternity services<sup>q</sup> in nine maternity services where there were safety concerns. The themes from the inspections were combined with interviews with Maternity Voice Partnership and engagement with Five X More and National Maternity Voices. Through this work<sup>119</sup>, the CQC identified the following areas for improvement:

- a. Leadership and culture: The interim Ockenden report<sup>120</sup> highlighted the importance of strengthening leadership and oversight for maternity, addressing toxic workplace behaviour and cultures, and fostering collaborative approaches. The leadership team is strongest when the service level manager, midwifery and obstetric leaders are all in place and work well together. In some of the services the CQC visited not all these leaders were in post, or they were held by interim postholders. The lack of stable leadership may prevent longterm collaboration and leadership development.
- b. Learning and improvement: The learning culture of services reviewed by the CQC varied. Staff lacked awareness of what constitutes an incident and faced practical barriers to reporting incidents due to workload. In services without a clear culture of learning, actions may not be taken to improve the safety of services. The review of maternity services in East Kent<sup>121</sup>, found a culture of denial meant that the Trust reacted to the CQC inspections or survey results defensively, rather than seeking to learn and improve.
- c. Support and teamwork: Staff are less likely to report issues or challenge poor practice where there is a blame culture and lack of support. Some staff in the CQC inspections did not feel clear on when to involve consultants or lacked the confidence to escalate concerns, putting safety of women and babies at risk. Issues with teamwork, both between professions (such as consultants and midwives) and within professions (such as between grades of midwives), affect the ability of services to deliver safe, high-quality care and to learn from any incidents.

The 2022 NHS staff survey found that while the majority of midwives and nurses felt their organisations respects individual differences and acts fairly, one in six did not (see Fig.38). A quarter of midwives had reported experiences of harassment, bullying or abuse from colleagues in the past 12 months.



q. The last thematic review of neonatal care was published in 2016

p. See Notes section.

# Midwives in England experienced more harassment, bullying and abuse from colleagues and managers in 2022



Chart: Sands & Tommy's Joint Policy Unit • Source: 2022 NHS Staff Survey (2022) • Created with Datawrapper

# Figure 38. Comparison of NHS staff survey results related to discrimination, harassment and bullying

The National Education and Training Survey 2021<sup>122</sup> found that 28.9% of midwifery students stated that they experienced bullying or harassment in their practice placement or training post.

d. Team training: Evidence suggests that regular multiprofessional training in maternity can improve patient outcomes. While regular multi-professional training did take place in services visited by the CQC, the impact of the training was not always consistent or evaluated. Particularly important is training centred on themes emerging from incidents – one service introduced unannounced short training sessions to respond to specific scenarios. One example was a woman giving birth to twins in a toilet. However, some services lacked training or training was not attended by some staff members, including consultants and anaesthetists, leading to concerns that some staff did not have the required skills and knowledge to perform certain tasks. Some services had switched to virtual training or paused training during the pandemic.

# A Just Culture for safer, personalised and equitable care

"A Just Culture is the balance of fairness, justice, learning – and taking responsibility for actions. It is not about seeking to blame the individuals involved when care in the NHS goes wrong. It is also not about an absence of responsibility and accountability"

### Being Fair, NHS Resolution 2019<sup>123</sup>.

A Just Culture supports safe care and is an important element of good bereavement care, by acknowledging that something has gone wrong and committing to understanding why. Sands has supported parents who have experienced the devastating death of their baby around the time of birth for more than 40 years. Parents have consistently told us that the word they value hearing is 'sorry'.

Currently, professionals may feel awkward saying sorry because it could be interpreted as an admission of liability. It is not. In UK law (except in Northern Ireland), saying sorry does not mean that you are admitting blame<sup>124</sup>. Some fear being unfairly blamed<sup>125</sup>, while others focus on issues in the health system which leads them to believe blaming individuals is unfair<sup>126</sup>.

We need a culture that is open and candid, to share what has gone wrong and what needs to improve. The end goal is not accountability or a learning culture, but safer, personalised and equitable care. Regulation, therefore, needs to support an approach which enables improvement rather than apportions blame.

> We want to know that things will be better for the next parents whose labour and births are like ours

> > **Bereaved parent**

# Improving the safety of services - learning from the past

Over the past several years there have been a range of reports and reviews into the safety of maternity and neonatal services across the UK. It is widely recognised that these consistently identify similar themes relevant to improving the safety of services, but despite numerous policy initiatives progress has been inadequate. Sands & Tommy's Joint Policy Unit is committed to ensuring that the learning from these reports is acted upon and that the government is held to account for progress. To support this, we have reviewed previous reports (See Appendix 3 for the list of reports) into maternity and neonatal safety to identify key themes, which are summarised in the table below. We are working to assess progress in these key areas and review the impact of current policy initiatives to help inform future approaches to improving services. This analysis will be published later in 2023.

Staffing levels and	Staffing levels need to be sufficient to ensure safe care and allow time for ongoing staff training. Workforce plans must be owned by the board with clear mitigation/escalation policies in place when staffing is unsafe. Staff must be suitably qualified with senior staff present on labour wards.
training	All staff must have access to the training that is required for them to carry our their roles safely and effectively. To support teamworking training should be multi-professional and support working together with a shared purpose, and include a focus on situational awareness and human factors.
Culture of safety within organisations	Staff must be able to escalate concerns about clinical care whenever necessary, with clear protocols in place to support this. Staff must be able to report safety concerns without fear of reprisal or repercussions . Organisations must review their approach to reputation management and ensure an open learning culture from board to ward level.
Organisational leadership	Boards must take effective ownership of the safety of maternity services with strong oversight of quality and performance of services. Clear arrangements should be in place for sharing patient experience at board level.
Personalisation of care and choice	All women should be able to make decisions about mode and place of birth – based on full, impartial information about the safety risks associated with all birth options.
Data collection and usage	Data collection must help identify variation in outcomes between maternity units, and among different patient groups (for example among women and birthing people from minoritised ethnic groups). Steps must be taken to understand the causes of variation and to inform improvements. Improved data collection needs to be supported by improving access to digital maternity records.
Learning from reviews and investigations	There should be a standardised, consistent approach to reviews and investigations of serious incidents, with families involved in a compassionate manner. Systems must be in place to support the sharing of learning locally, regionally and nationally – with clear actions implemented to address concerns raised. There must be adequate resources for comprehensive reviews and investigations to take place.
Engagement with service users	Services must actively engage with, learn from and listen to the needs of women. This should include targeted engagement with groups most likely to experience poor outcomes.
Delivering care in line with best practice/ national guidelines	Reports have consistently highlighted the need to provide timely and responsive care in line with national guidelines.

Table 9. Key themes from maternity and neonatal safety reviews based on Sands and Tommy's Joint Policy Unit analysis.

# How effective are our current policy approaches to improving the safety of maternity and neonatal services?

Over recent years several policy initiatives have been introduced with the aim of improving the safety of maternity care in England. Despite these initiatives, significant issues persist. It is important that any policy approaches designed to improve the safety of services are properly evaluated for their impact. Based on our initial review of current policy initiatives, it is clear that initiatives to incentivise, support or assure safe maternity care are infrequently evaluated for their effectiveness. Where evaluations have taken place, they are typically descriptive and explore the implementation of, or response to, a given initiative, rather than its effectiveness at improving safety. While measuring the impact of individual policy initiatives can be challenging, it is important that policy is informed by the best available evidence and that future initiatives have evaluation built into their implementation plans. This is a key part of developing a maternity and neonatal system that supports safe care.

Since the report of the Morecambe Bay Investigation in 2015, maternity services have been the subject of more significant policy initiatives than any other service. Yet, since then, there have been major service failures in Shrewsbury and Telford, in East Kent, and (it seems) in Nottingham. If we do not begin to tackle this differently, there will be more.

Independent Investigation into East Kent Maternity Services<sup>127</sup>

# Families' experience of care

Listening and learning from the experiences of women and birthing people using maternity services is vital to improving care. In England, the CQC conducts annual surveys of women<sup>7</sup> and birthing people, although those who have experienced bereavement are excluded. The survey results show that most respondents have a positive experience: the percentage reporting a positive response (including "yes, always" and "yes, sometimes") has been above 90% of respondents since 2013. The proportion of respondents who answered "yes, always" to a sample of questions was lower compared to those with a positive experience overall between 2013 and 2022. As shown in Figure 39, there was a decline across the board in the proportion of positive results in 2021 and 2022<sup>5</sup>.



# Figure 39. Proportion of 'always' positive responses to a selection of the CQC maternity survey questions between 2013 and 2022

#### Full survey questions were:

- 1. During your pregnancy, if you contacted a midwifery team, were you given the help you needed?
- 2. Thinking about your care during labour and birth, were you involved in decisions about your care?
- 3. Thinking about your care during labour and birth, were you treated with respect and dignity?
- 4. Did you have confidence and trust in the staff caring for you during your labour and birth?
- 5. If you contacted a midwifery or health visiting team were you given the help you needed?

Of the 23 questions relating to satisfaction in the care provided, with comparison available between 2017 and 2022, 82.6% (19 questions) saw a statistically significant decline during this fiveyear period. Of the 39 comparable questions between 2019 and 2022, almost all declined (92.3%) except for three questions related to mental health support which improved. The surveys also revealed different levels of satisfaction across different stages of care, with the lowest satisfaction for postnatal care<sup>t</sup>.

These results reveal declining satisfaction in maternity services in England<sup>u</sup>. While an important data source, there is some evidence that non-response bias, when those who chose not to respond to the survey are different from those who chose to respond, exists in the surveys. In 2022, women aged over 30 years were more likely to respond compared to younger women and while white women represented 70.6% of the sample, they represented 77.0% of the respondents. Non-response bias can work both ways: those with more positive views of care may be more likely to respond than those with negative views or vice versa so we cannot conclude whether the results are more or less positive than reality. Despite some uncertainty, the survey does provide a broad indicator of trends in parents' satisfaction, which unfortunately appears to be declining.

- r. Individuals for the 2022 survey were eligible if they had a live birth during February 2022, were aged 16 years or over at the time of delivery and gave birth under the care of an NHS trust (including home births).
- s. The survey did not run in 2020 due to the Covid-19 pandemic.
- t. See Notes in Appendix 1 for more information
- u. Comparable surveys have not taken place in the other UK nations.

# Supporting informed choices and personalised care

Personalised care and enabling parent choice have been a recurring themes in recent reviews of maternity services, summarised on p.42. Parents need clear, unbiased information to help them make decisions throughout their pregnancy and labour. Over three quarters of respondents felt they were always involved in decisions during their care in England. Respondents felt most involved during antenatal care (78%) and least involved during postnatal care (71%).



Figure 40. Respondents' involvement in decisions during antenatal, labour & birth, and postnatal care.

Despite broadly positive results, there are areas for improvement. Parents should always feel involved in their own care and the fact that some still do not is concerning. Recent reviews of maternity services, including of East Kent Trust published in 2022, found that some women and birthing people do not always feel like they have true choice, revealing instances where they felt pressured to make choices that fit in with services<sup>128</sup>.

Building trusting relationships with health care professionals is important for women and birthing people to enable sharing of information, joint decision-making and feeling safe. The National Maternity Review in 2016, found that women prefer to be cared for by one midwife or a small team of midwives throughout their maternity journey<sup>129</sup>. A Cochrane review<sup>130</sup> in 2016 found that women and birthing people who received midwife-led continuity models of care<sup>v</sup> were less likely to experience preterm birth and were less likely to lose their babies. Further research is needed to explore the relationship.

Although further research is needed to explore the Cochrane review findings, the Better Births 2016 plan<sup>132</sup> included an ambition for midwifery-led continuity of carer to become the default model of care available for women and birthing people in England. In the interim, where safe staffing allows, rollout has been prioritised to those most likely to experience poorer outcomes. However, implementation will require at least temporary increases in staffing levels and ring-fenced investment to ensure safe service is provided during the transition. The Independent Maternity Review team<sup>133</sup> has highlighted the challenges with introducing continuity of carer with little attention to its impact on an already overstretched and pressured maternity system. The review team noted that continuity of carer implementation has required budgetary overspend and placed additional pressure on staff, without a clear definition of what is meant by continuity of carer. Partial implementation risks creating a tick box exercise which may be an obstruction to real change. Even if it were fully implemented, concerns have been raised that continuity of carer is being used as a panacea for improving maternity care.

I was lucky enough to have support from the same midwife in my second pregnancy, during my third trimester. My anxiety was off the chart as we had no explanation as to why my first baby died and was in constant fear. We had to see lots of different consultants and she was a constant professional who knew our story. This really helped allay our fears as she knew me and understood my choices and why I made them and helped my partner and I avoid triggers."

Dawn<sup>131</sup>

v. Care provided by the same midwife, or small team of midwives, across all stages of care from antenatal, intrapartum and postnatal.

Data from the CQC suggests that continuity of carer remains far from reality in maternity care. There was a slight increase in the proportion who experienced continuity of carer, from 9% in 2019 to 11% in 2021 (see Fig.41). Most women and birthing people (59%) in England saw different midwives for their antenatal care, labour and postnatal care, a proportion which has increased each year since 2019. Further evidence is required to understand what proportion of those who are most likely to experience poorer outcomes currently receive continuity of carer.

### An increasing proportion of respondents in England were cared for postnatally by midwives who had not been involved in their labour or antenatal care



### Figure 41. Proportion of respondents receiving care from the same midwives in England between 2019 and 2022.

Part of building trusted relationships and feeling like an equal partner in care, is being listened to when there is a problem. Sadly, there has been a downward trend in the CQC survey results since 2017 for women and other pregnant people saying that if they raised a concern during labour and birth, they felt it was taken seriously. The East Kent report<sup>134</sup> found that many of the same issues which were raised by families and health care professionals but sadly they were often disregarded.

We also know from bereaved parents that when deaths do happen, they want people to acknowledge mistakes and learn from them. However, CQC surveys do not include bereaved parents who may be more likely to report negative experiences. Excluding this important group misses an opportunity to learn and improve services. It's an inequity of maternity service evaluation that the very people most affected by harm are the least likely to be asked about their experiences. Indeed the first and only national survey of bereaved parents' experiences of care was published in 2014. It's now a decade old and in the interim there have been countless reports about poor care triggered by individual parents who have effectively acted as a warning system of hospital failings that would not otherwise have been picked up. We must canvass bereaved parents to know if services are safe and meet their needs. Their experiences are the tip of the safety iceberg and have the potential to help identify near misses.

> **Charlotte Bevan,** Joint Head of Saving Babies Lives at Sands

# Impact of Covid-19 on access to services and experience of care



The 2021 CQC maternity survey results for England showed a decline in respondents' satisfaction with care, following year-on-year improvements previously. This has been attributed to the impact of the Covid-19 pandemic on staff and services – particularly partners' involvement, information and care, parents' involvement in decisions and staff availability.

There was a significant change in the ability of partners / companions to be involved as much as they wanted during labour and birth – a decrease from 97% in 2019 to 84% in 2021. 66% said that covid restrictions affected how involved partners / companions could be. By 2022 this proportion decreased to 42% and partners or companions being as involved as they wanted increased to 90%, although it has yet to reach pre-pandemic levels.

"I was terrified and alarmed as my husband was not allowed to come with me for an ultrasound. As he waited in the car park, the sonographer solemnly scanned me, her grim expression revealing our worst nightmare. As the hospital were concerned my pregnancy might be ectopic, I was not allowed to leave the hospital, and had to tell my husband over WhatsApp what had happened. I'm unsure who this experience has been more traumatic for; myself, living five days of hospital visits and intrusive examinations alone, or my husband, outcast and isolated from the whole process"

Lucy<sup>135</sup>

The impact of Covid-19 was also explored in a National Perinatal Epidemiology Unit (NPEU) survey<sup>w,136</sup>, which found that women received less information, guidance and support throughout care compared with women who gave birth pre-pandemic. However, the comparisons are based on less frequently collected data, which cannot be limited to the pandemic period. For example, data on women feeling involved in decisions about their antenatal care compared survey results from 2014 and 2020.

The NPEU surveys did find an increase in self-identified anxiety during pregnancy from 13% in 2018 to 22% in 2020. Some (35%) reported stopping exercise during pregnancy because they did not feel safe due to Covid-19 or because they were shielding or self-isolating.

The survey also found an impact on women's access to care:

- 53% had experienced changes to care due to Covid-19
- 36% had appointments cancelled
- 13% chose not to attend appointments because of Covid-19
- Home visits from midwives decreased from an average of 3 per pregnancy in 2018 to 1 in 2020.

While the decline seen in 2021 CQC maternity survey results was widely attributed to the impact of the Covid-19 pandemic, the results from 2022 suggest that availability of staff, confidence and trust in services, and communication and interaction with staff has continued to fall. Of the 44 comparable questions, 59.1% declined or remained at 2021 levels, while 40.9% improved.

Surveys are shared with people who gave birth in February each year, so it is likely that some hospitals still had Covid-19 restrictions in place for the 2022 survey results. The impact of Covid-19 on patient satisfaction may have varied during the pandemic period and across different maternity services as restrictions were introduced and removed at different points. We need to monitor trends from maternity surveys over the next few years to understand what may have been attributable to the direct and indirect effects of the pandemic.

w. With a sample size of 4,611 women.

# Ensuring appropriate staffing levels to deliver safe maternity and neonatal care

Workforce planning is complex for maternity: each care episode lasts around 40 weeks across hospital and community settings and includes regular, scheduled appointments and, for many, additional unscheduled care. Births can also take place across different settings and may require risk escalation and transfer of women between low and high-risk settings. Services are delivered by multi-disciplinary teams where midwives work alongside general practitioners, obstetricians, paediatricians, nurses, health visitors, support workers and sonographers.

Safe staffing means ensuring the right staffing levels and mix of staff to always provide safe care, even when services are busy. Staff shortages remain a persistent issue raised by health care professionals, organisations and families. The All-Party Parliamentary Group (APPG) on Baby Loss and APPG on Maternity published a joint report<sup>137</sup> on the impact of staffing shortages in October 2022 based on over 100 submissions to an open call for evidence. The submissions described an overworked, burnt out and stressed workforce which directly impacts the quality of care. In 2021 the Health and Social Care Select Committee<sup>138</sup> recommended that the government take urgent action to increase the maternity workforce in order to deliver safer care. This was subsequently reiterated in the Ockenden Report<sup>139</sup> – the recommendations of which were accepted in full by the government. The impact of staffing issues across antenatal, intrapartum and postnatal care is explored in Chapter 7.

# Staffing levels - the current picture

Comparing average staffing totals for different health professional roles with the annual number of deliveries for England between 2009-10 and 2021-22<sup>140</sup> there were:

2009-10	2021-22
1 midwife for	1 midwife for
every 33 births	every 26 births
1 obstetrician or	1 obstetrician or
gynaecologist for	gynaecologist for
every 126 births in 2009-10	every 90 births
Not recorded	1 neonatal nurse for every 17 neonatal admissions*
1 maternity nurse for	1 maternity nurse** for
every 108 births	every 247 births

 Table 10.
 Comparison of staffing ratios in 2009-10 and 2021-22

 \* Based on 2021/22 admissions captured by Neonatal Data Analysis Unit
 \*\* Within NHS England staff data (005) Nurses and health visitors are presented according to sub-groups (006) Nurses – adults. Within this group nurses who work in (003) Maternity Services are reported, including Nurse Consultant, Modern Matron, Nurse Manager, Children's Nurse, Other 1st Level Nurse, and Other 2nd Level Nurse. The number of midwives per 10,000 deliveries increased between 2009-10 and 2020-21, before starting to decline in 2021-22. The number of most other staffing groups also increased relative to total deliveries between 2009-10 and 2020-21, before declining in 2021-22. However, the number of nurses working in maternity services has steadily declined relative to total deliveries since 2009-10. The ratio of staff groups to total deliveries is affected by both the number of staff members and the total number of deliveries. Since 2009-10, total deliveries have broadly declined in England suggesting that the improving ratios may be partly, although not entirely, due to the falling number of deliveries

# Most staff groups involved in maternity and neonatal services increased in relation to total deliveries in England between 2009 and 2022



### Figure 42. Average number of health staff engaged in maternity care per 10,000 total deliveries in NHS hospitals in England for each financial year.

In 2003, Birthrate Plus<sup>×</sup> estimated that the NHS in England needs 1 clinical midwife for every 28 births. Birthrate Plus updated this ratio to 1:29.5 in 2010<sup>141</sup>, suggesting slightly fewer midwives are required overall based on changing patterns of care. More recent national estimates have not been provided by Birthrate Plus.

Neonatal care is delivered across neonatal intensive care units (NICU), local neonatal units (LNU) and special care units (SCUs). Each neonatal network should comprise several maternity and neonatal services with one or two NICUs and a small number of LNUs and SCUs. The British Association of Perinatal Medicine (BAPM) recommends minimum nurse:patient staffing ratios of 1:1 for intensive care, 1:2 for high dependency care and 1:4 for special care.<sup>y,142</sup> It found that only 44 (28%) have the correct establishment (the funding in place for each nursing role) for their activity and even fewer (24 units or 15%) had the appropriate number of staff in post. Neonatal Intensive Care Units (NICUs) are the worst affected with only three units (7%) with the correct establishment for activity and no units with the correct staff in post.

x. Birthrate Plus is a workforce planning and decision-making system which assesses the needs of women for midwifery care throughout pregnancy, labour and the postnatal period, in hospital and community settings. The methodology calculates the number of midwives required based on defined standards and models of care, and incorporating local population needs. Birthrate Plus is used by individual maternity units for workforce planning and publishes a limited amount of national data.

y. A national programme designed to improve the treatment and care of patients through in-depth reviews of care

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Determining the correct staffing level and staffing mix is complicated and should reflect broader population trends, such as birth rates and co-morbidities, as well as the profile of the local population, including social care needs, safeguarding needs, and health inequalities (as discussed in Chapter 3). The changing profile of the birthing population (including increasing maternal age, complexity of social needs and prevalence of co-morbidities), increasing interventions in pregnancy (due to better knowledge of reduced fetal movements among other factors), and improved ability to save more extremely preterm babies has increased the support required during the antenatal, intrapartum and postnatal periods.

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.

While national data indicate that staffing levels are increasing, national ratios provide a limited view of the reality for individual Trusts and maternity units. Although Trusts receive tailored staffing ratios from Birthrate Plus for midwives based on local demographics, case mix, and models of care, these ratios are not publicly available, which prevents external analysis.

There are several important limitations to using national staffing ratios to analyse the maternity and neonatal workforce:

**There are regional variations in staffing levels.** According to the Royal College of Midwives (RCM)<sup>143</sup>, London and the South East have traditionally faced the biggest recruitment and retention issues due to the higher cost of living associated with these areas. More remote and rural maternity units can also struggle to recruit and retain staff, which was an issue identified for East Kent Trust – particularly due to the coastal location<sup>144</sup>.

2019 data from England shown in Table 11<sup>145</sup>, show that the shortfall of nurses in neonatal units is particularly severe in some regions – particularly parts of London and the West Midlands - compared to the number of funded posts ('the current establishment') and the number of staff required to achieve BAPM recommended nurse to patient ratios. Table 11 shows the scale of the challenge is particularly severe in some regions – particularly parts of London and the West Midlands.

# Neonatal networks in some regions and areas face a higher staffing gap compared to others

< -216 -216--163 -163--110 -110--57 ≥ -57</p>

Neonatal Operational Delivery Network	WTE vacancies against current establishment	WTE gap against staff in post to achieve BAPM standards				
Northern	-14	-63				
East Midlands	-42	-84				
South West	-4	-97				
East of England	-56	-118				
Kent, Surrey & Sussex	-33	-131				
London - North West	-36	-169				
Yorkshire & Humber	-66	-170				
North West	-67	-193				
Thames Valley & Wessex	-48	-204				
West Midlands	-122	-241				
London - North Central & East	-93	-256				
London - South	-105	-269				
Data are for England only based on GIRFT data collection in 2019						

Table: Sands & Tommy's Joint Policy Unit · Source: GIRFT (2022) · Created with Datawrappe

 
 Table 11. Regional differences between WTE vacancies and current establishment and the gap between staff in post and number needed to achieve BAPM standards.
 The annual averages obscure variations in staffing levels across the year. Midwifery staffing levels follow a cyclical pattern connected to the academic year with a surge in numbers during the autumn intake followed by a decline from December until August each year. This can create fluctuating levels of pressure on services which must maintain patient care at the same level throughout the year.

Total number of midwives in England follows a cyclical pattern with large increases in the autumn followed by declining numbers between December and August each year



Figure 43. Monthly number of midwives in England between 2010 and 2022

Total staffing ratios do not account for staff absence. Monthly sickness absence rates are higher among midwives and nurses & health visitors compared to all professionally qualified staff, although below ambulance staff who report the highest rates of sickness absence.



Sickness absence is calculated by dividing the sum total sickness absence days (including non-working days) by the sum total days available per month for each member of staff. While lower sickness absence rates generally indicate lower levels of sickness, lower rates may also indicate underreporting of sickness absence. Chart: Sands and Tommy's Policy Unit + Source: NHS Digital + Created with Datawrapper

Figure 44. Sickness absence rates across staff groups in the NHS between 2017 and 2023.

The most commonly cited reason for sickness absence for all NHS staff is anxiety, stress, depression or any other psychiatric illnesses. This accounted for 31.3% of midwifes' sickness absence in September 2022 – or 12,826 full-time equivalent days lost. This rate is higher than any other staffing group with the exception of NHS infrastructure support managers (32.7%).

Total staffing ratios ignore individuals' level of experience and the skills mix within staff groups. Within staffing groups, it is also important to have an appropriate mix in levels of experience in order to deliver high quality care, as well as provide ongoing professional development training for junior staff.

Between 2009-10 and 2021-22, while the annual average full-time equivalent (FTE) obstetricians and gynaecologists in the NHS workforce increased, the average FTE among the most junior grades fell (see Figure 45). This could have implications for the future pipeline of more experienced doctors, if there is a lack of junior grades being trained currently.

## The total number of obstetricians and gynaecologists increased between 2009-10 and 2021-22 but there was also a change grade composition



Annual average FTE obstetricians and gynaecologists in NHS workforce at each staff grade in 2009-10 and 2021-22 in England

Chart: Sands & Tommy's Joint Policy Unit  $\cdot$  Source: NHS Digital (2023)  $\cdot$  Created with Datawrapper

Figure 45. Change in proportion of obstetricians and gynaecologists across levels of seniority in England between 2009-10 and 2021-22

Figure 45 was corrected in June 2023 to reflect the annual average FTE obstetricians and gynaecologists at each staff grade, rather than the annual cumulative total which was originally published in May 2023.

BAPM standards<sup>146</sup> require 70% of nurses within a neonatal service to be Qualified in Specialty (QIS). Getting It Right First Time (GIRFT) benchmarking<sup>147</sup>found that 48% of neonatal units had sufficient QIS nurses giving direct care, with the lowest results in NICUs (28%). While GIRFT benchmarking does indicate a shortfall in the qualified staffing levels, it also does not fully account for all roles, including non-direct care roles, and their contribution to service delivery.

**Top-line ratios excludes cross-cutting staff groups**, such as sonographers, anaesthetists, support staff, managerial and operational staff, which are not disaggregated for maternity services. This can ignore critical staffing issues in particular staff groups which affect maternity and neonatal services.

## Shortage of perinatal pathologists

There is a critical shortage of perinatal pathologists across the UK. The shortage has been building for many years and is leading to long waits for post-mortem reports, as described by parents and healthcare professionals in recent Sands surveys. Providing timely post-mortems is critical for understanding the cause of baby deaths for parents and health services.

The workforce of perinatal pathologists is unevenly distributed: in some parts of the UK services remain acceptable, while elsewhere there are too few or no specialist pathologists. Mutual aid between pathology centres has functioned in recent years but has been breaking down as overburdened centres have dwindling capacity to pick up cases beyond their own area. In some areas alternative approaches to service provision have been adopted.

An interim policy to triage the commissioning of perinatal post-mortems has recently been adopted across England, Scotland and Wales. The policy allows for the pathologist to assess different levels of post-mortem as appropriate, to most likely reveal information about the cause of death. While this approach is acceptable in principle, parents' wishes and rights need to be built into the process. It's vital the implications of the policy are properly communicated to bereaved parents so they understand fully what they are consenting to. For this to happen all health care professionals involved in taking consent need to be aware of the policy and able to answer parents' questions about the service provision in their Trust or Health Board.

Staff levels alone can also conceal issues in staffing dynamics which affect how well units operate, as discussed in Section A. The independent investigation into maternity services at East Kent<sup>148</sup> also found that some obstetric consultants expected junior staff and locum doctors to manage clinical problems themselves rather than escalating to consultants, and on occasion refused to attend out of hours, putting patient safety at significant risk. An unsupportive culture was not limited to obstetricians, staff also told the East Kent review that senior midwives formed cliques which excluded junior midwives and created a hostile and bullying environment which is not conducive to staff development or patient safety. Staffing levels can also vary within maternity and neonatal units. Staff may be moved from one area of care to another, leaving some areas under-resourced. Headcount data alone cannot be relied on to determine whether staffing levels are adequate to provide safe care.

The ratio of staff to births ignores the impact of temporary staff on services. Nuffield Trust analysis<sup>149</sup> in May 2021 estimated that four in five registered nurse vacancies were filled by temporary staff, which includes agency workers and the NHS in-house equivalent ('bank' staffing). Using bank and agency staff adds a burden to existing staff who need to smooth the transition and ensure care for patients is not compromised. GIRFT analysis found total expenditure on bank and agency staffing was nearly £26.8m in 2018/19<sup>150</sup>.

### Retention

Despite increasing staffing levels relative to the number of deliveries between 2009-10 and 2020-21, successive reports, research projects and surveys have shown the pressure that current staffing levels have and its impact on the system's ability to deliver personalised care.

The 2022 NHS staff survey for England highlights several key issues for retaining midwives<sup>2</sup> including stress and burnout, lack of worklife balance and dissatisfaction with pay. The survey indicated that around a quarter of midwives would leave as soon as they can find another job. While this question should be treated with caution as it does not include information on the proportion who are actively seeking other jobs, staffing levels did start to decline in 2021-22.



Figure 46. 2022 NHS staff survey responses based on wellbeing, satisfaction and plans to leave, across staff groups

Stress and burnout emerge as an issue in the survey as two-thirds felt they had unrealistic time pressures and had felt unwell in the past 12 months due to stress. This is reflected in the one in five people<sup>aa</sup> who left the NMC register between January and December 2021 citing pressure and its impact on mental health as one of the three reasons for leaving<sup>151</sup>. This pressure is also reflected in the data on sickness absence outlined in the previous section. Sense of fear and stress, and the impact on mental health was also a recurring theme in APPG staffing shortages report:



FEAR. Staff are frightened to work in an understaffed under-resourced unit, for fear of mistakes or incidents occurring due to the high activity and understaffing. Fear of investigations as a consequence and fear for their mental health and wellbeing as a result. Fear of the impact this has on their family life, fear that it will make them ill. I cannot emphasise FEAR enough, it is sometimes enough to make people go off sick.

Midwife<sup>152</sup>

In addition to sickness absence, analysis of retention should look at turnover rates, planned long-term leave (including parental leave) and the retirement rate. Retirement was the most frequently selected reason (42.9%) for leaving the NMC register in the 2022 leavers' survey. However, some mentioned in free text boxes that they felt they had no other option due to pressure, stress and unrealistic workload (159 respondents, 6.7% of all additional comments), just above those who mentioned reaching appropriate retirement age (145 respondents, 6.2%) or reaching a natural conclusion to their career (104, 4.4%).

Increasing recruitment and staffing levels may help to reduce stress and burnout among existing staff, and in turn increase retention. Conversely, ongoing staffing shortages may contribute to higher rates of people leaving the NHS.

Other avenues for improving retention<sup>ab</sup> include:

- **Flexible working** can be used to improve retention, including retaining staff nearing retirement age or allowing staff to meet caring responsibilities. The lack of flexible working options as well as work-life balance was a clear message from the NHS 2021 staff survey. RCM research in 2021<sup>153</sup> found that 67% of midwives and midwifery support workers who had left or were considering leaving the NHS could be encouraged to return if there were greater opportunities to work flexibly. Given 65% of members have some form of caring responsibilities, RCM believes that flexible working is good for their members and good for retention.
- Personal development: Insufficient staffing not only has . an impact on the number of healthcare professionals available to deliver care, but also the availability of staff to participate in training which affects both their personal development and retention, as well as patient safety. The impact of cancellation and postponement of training on the quality and safety of maternity services was highlighted in the APPG report of staffing shortages<sup>154</sup>. In its *Mind* the gap report<sup>155</sup>, the charity Baby Lifeline has highlighted significant gaps in maternity training, with fewer than a quarter of services in England providing all the training elements outlined in NHS England Saving Babies' Lives Care Bundle. The 2022 staff survey in England found that less than half of midwives (46.9%) felt supported to develop their potential, compared to 54.7% of all staff.

Current staffing levels in the NHS pose concerns for patient safety, which are reiterated in the NHS staff survey. The impact of staffing shortages on the provision of maternity and neonatal care will be explored in more detail in Chapter 7.

- aa. Including both nurses and midwives, although midwife representation in the leavers' survey was low at 6.8%.
- ab. These include non-financial measures. However, in the March 2023 Budget the Chancellor announced some changes to pension taxation policies which are intended to improve retention for senior health care professionals.

z. It is only possible to disaggregate survey results for midwives working maternity units. Doctors, nurses and other staff working in maternity and neonatal units are summarised according to staff group rather than their service area.

### Recruitment

One important component of safe staffing levels is the ongoing training and recruitment of new maternity and neonatal staff. A strong pipeline of candidates is critical to replace those leaving the NHS.





Across the UK, there was a 9% drop in applications for midwifery courses at university in 2022 compared to 2021, with the highest fall amongst those aged 21 or over (see Fig. 47). Applications increased during the pandemic and while they remained steady for students aged 18 – 20 years old, the greatest decline was among those aged 25 or over. This impacts the diversity of the workforce and may reflect the costs associated with education.

Retention of students is also a concern – the Reducing Pre-Registration attrition and Improving Retention (RePAIR) project<sup>156</sup> was set up in 2015 by the Department of Health to reduce avoidable attrition between pre-enrolment and the first two years of employment. According to Health Education England (HEE) attrition figures for 2013/14 and 2014/15, just under a third of students who started midwifery and children's nursing degrees completed them<sup>ac</sup> - 30.97% and 29.47% respectively; although this was lower than some other nursing competencies such as learning disabilities nursing (39.11%) and adult nursing (33.35%). However, after 2015, HEE no longer had formal remit to collect data on attrition and comparable data are not published. Instead, we are reliant on ad hoc investigations by Royal Colleges and professional journals which lack the transparency of HEE data and are therefore hard to compare between professional groups and over time.

An investigation by Nursing Standard<sup>157</sup> found that one in three (33%) of nursing degree students dropped out in 2020. A survey of student midwives in 2021<sup>158</sup> found that 55% considered leaving their course, although this is likely to be higher than the actual attrition rates. An RCM survey of student midwifes in 2019 found that almost half considered leaving their course due to financial pressures and debt<sup>159</sup>.

Alongside financial pressures, heavy workload, variable quality of clinical placements (including level of support, complexity of challenges) and level of student confidence in their abilities were also found to influence attrition rates<sup>160</sup>. Universities have highlighted the impact of staffing levels on student midwives' education and their ability to experience sufficient clinical experience. When midwives lack capacity to deliver services for women, they may not be able to meet requirements for clinical placements of students. Staff shortages have a profound impact on the student midwife learning experience, which includes achieving competence and confidence in clinical practice... reduced learning opportunities result in students having to extend their programme, delaying their entry into the NHS workforce.

University of Bournemouth<sup>161</sup>

Neonatal services faced particular recruitment challenges due to the lack of exposure to neonatal specialities – there is a lack of opportunities for most pre-registration nurses to access neonatal-specific placements and limited exposure to neonatology for midwives in training. The lack of clear career structure or remuneration for neonatal specialist training may make neonatology a less attractive option for newly qualified nurses.

### **Recruitment from overseas**

As well as increasing the number of medical students, recruitment from overseas has been another approach used by the NHS to increase staffing levels. The proportion of nurses and midwives joining the Nursing and Midwifery Council (NMC) register in England who were trained in the UK has declined since 2018. There has been a particularly sharp increase in those who were trained outside of the UK and Europe. In 2022, a quarter of new registrants had trained outside of Europe. Although part of the drive to increase staffing, practical, political and ethical considerations mean that overseas recruitment alone will not ensure a sustainable staffing supply<sup>162</sup>.

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ac. Based on the number of non-completers divided by the number of starters
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Additional funding required for the maternity and neonatal workforce

The 2021 safety of maternity services in England report<sup>163</sup> recommended an additional 1,932 midwives and 496 obstetricians to operate at a safe level according to Birthrate Plus. For midwives this assumes that one midwife is required for every 24 births<sup>164</sup> – based on ratios collated from 55 Trusts that undertook a Birthrate Plus assessment in 2019 and 2020 rather than the national ratio suggested by Birthrate Plus in 2010.

Applying this ratio to 2021-22 births suggests that 24,107 FTE midwives are required – a difference of 1,993 FTE midwives compared to the number of FTE midwives reported by NHS England in October 2022. However, due to variations in monthly staffing levels, with October typically a peak in staff levels for midwives, taking the average number of midwives for 2021-22 may be more accurate. Using the average annual number suggests a gap of 1,989 midwives.

### Existing funding commitments in England

NHS England and NHS Improvement committed an additional £95m during 2021/22 to increase workforce numbers, training and development programmes to support culture and leadership, and to strengthen board assurance and surveillance. This has been allocated across:

- £46.7m will fund the establishment of more than 1,000 midwifery posts which will be distributed during 2021/22
- £10.6m will be used to fund an increase in consultant time equivalent to 80 WTE in 2021/22

However, NHS Providers stated<sup>165</sup> that additional annual funding of at least £250m is required to meet staffing shortfalls. This would fund:

- A 20% increase in obstetric consultants is estimated to require £81m per year
- An increase of 3,000 midwives would require £161m

The total of £242m has been rounded to £250m for additional costs such as recruitment and ongoing professional development. If shortfalls in neonatal nurses, maternity support workers and anaesthetists are included the total annual funding could reach £400m.

In November 2022, the Chancellor's autumn statement included the commitment to recruit 2,000 more midwives and to publish a comprehensive NHS workforce plan, including independently verified workforce forecasts.

# 6. Lessons are still not being learnt when babies die

## **Chapter Summary**

- Understanding the cause of stillbirths and neonatal deaths is essential to prevent future deaths through research and improvements in care, but there is a lot we still don't know: in 2021, the causes of 33% of stillbirths and 7% of neonatal deaths were unknown.
- The most common cause of stillbirths in 2020 was placental. Two-thirds of neonatal deaths were due to neonatal complications, including extreme prematurity, cardio-respiratory issues and neurological problems.
- Standardised hospital reviews following the death of baby are essential to provide answers for parents and families as well providing information for Trusts to know where to improve. In 2021-22, nearly a fifth of stillbirths were found to be potentially avoidable if better care had been provided.
- The quality and thoroughness of reviews appears to be improving, including through increasing parents' engagement, involving a larger and multi-disciplinary team, and including external reviewers. This may also increase the number of issues with care that are identified and increase the number of deaths that are classified as potentially avoidable.
- Health services need to learn from, and act on, the findings of reviews and investigations to improve care and reduce avoidable deaths.

# 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<sup>[ii]</sup>, 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.

[ii] 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.

# Common causes of stillbirths and neonatal deaths

Understanding causes of perinatal deaths, including differences across antenatal stillbirth, intrapartum stillbirth, early neonatal death and late neonatal death, can help to direct efforts to reduce pregnancy and baby loss by targeting research and improvements in care. MBRRACE-UK uses the Causes of Death and Associated Conditions (CODAC) system to classify and record pathological causes of perinatal deaths. There are three levels within the CODAC classification system: level 1 describes the primary cause of death and levels 2 and 3 describe associated conditions<sup>166</sup>.

The most common causes of stillbirths between 2016 and 2020 were either due to placental causes or were unknown (see Fig.48)<sup>ad</sup>, meaning that the investigation into why the baby died was inconclusive. While classification has improved since 2016, the cause of a third of stillbirths was still unknown in 2020.



Figure 48. Percentage of stillbirths in each CODAC\* cause of death level 1 category from 2016 and 2020

ad. Where cause of death is not recorded it is reported as missing - this has remained constant at 4% of stillbirths in 2016 and 2020, although it reached a high of 7% in 2018.

Two-fifths of neonatal deaths were due to neonatal causes, including neurological, extreme prematurity, cardio-respiratory, and a third were due to congenital anomalies in 2020 (see Fig.49). The proportion of deaths that were due to an unknown cause was lower compared to stillbirths, although there was an increase from 5 to 7% between 2016 and 2020. While the most common causes of death through the five-year period were neonatal, rates have declined from 0.75 to 0.64 per 1,000 live births between 2016 and 2020.



Figure 49. Percentage of neonatal deaths in each CODAC\* cause of death level 1 category from 2016 and 2020

The percentage of deaths attributable to specific conditions, or associated causes, (classified as CODAC level 2) can be more variable year-on-year due to the small number of deaths within each category. However, extreme prematurity, neurological and cardio-respiratory conditions were associated with the greatest proportion of neonatal deaths between 2016 and 2020 (see Fig.50).



Figure 50. Percentage of neonatal deaths in each CODAC\* cause of death level 2 category from 2016 and 2020

# Identifying when a stillbirth or neonatal death could have been avoided

In addition to identifying the pathological cause of death through postmortems, reviews of the care provided are important to identify any issues which may have contributed to a baby's death. The National Perinatal Mortality Review tool (PMRT) helps to support objective, robust and standardised hospital reviews of care and the Healthcare Safety Investigation Branch (HSIB) carries out independent investigations of maternity and neonatal incidents<sup>ae</sup>, meeting certain criteria.

The most recent PMRT report<sup>167</sup> presents evidence from 4,199 reviews completed between March 2021 and February 2022. The PMRT uses a graded system to identify where better care could have prevented deaths: grade C if care issues may have made a difference to the death and grade D if care issues were likely to have made a difference. Grades C & D, therefore, identify potentially avoidable deaths. While an increasing proportion of Grades C or D indicate a higher proportion of avoidable deaths (and therefore sub-standard care), this may be due to worsening care and/or increasing quality and thoroughness of reviews. Trusts with fewer deaths graded C or D, may not necessarily provide better care, it may be that quality of reviews are poorer. More thorough, high-quality reviews may be more likely to identify issues with care, particularly where external reviewers involved.

There is limited external oversight and accountability of reviews led by hospitals where deaths occurred. Quality of the review is influenced by the availability of relevant information, a larger, multi-disciplinary team undertaking the review (including a neonatologist or paediatrician), parents' involvement, and external involvement. There have been some high-level improvements in reviews since 2018 - the median number of staff present has increased from five in 2018-19 to eight in 2021-22 and 83% of reviews had a neonatologist or paediatrician present in 2021-22, compared to 23% in 2018-19. A review is not dependent on the existence of an external panel member, as recommended by the PMRT collaboration. In addition, there is no analysis available on the quality of hospital reviews and any association with a higher proportion of grades C and D.

There is also no oversight as to whether findings from the PMRT reviews are acted upon. To meet the requirements of the Maternity Incentive Scheme, Trusts in England are required to use the PMRT to review perinatal deaths and create action plans to integrate its lessons. In its 2022 report, only 19% of these action plans were rated 'strong' by the PMRT meaning that they would introduce system level changes rather than relying on individuals to choose the correct action.

The PMRT's latest report suggests improvements in parents' engagement. 95% of reviews sought parents' perspectives in 2021-22, compared to 75% in 2018-19. Sands research<sup>168</sup> has found that while some parents describe a positive experience, others report poor communication, delays, and explanations about their baby's death which still leaves them with questions. 1 in 5 parents surveyed by Sands did not understand what the review entailed which limited their ability to engage in the process. 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<sup>169</sup>

A trust had received repeated recommendations from six HSIB investigations relating to fetal monitoring, paying particular attention to intermittent auscultation and continuous fetal monitoring from the perspective of interpretation and escalation. The trust used the findings to establish a new fetal surveillance midwife post.

HSIB maternity programme year in review 2020/21<sup>170</sup>

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<sup>171</sup>

ae. HSIB only review cases which meet their criteria for investigation. This includes all term babies born following labour (at least 37 completed weeks of gestation), who have one of the following outcomes: intrapartum stillbirth, early neonatal death, or potential severe brain injury.



There was an increase in the overall number of the PMRT reviews of late fetal losses<sup>af</sup> and stillbirths between 2018-19 and 2021-22 (see Fig.51), and a decline in the percentage of reviews graded A (where no care issues were identified). This may reflect some of the improvements in the number and mixture of staff participating in reviews, which would suggest that higher quality reviews may be more likely to identify issues with the provision of care.



Figure 51. The PMRT reviews of late fetal losses and stillbirths graded A – D between 2018-19 and 2021-22.

The proportion of reviews graded C and D increased during this period and accounted for over 400 avoidable deaths each year since 2019-20 (see Table 12). In 2021-22, nearly a fifth of reviews found care issues related to potentially avoidable stillbirths. Changes to grade D - where care issues were likely to have made a difference – is of particular interest for reducing avoidable deaths. Issues graded D were the smallest proportion (4% in 2021-22), although this still relates to 124 potentially avoidable stillbirths.

Year	2018-19	2019-20	2020-21	2021-22	
Number of the PMRT reviews	1154	2607	2600	2810	
Number (%) of care issues graded C	114 (10%)	329 (13%)	357 (14%)	394 (14%)	
Number (%) of care issues graded D	30 (3%)	72 (3%)	83 (3%)	124 (4%)	
Number (%) of care issues graded C or D	144 (12%)	401 (15%)	440 (17%)	518 (18%)	
Table: Sands & Tommy's Joint Policy Unit • Source: MBRRACE-UK/PMRT collaboration • Created with Datawrapper					

Table 12. Number and proportion of the PMRT reviews of late fetal losses and stillbirths graded C and D

af. While the PMRT describes late fetal losses as late miscarriages, in this report we have used the terminology which distinct experience of losses after 22 weeks gestation which are covered by the PMRT. See glossary for more detail.

The PMRT findings for neonatal deaths are presented separately based on care during pregnancy, labour and birth, and care after birth. The number of care issues graded C or D during pregnancy, labour and birth increased from 8% to 13% between 2018-19 and 2021-22 (see Fig. 52). The proportion of issues graded D, where care was likely to have made a difference to neonatal deaths, increased from 1% to 3%, or from 7 to 37 care issues in total.

# Increase in the proportion of the PMRT reports identifying issues with care during pregnancy, labour and birth that likely led to neonatal deaths from 2018-2021



**Figure 52.** The PMRT reviews of care during pregnancy, labour and birth that led to neonatal deaths graded A – D between 2018-19 and 2021-22.

Year	2018-19	2019-20	2020-21	2021-22	
Number of PMRT reviews	346	1086	1381	1389	
Number (%) of care issues graded C	20 (6%)	84 (8%)	111 (8%)	148 (11%)	
Number (%) of care issues graded D	7 (1%)	18 (2%)	41 (3%)	37 (3%)	
Number (%) of care issues graded C or D	27 (8%)	102 (9%)	152 (11%)	185 (13%)	
Table: Sands & Tommy's Joint Policy Unit • Source: MBRRACE-UK/PMRT collaboration • Created with Datawrapper					

Table 13. Number and proportion of the PMRT reviews of care during pregnancy, labour and birth that led to neonatal deaths graded C and D

The proportion of care issues related to potentially avoidable neonatal deaths from birth to the death of the baby were lower (8%) compared to care during pregnancy, labour and birth (13%). This is not necessarily indicative of better care as the neonatal period could be a very short period of time with less opportunity for poor care. However, the proportion of care issues has doubled since 2018-19 (see Fig.53). This change was driven by increases in issues graded C as issues graded D remained at 1% in each annual dataset.

# Slight increase in the proportion of the PMRT reports identifying issues with care that likely led to late fetal losses and stillbirths from 2018-2021



Figure 53. The PMRT reviews of care after birth that led to neonatal deaths graded A – D between 2018-19 and 2021-22.

Year	2018-19	2019-20	2020-21	2021-22
Number of the PMRT reviews	346	1086	1381	1389
Number (%) of care issues graded C	11 (3%)	46 (4%)	68 (5%)	100 (7%)
Number (%) of care issues graded D	1 (1%)	8 (1%)	10 (1%)	7 (1%)
Number (%) of care issues graded C or D	12 (3%)	54 (5%)	78 (6%)	107 (8%)
Table: Sands & Tommy's Joint Policy Unit • Source: MBRRACE-UK/PMRT collaboration • Created with Datawrapper				

# Table 14.Number and proportion of the PMRT reviews of care from birth to death of the baby that<br/>led to neonatal deaths graded C and D

Overall, the PMRT reviews identified 168 care issues in 2021-22 which were likely to have made a difference to stillbirths and neonatal deaths (grade D), an increase from 134 in 2020-21. A further 642 care issues were identified in 2021-22 which may have made a difference to mortality outcomes (grade C), an increase from 536 issues in 2020-21. Although the number of reviews increased in the two-year period, which increased the overall numbers, there was also an increase in the proportion of care issues graded C or D for all mortality outcomes and stages of care. As outlined previously, this may not be indicative of worsening care but may be due to more thorough and better-quality reviews. As the quality of reviews improves, this may mean that more deaths are identified as potentially avoidable.



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

# **Chapter Summary**

- There are variations in the standard of care experienced at each stage of pregnancy, birth and in the neonatal period. Too often avoidable losses continue to occur as a result of care that is not in line with recommendations in NICE guidance and other nationally-agreed standards (such as the Saving Babies' Lives Care Bundle). There is also a lack of comprehensive data on the implementation of national standards and guidance.
- This chapter focusses on aspects of care commonly identified in the PMRT reviews, which may have an important impact on the number of stillbirths and neonatal deaths, as well as on care associated with loss earlier in pregnancy. Figures showing the most common care issues identified by PMRT and trends over time are included in Appendix 5.
- Common themes across pregnancy, delivery, postnatal and neonatal care include ensuring women and birthing people have access to services, personalised care based on a good understanding of individual characteristics and context, and communication.



# 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.

# Variations in care provided during pregnancy

Antenatal care is provided throughout pregnancy to check the ongoing health of the mother and baby, provide pregnancy information and prepare for labour and birth. Antenatal care is the point at which four out of the five elements of care from the Saving Babies' Lives Care Bundle version 2<sup>172</sup> are delivered: reducing smoking in pregnancy; risk assessment, prevention and surveillance of pregnancies at risk of fetal growth restriction; raising awareness of reduced fetal movements; and preventing preterm birth wherever possible. Antenatal care also offers an opportunity to identify parents' needs, including previous bereavement, mental health, domestic violence or complex social needs.

### Access to antenatal care

NICE guidelines recommend the first antenatal care appointment for pregnancy assessment should take place by 10+0 weeks of pregnancy<sup>173</sup>, although initial contact and referral (which includes early pregnancy information regarding folic acid supplements and stopping smoking) might have happened several weeks earlier. Data for England show 40% of women and birthing people do not meet NICE guidelines for first antenatal assessment by 10<sup>+0</sup> weeks gestation, although this has decreased since 2017-18 (see Fig. 54).





# Figure 54. Proportion of deliveries attending first antenatal appointment before 10 weeks and after 10 weeks in England between 2017-18 and 2021-22

Late booking or not booking for antenatal care was identified as an issue in a quarter of the PMRT reviews in 2021-22 (24%) but only 9% of the issues were deemed to be relevant to mortality outcomes (see Appendix 5). However, late or no use of antenatal care is indicative of broader access to care issues and may also be linked to other care issues, such as delayed diagnoses or management of health or social problems.

### Delay in diagnosis or management of problems

Antenatal care is also an opportunity to build trust with women and birthing people, to identify how to personalise care and understand additional support that may be needed. This includes a risk assessment, although, as described in Chapter 3, correct risk assessment is vulnerable to inaccuracies and bias. Delay in diagnosis or inappropriate management of significant medical, surgical or social problems during pregnancy was the area most commonly identified as relevant to baby deaths in the PMRT reviews (25% in 2021-22) (see Appendix 5). Under the current system, time pressures mean that antenatal appointments are shorter and increasingly rushed, leaving midwives unable to provide more than basic care. One obstetrician said that "it also increases the risk of missing important clinical information and not providing the level of care required due to inability for senior medical staff to provide oversight"<sup>174</sup>.

Some of these concerns were shared by respondents to the CQC's maternity survey in February 2022<sup>ag</sup> (see Figure 55) and NPEU's National Maternity survey. While most responses were broadly positive, there was a decline in the 'Yes, always' responses over time for many of the categories. It is particularly concerning that just under half of respondents replied 'yes, always' to medical staff being aware of medical history – particularly given the proportion of the PMRT reviews which found that delays in diagnosis or inappropriate management of medical, surgical or social problems were relevant to mortality outcomes.



Figure 55. Proportion of positive and negative responses to the CQC maternity survey in 2022 related to antenatal care

Understanding women and birthing people's medical and social history can help to tailor the care that they receive during their pregnancy and labour. The PRISM study<sup>175</sup> found that progesterone treatment increased the rate of live births for those with early pregnancy bleeding and a history of previous miscarriage. Following this research, NICE guidelines were updated to recommend the use of progesterone for women and birthing people with early pregnancy bleeding who previously had a miscarriage. While a survey<sup>176</sup> led by Tommy's National Centre for Miscarriage research has indicated that the proportion of survey participants who prescribed progesterone to those who could benefit increased from 13% in 2018 (before the publication of the PRISM study) to 86% in 2022 (after the publication of the study and integration into NICE guidelines), we still need a better understanding of how research findings and updates to national guidelines are translated into frontline care.

ag. Which does not include the experience of bereaved parents.

### Fetal growth and movement surveillance

Inadequate growth surveillance was frequently identified as an issue in the PMRT reviews. NICE guidance<sup>177</sup> recommends risk assessment for fetal growth restriction during early pregnancy and increased monitoring of babies at higher risk. However, NICE guidance states that current methods - ultrasound scans and symphysis fundal height measurement - do not accurately predict a baby being born small or large for gestational age, although they continue to be routine practice as a simple and low-cost intervention. The MBRRACE-UK confidential enquiry into antepartum stillbirths also found that where growth failure was found, appropriate action was not always taken<sup>178</sup>.

Fetal movements are the most readily available measure of fetal wellbeing and failure to monitor changes to movements appropriately are missed opportunities to intervene<sup>179</sup>. Inadequate investigation or management of reduced fetal movements was the third most commonly identified issue related to mortality outcomes. The Saving Babies' Lives Care Bundle Version 2 includes an element on raising awareness of reduced fetal movements through distribution of information to pregnant women by 28<sup>+0</sup> weeks of pregnancy. Correlation between reduced fetal movements and stillbirths have been found in a growing number of studies; a relationship which increases in strength when women have multiple episodes of reduced fetal movements after 28 weeks' gestation<sup>180</sup>.

Inappropriate information for mothers is just one component of care issues related to fetal movements identified by the PMRT reviews. Other components include a lack of risk assessment, lack of investigations, and poor quality or incorrectly interpreted electronic fetal monitoring.

### Early pregnancy units

In addition to regular antenatal check-ups, women and birthing people who experience symptoms of pregnancy complications may need to access emergency care, either through emergency departments or dedicated early pregnancy units (EPUs). NICE guidelines recommend that women and birthing people who are referred to early pregnancy assessment services should be seen within at least 24 hours of referral. However, current variation in opening times across the UK means that this standard is not met for all.

### Awareness of fetal movements and care package to reduce fetal mortality (AFFIRM) study – reduced fetal movement meta-analysis<sup>181</sup>

Studies have shown the link between reduced fetal movements, stillbirth and fetal growth restriction related to placental insufficiency. However, studies looking at the impact of interventions to raise awareness of fetal movements and the clinical management of women and birthing people who present with reduced fetal movements have shown varying results. The research team reviewed 18 studies and found insufficient evidence of the effect of fetal movements awareness or fetal movements counting interventions on perinatal deaths, compared to standard care. There have been few studies on the subsequent clinical management of reduced fetal movements, so no conclusions can be drawn on whether ultrasound screening or blood tests for placental markers are effective interventions

The meta-analysis did find evidence that encouraging awareness of fetal movements may lower NICU admissions and encouraging fetal movements counting may lead to higher maternal-fetal attachment and lower maternal anxiety compared with standard care.

The lack of conclusive evidence is not proof of no effect, but does reveal the challenge in evaluating complicated interventions and rare outcomes. The lack of conclusive evidence may be due, in part, to the relative rarity of stillbirths and neonatal deaths, and the size of trials, rather than due to the effectiveness of the interventions themselves. There was also wide variation in the measured outcomes in included studies which impeded the metaanalysis. In response to this challenge, the research team is developing a core outcome set – a list of outcomes which studies on reduced fetal movements should include - which can be used in future studies to ensure consistency and comparability.

# Variations in care provided during labour and birth

The provision of good intrapartum care (care from the onset of labour until the completion of delivery), including management of preterm births, appropriate locations of birth and management of risk during labour is closely connected to the correct assessment and management of risk during antenatal appointments as well as parents' involvement in decision-making.

# Risk and need assessment and impact on birth plan and management:

Issues with delayed or inappropriate assessment of mothers' risk during antenatal care may subsequently affect labour management as well as the location and mode of delivery. Lack of assessment, or inadequate management, of maternal risk before and during labour was the third most commonly identified issue which was relevant to baby deaths in the PMRT reviews in 2021-21 (11%) (See Appendix 4). Worryingly, a sixth of respondents to the CQC maternity survey<sup>ah</sup> in England said that midwives or doctors did not appear to be aware of their medical history, rising to 40% including those who responded 'sometimes' (see Fig.56). A quarter of parents also did not feel that they were always involved in decisions about their care or that their concerns were taken seriously.

40% of respondents said that midwives and doctors were not always aware of their medical history and a quarter did not always feel involved or like their concerns were taken seriously Tes, always Tes, sometimes To Not the function of the sometimes To Not the function of the sometimes of the sometimes of the sometime of the sometimes of the sometime of the sometimes of the so

Figure 56. Proportion of positive and negative responses to CQC maternity survey related to intrapartum care in 2022.

Inappropriate birth location was the fourth most frequently cited care issue in the PMRT relevant to baby deaths (10% in 2021-22). NICE guidance<sup>182</sup> states that women should be able to choose any birth setting, although low-risk women and birthing people with previous children may be better suited to birth at home or in a midwifery-led unit compared to women and birthing people with medical conditions, previous pregnancy complications, gynaecological history or risks associated with the current pregnancy (including multiple birth, placenta praevia, substance or alcohol use, small for gestational age, malpresentation). Appropriate birth location is reliant on the correct assessment and discussion of risk with parents to inform decision-making as well as availability of staff to deliver all care options. Submissions to the APPG staffing report described how staffing shortages are impacting the choice of birth location available to women and families. Midwives being moved from midwife-led units to staff obstetric units has led to those units closing their services, leading to less choice for women.

Mode of birth was an issue for 8% of the PMRT reviews, including inappropriate choice, timing and management. 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. Women told that the review team that the Shrewsbury and Telford Hospital NHS Trust wanted to keep caesarean section rates low, because this was perceived to represent good maternity care<sup>183</sup>. There did not appear to be a consideration of whether this preference led to unnecessary harm. Women using the maternity services appeared to have little or no freedom to express a preference for a caesarean delivery.



Contributor to the East Kent Review<sup>184</sup>

A recent systematic review<sup>185</sup> highlighted the role of patient decision aids to support personalised care planning and informed decision-making, particularly in women and birthing people with pre-existing morbidity. These tools were found to help women who may have conflicting maternal and perinatal priorities to make decisions based on the best available evidence. There is a need to develop and roll-out these tools for key decisions such as place of birth, mode of birth, induction and reduced fetal movements to support both women and birthing people, and health care professionals.

ah. These responses do not include bereaved parents who may have had a worse experience of care.

### Management of preterm births

Reducing preterm births is another element of the Saving Babies' Lives Care Bundle. The critical pathways<sup>186</sup> for the management of preterm births are to:

- Predict: using risk assessment;
- Prevent: through the prescription of aspirin, smoking reduction, testing for asymptomatic bacteriuria and referral for complex cases; and
- Prepare: including choosing birth location, offering magnesium sulphate depending on the stage of pregnancy, and ensuring multi-disciplinary planning with parents, neonatal teams, midwives and obstetricians.

According to guidance from BAPM, women and birthing people who are at risk of preterm labour before 27<sup>+0</sup> weeks' gestation in a singleton pregnancy or under 28 weeks' gestation for multiple pregnancies should be transferred antenatally to maternity units with a co-located neonatal intensive case unit (NICU) and/or neonatal surgical centre<sup>187</sup>. Staff in NICUs are more likely to have specialist training and experience of managing preterm babies, which gives extremely preterm babies the best chance of good outcomes. However, in England and Wales, 21% of preterm babies were born in a hospital without a NICU (see Fig.57), ranging from 13.2% to 32.4% across neonatal networks.

### While the majority of eligible mothers were given antenatal steroids and magnesium sulphate, a fifth of babies born under 27 weeks' gestation were born at a centre without a NICU



Figure 57. Proportion of mothers receiving recommended care for management of preterm births in England and Wales in 2021.

The charity Bliss<sup>188</sup> has highlighted the impact of staff shortages which can result in women not being transferred to a hospital with a NICU for birth, which means that transfers are done post-birth. This may lead to poorer outcomes and increase the likelihood of separation of babies and parents.

There is no data for in-utero transfers but data on transfers after birth (ex-utero) show that transfers were low for extremely preterm babies. There was a six-fold difference between networks in the proportion of transfers of babies born between 27 – 34 weeks' gestation due to limited capacity, with the highest proportion in Northern, East Midlands and South West<sup>189</sup>. The GIRFT study called for greater maternity and obstetric awareness of the importance of transferring women and birthing people at high risk of preterm births to maternity units with NICU, as well as simplifying the process of antenatal transfers and improving collaboration between different neonatal networks, as well as between maternity and neonatal services.

### Fetal and maternal monitoring

Fetal monitoring was the most commonly identified care issue relevant to baby deaths in the PMRT reviews (19% in 2021-22). Either intermittent auscultation (listening and counting fetal heart rate for short periods during active labour) or cardiotocograph (CTG, which monitors heart rate for longer periods and identifies low levels of oxygen<sup>190</sup>) are recommended by NICE guidelines depending on the initial and ongoing risk assessment of mother and pregnancy. Failure to successfully monitor the baby during labour may be due to errors in the technique, equipment or timing of monitoring or blood sampling; the interpretation of monitoring; and failing to act upon findings<sup>191</sup>.

# *Example of intermittent auscultation not following national guidance*

The ESMiE confidential enquiry<sup>192</sup> reviewed intrapartum stillbirths and intrapartum-related neonatal deaths in births planned in alongside midwifery units, freestanding midwifery units or at home, using a sample of perinatal surveillance data for 2015/16 (for alongside midwifery units) and 2013-16 (for freestanding midwifery units and home births). Of the 64 deaths reviewed, 46 women (72%) had intermittent auscultation at some stage during labour. Issues with intermittent auscultation were identified by the review panel for over half (28 women) of cases. The study included the following vignette to illustrate issues with care:

A low-risk woman was booked appropriately for an alongside midwifery unit birth. On arrival at the alongside midwifery unit in early labour she reported reduced fetal movements in the 24 hours before admission; however, there was no documentation of a risk assessment taking this into account. The fetal heart rate was not monitored according to national guidance throughout labour: the heart rate was always rounded to the nearest five; baseline tachycardia was inappropriately recorded as a range; the frequency of intermittent auscultation was inappropriate; and there was no appropriate response to decelerations in the second stage of labour. The baby was born in poor condition and resuscitated, but later died <sup>193</sup>.

NIHR is funding a three-year programme to improve the way that midwives monitor fetal heart rate for women who are having an uncomplicated labour. The Listen2Baby study will be completed by mid-2025. Interpreting CTG requires healthcare professionals to consider the baby's heart rate and maternal contractions and interpret them in the light of the clinical circumstances of mother, baby and the status of labour to decide whether it is normal or requires intervention. CTG interpretation is susceptible to varying judgement between different clinicians and by the same clinician over time<sup>194</sup>. This variation can lead to inappropriate care planning which can impact on perinatal outcomes<sup>195</sup>. NICE guidelines recommends that CTGs should be interpreted in the context of maternal or fetal risk factors; work is currently being done to research tools which incorporates wider sources of data<sup>196</sup>.

The Saving Babies' Lives Care Bundle Version 2 recommends a formal annual competency assessment (along with adequate training), the development of a standardised risk assessment tool, and regular (at least hourly) fetal wellbeing assessment during labour. However, there is a lack of clarity about the effects of CTG training and which types of training work best to improve maternal and neonatal outcomes.

Maternal monitoring, including issues related to infrequent observations and not recording observations, was the second most commonly identified issue relevant to baby deaths in the PMRT reviews in 2018-19 (15%) and was identified in over a third of reviews overall (34%)(see Appendix 5). Since 2018-19, the proportion of reviews identifying issues with maternal monitoring has decreased, both for issues that were relevant to deaths and issues overall. While this suggests improvements in maternal monitoring, the CQC maternity survey in England highlighted the issue of women being left alone during labour and birth (see Fig.58) – which may also affect health care professionals' ability to monitor mother and baby. Worryingly, a quarter of respondents said they were left alone by midwives or doctors at a time that worried them in 2022.

# The proportion of respondents who were left alone by midwives or doctors at a time that worried them has increased since 2019 in England



Figure 58. Percentage of respondents who were left alone by midwives or doctors at a time that worried them across stages of care in England between 2013 and 2022, based on the CQC maternity survey. In 2022, 13% of respondents said that they were left alone by midwives or doctors at a time that worried them during early labour, an increase from 9% in 2019. The proportion who were left alone during later stages of labour and during the birth was lower, 8% and 2% respectively.

More positively, the proportion of respondents to the CQC survey who always had a member of staff with them increased from 9% in 2019 to 12% in 2022. However, the picture appears worse for those who did not have staff on hand at all times, as the proportion who could not get help when needed doubled from 3% in 2019 to 6% in 2022 (see Fig. 59). Including those who were only sometimes able to get a member of staff when needed, this increased to a quarter of respondents in 2022.

### The proportion of respondents who weren't always with, or able to get a member of staff, during birth increased from 19% to 25% between 2019 and 2022 in England

- Yes, always - Yes, sometimes - No - A member of staff was with me all the time





# Variations in care after birth

Key aspects of postnatal care include checking the physical and mental health of the mother or parent, the baby's health, and providing information for early parenthood. While postnatal care is less relevant for the prevention of miscarriages, stillbirths and neonatal deaths, it remains important for ongoing infant and maternal health, as well as referral for further social support. While out of scope of this report, lower parent satisfaction in postnatal care compared with other stages of pregnancy and birth suggests room for service improvement which could improve outcomes for mothers and babies.

# Variations in care for babies admitted to neonatal units

Babies may be admitted to neonatal care if they are preterm or low birth weight, have an infection or jaundice, or any other medical needs. Neonatal care is delivered across neonatal intensive care units (NICU), local neonatal units (LNU) and special care units (SCUs). Each neonatal network should comprise several maternity and neonatal services with one or two NICUs and a small number of LNUs and SCUs<sup>197</sup>. NHS England has designed the neonatal networks with the intention that together the units deliver a local care pathway for women and babies in the network area, except neonatal surgical, cardiac services or extremely rare conditions that are provided on a regional or supra-regional service.

### **Thermal management**

BAPM recommend regular monitoring of babies' temperature after birth<sup>198</sup>, and the temperature at admission to neonatal care should be recorded as a prognostic and quality indicator<sup>199</sup>. Thermal management is the issue most commonly identified as relevant to baby deaths (27% in 2021/22) and was identified as an issue most frequently during transfer to neonatal unit (18%). This may be due to issues in the ways of working between maternity and neonatal units who often work independently, despite often being physically close.

The National Neonatal Audit Programme (NNAP) found that 73.2% of very preterm babies in England and Wales were admitted with a temperature within the recommended range of 26.5 - 37.5°C, although this ranged from 63.8% to 82.9% across neonatal networks<sup>200</sup>. No network met the NNAP developmental standard of 90% of babies with a temperature taken within an hour of birth measuring within the normal range. Keeping babies at the right temperature after birth is also a modifiable factor for reducing neonatal admissions for respiratory symptoms for babies born at full-term<sup>201</sup>.

### **Respiratory management**

Preterm babies often have under-developed lungs or have ongoing breathing difficulties and may need support from a ventilator or other device. However, being on a ventilator can damage the lungs, cause morbidities and put babies at risk of chest infection. There are a range of respiratory management options and ventilation modes to avoid ventilationinduced lung injury.

Babies who survive can develop chest infections, so reporting rates of chest infections alongside mortality rates allows the NNAP to capture mortality and morbidity for cohorts over three year periods. For babies born at less than 32 weeks' gestational age who were discharged from neonatal care between January 2019 and December 2021, 38.8% had a chest infection or died. There was no notable change with the previous cohort which echoes the PMRT findings that respiratory management is an ongoing issue in neonatal care.

The APPG report on staffing shortages<sup>202</sup> presented evidence that neonatal resuscitation is not always being led by appropriately skilled staff and delays in neonatal team attendance can occur when simultaneous or complex delivers occur. NNAP also highlighted differences in chest infection rates or death rates between neonatal networks, which remain after adjusting for case mix suggesting that there may be opportunities to reduce avoidable deaths with better care in some networks.

### Delaying cord clamping for preterm babies

NICE guidelines currently recommend delaying cord clamping until at least 60 seconds, unless there are specific maternal or fetal conditions that require earlier clamping<sup>203</sup>. NNAP data from 2021 show that 43% of very preterm babies had their cord clamped at or after one minute, although this has increased from 28.9% in 2020. However, rates between neonatal networks were variable – ranging from 13.9% to 68.1%.



Figure 60. Proportion of very preterm babies whose cord clamping was delayed in England & Wales in 2021

# The Twin's Trust review of NICE guidelines for multiple pregnancies

The Twin's Trust reviewed NICE antenatal guidelines for multiple pregnancies<sup>204</sup>. Following an initial audit of 30 maternity units' level of adherence to NICE quality standards, The Twin's Trust worked with the units to identify and implement changes to antenatal care to increase adherence to NICE quality standards. Followup audits were carried out which 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 quality standards could lead to a considerable fall in stillbirth rates.

Overall the project showed that in the best case, after five years, the lives of up to 100 stillborn babies could be saved every year if all maternity units followed NICE quality standards, as well as achieving at least £8m of financial savings.



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

# **Chapter Summary**

- 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 complications and investigating solutions to reduce its occurrence. However, other areas receive significantly less funding including social science, economic analysis and policy research, which are critical to evaluating existing interventions.

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## 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.

The most recent review of spending on pregnancy research in the UK was undertaken by RAND<sup>205</sup> in 2020, looking at data from 2013 to 2017. The review found that £51 million is invested each year in pregnancy research in the UK, compared to the £5.8 billion in pregnancy-related care costs which the NHS spends per year. In other words, the NHS spends 1p on pregnancy research for every £1 spent on maternity care, compared to 7p for every £1 on heart disease or 12p for every £1 on cancer.

# Topics of pregnancy-related research

Of the £255 million that was spent in total on pregnancy research from 2013 – 2017 in the UK, the biggest area - accounting for over £40 million of funding - was pregnancy care complications and care during pregnancy.

# Pregnancy complications and care during pregnancy were the biggest recipient of research funding in the UK 2013-17



Figure 61. Total funding according to the 14 largest research categories in the UK between 2013 and 2017

Stakeholders who were consulted by RAND, including researchers, healthcare professionals and the public, agreed that perinatal mental health is a top priority, although it currently only receives 4% of UK pregnancy research funding. Stillbirth also emerged as an important priority for future research from the stakeholder consultation although it received around 2% of pregnancy research funding (£5.8m), 43% of which came from Sands and Tommy's.

Although inequalities in outcomes are stark, as outlined in Chapter 4, research focused on inequalities was one of the smallest recipients of funding. As outlined in this report, we lack an understanding of the drivers of inequalities, beyond aggregate measures of ethnicity or deprivation, and how different facets of inequalities interact. We also lack research on the effectiveness of interventions which are intended to reduce inequalities. Given how stark the inequalities in pregnancy outcomes currently are in the UK, further research is urgently needed.

# Type of research

Most funding was spent on discovery (or exploratory) research, followed by clinical trials and observational clinical research. These types of research remain critical to understanding causes of pregnancy complications and investigating solutions to reduce it's occurrence.





However, other areas of research are also vitally important to identify the best ways to implement clinical discoveries, including applied research, economic analysis and social science research. High quality qualitative research can provide vital evidence to understand any barriers to implementing changes to clinical research.

While governments are called upon to take action in response to annual mortality data or maternity service reviews, we still lack a good understanding of the existing policies which successive governments have introduced and what works to reduce deaths. Policy research only received £1.7 million in funding between 2013-2017. One example of clinical research, which is seeking a solution to the issues associated with pregnancy risk identification and management is Tommy's Clinical Decision Support Tool:

## Tommy's National Centre for Maternity Improvement: Tommy's Pathway Clinical Decision Support Tool

Tommy's clinical decision support tool uses validated algorithms to help midwives and doctors more accurately assess the chance of preterm birth or developing problems with the placenta which may lead to stillbirth. Assessing the chance of these complications early means that maternity care professionals can offer the right care at the right time. The tool requires data inputs on age, BMI, polycystic ovary diagnosis, number of previous miscarriages, number of previous live births, ethnicity, Index of Multiple Deprivation (IMD), health conditions and smoking status to accurately determine the probability of a successful pregnancy.

A study<sup>206</sup> found that the first trimester screening algorithm for pre-eclampsia risk assessment (and offer of 150 mg aspirin before 16 weeks' gestation, serial growth scans and elective birth at 40 weeks for those considered high-risk) led to a lower perinatal death rate in non-white women 3.22 per 1,000 births compared to 7.95 per 1,000 births in non-white women who received care in line with NICE guidance. The fall in perinatal death rate among non-white women meant that it was no longer significantly different from the perinatal death rate among white women in the algorithm screening cohort (3.22 vs 2.55 per 1,000 births or an odds ratio of 1.261, 95% Confidence interval 0.641 - 2.483), whereas the rate among the cohort receiving care in line with NICE guidance was significantly higher among non-white women compared to white women (7.95 vs 2.63 per 1,000 births, an odds ratio of 3.035, 95% CI 1.551 - 5.941)

The tool has a separate log-in for pregnant users who can access their own profile and care information, view guidance based on their stage of pregnancy and share information with different hospitals if needed. It's designed to support women and birthing people to ask questions and to feel heard where they have concerns.

With £1.8 million funding from the National Institute for Health and Care Research, the tool will be trialled in 26 NHS maternity units over 36 months around the UK to assess how it works in practice.

"We believe this simple tool could help prevent up to 600 stillbirths and 12,000 premature births a year by enabling the standardisation and equitable delivery of care across the NHS"

> Professor Basky Thilaganathan, Clinical Director of Tommy's National Centre for Maternity Improvement.

# Appendix 1

# Existing miscarriage data

Although total miscarriage figures are not reported, across the four nations some data on miscarriages are collected. NHS England reports annual hospital admissions for miscarriage management. Using ONS data on total deliveries for the same period, we have created a rate\* of miscarriages resulting in a hospital stay, shown in Figure 63, which has remained constant since 2013.



# Figure 63. Rate of miscarriages resulting in a hospital stay per 100 deliveries in England

However, we don't know if the declining number of miscarriages which resulted in a hospital stay reflects a broader decline in the number of miscarriages. Miscarriages are commonly managed at home or through General Practitioners, or may not be known to the women themselves, and women are therefore never referred to hospital. The number of miscarriages recorded through hospital data is likely to considerably underestimate the true number of miscarriages.

Information Service Division Scotland (now Public Health Scotland) used to collect data on the number of miscarriages requiring in-patient treatment. However, from 2017 it was decided not to publish these data as it was deemed of low clinical value as an accurate assessment of the number of miscarriages that occur is not possible from hospital-based data only<sup>207</sup>. Data on the number of miscarriages resulting in in-patient treatment are collected by Trusts in Northern Ireland and Wales but are not collated and reported at a national level.

<sup>\*</sup> Miscarriages are not included in total deliveries (or the numerator is not included in the denominator) so the miscarriage rate is a ratio. Data are not available on miscarriages which do not result in a hospital stay.

# Appendix 2 Factors associated with higher risk for pregnancy and baby loss

UK & Crown Dependencies	Stillbirth (rate per 1,000 total births)			Neonatal w	deaths (per eeks' gestat	1,000 live bi ion and abo	rths) at 24 ve	
	2018	2019	2020	Average	2018	2019	2020	Average
Sex								
Male	3.42	3.23	3.30	3.30	1.71	1.76	1.64	1.71
Female	3.49	3.40	3.25	3.40	1.55	1.45	1.39	1.45
Not Known			F	Rates cannot	be calculate	d		
Multiplicity								
1	3.42	3.24	3.21	3.24	1.48	1.48	1.39	1.48
2	6.07	6.68	7.33	6.68	6.38	5.98	6.18	6.18
3 or more	20.36	15.07	27.43	20.36	6.93	7.65	23.08	7.65
Birthweight (g)								
Under 1,500	149.79	143.88	144.08	144.08	77.33	79.07	71.34	77.33
1,500 – 2,499	13.95	1226	13.98	13.95	6.21	5.71	6.4	6.21
2,500 – 3,499	1.62	1.55	1.60	1.60	0.84	0.84	0.77	0.83
3,500 – 4,499	0.58	0.76	0.68	0.68	0.34	0.88	0.78	0.34
4,500 and over	1.14	1.43	1.78	1.43	0.83	0.88	0.78	0.83
Baby's ethnicity								
White	3.39	3.22	3.17	3.26	1.65	1.62	1.51	1.59
Mixed	4.25	3.58	4.09	3.97	1.56	1.25	1.82	1.54
Asian, Asian British	5.31	5.05	4.97	5.11	2.63	2.57	2.06	2.42
Black, black British	7.35	7.23	6.41	7.00	2.39	2.32	2.71	2.47
Other	3.29	2.95	5.57	3.94	1.34	1.95	1.58	1.62
Declined / Unknown	Rates cannot be calculated							

Table 15. MBRRACE-UK data on risk factors related to baby's characteristics

UK & Crown Dependencies	Stillbirth (rate per 1,000 total births)			Neonatal w	deaths (per eeks' gestat	1,000 live bi	rths) at 24 ve	
	2018	2019	2020	Average	2018	2019	2020	Average
Maternal age								
< 20	5.25	4.20	3.99	4.48	2.47	2.62	1.92	2.34
20 – 24	4.24	3.82	4.29	4.12	2.07	1.88	1.78	1.91
25 - 29	3.22	3.26	3.04	3.17	1.61	1.68	1.52	1.60
30 - 34	3.19	3.15	3.29	3.21	1.46	1.50	1.49	1.33
35 – 39	3.88	3.61	3.59	3.69	1.66	1.57	1.52	1.58
40 and over	5.30	4.45	4.63	4.79	2.32	2.06	2.64	2.34
Not known	0.00	0.04	0.05	0.03	0.00	0.00	3.1	1.03

Table 16. MBRRACE-UK data on stillbirth and neonatal death according to maternal age

# Appendix 3

# List of reports on maternal and neonatal safety reviewed by the Joint Policy Unit

Individual services	National reports	National strategies/reviews
Independent Investigation into East Kent Maternity Services (2022) <sup>208</sup>	CQC – Safety, equity and engagement in maternity services (2022) <sup>214</sup>	The Best Start Scotland (five year forward plan) (2016) <sup>223</sup>
Ockenden report (2022) <sup>209</sup>	CQC – Getting safer faster (2020) <sup>215</sup>	Better Births National Maternity Review (2016) <sup>224</sup>
Report of the Morecambe Bay Investigation (2015) <sup>210</sup>	HSIB maternity themes (2020) <sup>216</sup>	Healthcare Inspectorate Wales – National review of maternity services phase one (2020) <sup>225</sup>
Review of Maternity Services at Cwm Taf (2019) <sup>211</sup>	Health and Social Care Committee report into maternity safety <sup>217</sup>	Saving babies' lives care bundle V2 (2019) <sup>226</sup>
Report on the RQIA Review of Intrapartum Care (Northern Health and Social Care Trust - NI) <sup>212</sup>	MBBRACE- Perinatal confidential inquiry (2017) <sup>218</sup>	Recommendations of the Neonatal Critical Care Transformation Review (2019) <sup>227</sup>
HIS Review of Ayrshire Maternity Unit – NHS Ayrshire and Arran <sup>213</sup>	MBRRACE-UK Perinatal Mortality Surveillance Full Report 2019 (published in 2021) <sup>219</sup>	
	National Maternity and Perinatal Audit Organisational report (2019) <sup>220</sup>	
	National Perinatal Mortality Review Tool Annual Report (2021) <sup>221</sup>	
	Each Baby Counts (key recommendations for care) (2015) <sup>222</sup>	
## Appendix 4 Measures of deprivation

Current measures are place-based, using individuals' postcode to make inferences about their socioeconomic status, either based on absolute poverty – such as the income level or access to services – or relative levels, which look at how income (or other aspects) in one area compares with the rest of society. Relative measures cannot be used to state absolute levels of deprivation and caution should be used when interpreting changes over time.

Beyond single measures there are also indices which bring together several indicators to provide a more holistic estimate of poverty and deprivation. This requires decisions about what indicators to include and how to weight them which can be open to critique when reviewing data.

Measure	Relative / absolute	Frequency	Geography
Measures			
Households below average income	Relative and absolute	Annual	UK: Region
Children living in low-income families	Relative and absolute	Annual	UK: local authority, Westminster parliamentary constituency, ward, Middle Super Output Area (MSOA)
Proxy measures			
People on Universal Credit	Absolute	Monthly	Great Britain: Country, region, local authority, MSOA, LSOA, ward
Children on free school meals	Absolute	Annual	England: region, local authority
Indices			
English Indices of Deprivation	Relative	Every 4 – 5 years	England: Local authority, local enterprise partnership, ICS, lower super output area (LSOA)

## Appendix 5 Common issues with care identified in the PMRT reviews

The PMRT identified the eight most common issues in pre-conception and antenatal care which were relevant to late miscarriages, stillbirths or neonatal deaths, between January 2018 and February 2022.



Figure 64. Eight most frequent care issues relevant to baby deaths identified in preconception and antenatal care



The PMRT identified the eight most commonly identified issues with intrapartum care which could have prevented baby deaths, shown in Figure 65.

Figure 65. Eight most frequent care issues relevant to baby deaths identified in intrapartum care

The PMRT identified the five most frequent care issues with neonatal care which could have prevented baby deaths, shown in Figure 66.



Figure 66. Five most frequent care issues relevant to baby deaths identified in neonatal care

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